

**Having a Say:
An Investigation of service users' and carers' views of Child
and Adolescent Mental Health Services in Northern Ireland**

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Report summary

The Review of Mental Health and Learning Disability, Northern Ireland commissioned the present consultation to support the work of its Child and Adolescent Mental Health sub-group. The investigation employed a two stage qualitative approach to explore views and opinions held by users and carers about CAMH services. Nineteen services distributed questionnaires on a single day between 13th and 15th October, 2004 in order to provide a 'snapshot' of service user's views. Four focus groups, 2 consisting of parents/carers and 2 consisting of young people were conducted. Responses from both stages were content analysed and key themes drawn out.

Content analysis of responses from the questionnaire study showed that 40% (6) of derived categories described negative experiences of CAMH services, with 60% (9) of categories expressing positive views. Analysis of focus group data produced a total of 14 categories (88%) indicating dissatisfaction with CAMH services and 2 categories (12%) expressing generally positive views.

Findings suggest that whilst users and carers valued CAMH services they felt more could be done to help their children and wider families. Major areas for development highlighted include increasing capacity at all tiers of service, developing collaborative models of practice, developing public knowledge about child and adolescent mental health and establishing meaningful structures for increased user participation in the planning and monitoring of CAMH services.

Introduction

The Review of Mental Health and Learning Disability has employed a range of forms of consultation to elicit the views, opinions and advice of interested individuals and groups. Within the expert working group addressing the review towards Child and Adolescent Mental Health Services and its sub-committees, a range of stakeholders was represented. These included workers from statutory health, education and voluntary service backgrounds as well as some representatives from service user/carer groups. The committee also received submissions both in written and oral form from a range of interested groups. Invitations were widely circulated and around forty submissions were made over four days of presentations in June and September '04. Although some user/carer groups were represented at these events, the format lends itself best to utilisation by professional and voluntary group interests. The present project represents the CAMHS committee's most significant attempt to elicit the views of a wide range of adults and young people who use or have used CAMH services.

Why should we consult with service users and carers?

The benefits to health services of involving users and carers in planning, provision and evaluation are well established (eg. National Consumer Council, 1995). Some of these benefits as articulated by The NHS Executive (NHS Executive, 1997) are presented in box 1

Box 1. Benefits of consulting users

- ❑ Services are more likely to be appropriate and effective if based on needs identified together with users/carers
- ❑ Users/carers are increasingly seeking more openness and accountability
- ❑ Users/carers want adequate information about their health condition, treatment and care
- ❑ Involving patients in their own care may improve healthcare outcomes and increase patient satisfaction
- ❑ Users/carers need access to reliable and relevant information to be able to assess clinical effectiveness themselves

Source: NHS Executive, 1997

The Audit Commission's Report – Children in Mind (Audit Commission, 1999) stated that CAMHS commissioners and service providers needed to take a holistic approach and assess needs systematically by consulting widely, including children and their parents. The need to involve children in service planning and evaluation has become clearer since the UK Government ratified the United Nations Convention on the Rights of the Child (UNCRC) and since the implementation of the Children Order (1995). Draft conclusions of a 2004 WHO European Region conference entitled "The Mental Health of Children and Adolescents" dealt with the issue of consultation as follows:

“Addressing mental disorder and promoting mental health in Europe has to be seen within the framework of the respect for human rights (including the rights of children and adolescents) that lies at the heart of a democratic Europe...It is important too that any action taken to improve mental health respect the human rights of those involved. Actions need to be planned in consultation with end users, and take place with the consent and participation of those at whom they are directed. This includes children and adolescents, who need to be consulted and involved in ways appropriate to their age and development”

The pressures placed on parents and carers when young people experience mental ill-health can be significant. This has been recognised for some time and in Britain the requirement to engage with carers to assess and meet their needs has been established through the National Service Framework for Mental Health, Standard 6. In a broader sense the importance of engaging carers' expertise in helping to shape individual care plans and in contributing to service planning and evaluation is also widely recognised and methods for doing this have been described (eg. Carers Northern Ireland, 2000). In view of these issues the case for involving service users and carers in the most significant review of CAMH services ever undertaken in Northern Ireland is clear.

What consultations have been carried out to date?

Within Northern Ireland many consultations have been carried out, mostly with parents/carers and some with young people. Most have been studies of client satisfaction and few appear to have been published. A number of projects have been written up, however, and are available from the authors or services involved. For example, the Family Trauma Centre has presented its own exploration of client views about family therapy (Harrison and Brown, 2003). In this qualitative study five families were invited to discuss issues surrounding the process of therapy. Transcripts of the recorded discussions were analysed into themes and these have been used to inform the centres thinking and policy around issues such as providing information to minimise client anxiety and misconceptions, including siblings and maintaining a flexible open door approach.

Using a brief semi-structured interview, Gordon, Russo and Hughs (2005) have explored the experiences and understandings of children and adolescents attending clinical psychology outpatient appointments at the Royal Belfast Hospital for Sick Children. Content analysis of the responses of 15 young people aged between 7 and 17 years suggested that all of the children considered their attendance at the service to have been positive and helpful and all had a clear understanding of the role of the clinical psychologist. Younger children had more difficulty verbalising the manner in which the therapeutic experience was helpful. Adolescents were able to comment on the therapeutic experience and describe how it was helpful. An important finding was that many of the young people were not consulted at the point of referral and many initially did not know why they were attending.

The study helps clarify some issues about consulting with young people at different ages and developmental stages and is a helpful support to the body of research that makes clear that children can be meaningfully consulted about their experience of receiving care.

A significant consultation was undertaken recently by Voices of Young People in Care (VOYPIC) and The Young People's Centre (YPC). Although unpublished, the project methodology was presented to the Review's CAMHS working group. In an attempt to integrate a clear model for involving adolescent service users in service evaluation and development, the YPC sought support from VOYPIC to develop a model that enabled young people to "have their say" in a way that allowed them to have a meaningful impact on service delivery and planning.

Using a participatory action research model young people attended a series of ten group sessions and were involved in designing, conducting and, presenting the results of an evaluation of the service. Evaluation of the project suggests that it met its aims. The experience of VOYPIC workers appears to have provided crucial learning for the YPC in terms of user involvement in project development, design and implementation. There were also indirect benefits as it established pathways to promoting advocacy within the service. Also among the outcomes was a raising of expectations about what services young people should and could receive alongside the support that staff require to ensure standards of good practice. This project is significant in that it is one of the few conducted locally in which consultation was developed as a process rather than a single event. While such an approach is not feasible for the CAMHS review's own consultation, it has much to offer as a guide to subsequent projects.

There are at this stage many examples of good practice in consulting service users and carers about CAMH services. One of the most useful is that carried out recently for the Scottish Needs Assessment Programme (Public Health Institute of Scotland, 2003). A broadly based description of the strengths and weaknesses of Scottish CAMHS was seen as essential to a three-year programme of needs assessment. The consultation had two phases. In the initial phase public health directors, planners and leaders of health services were surveyed to develop an account of strategic and operational activities related to CAMHS. In the second, three groups were surveyed: young people and parents, people working routinely with young people and people who specialise in mental health work with children and young people. Service users and carers were specifically engaged through a series of seminars, a national one for young people and three regional seminars for people with an interest in CAMHS including service users. Service user and carer input to these seminars had a significant impact on the Needs Assessment as is evident from the following summarising comment from the consultation report:

"In order for children and young people and their parents to get the sort of services they require, it will be necessary to build into the system a lot of 'second chances'. If a service or resource does not suit someone or they cannot manage to

attend at the time given then there needs to be an alternative, which is readily available. It is also the case, however, that many young people and their parents are not getting to have their first chance: parents and young people have spoken about not getting help when they need it, how things have to become serious before help is offered...Both young people and parents are quick to acknowledge the right type of support or someone who goes the extra mile for them. The task ahead is to ensure that these good examples become the norm across Scotland”

(Public Health Institute of Scotland, 2003, p66)

It is also clear that young people themselves can be important contributors to consultations. ‘Highlight’, a monthly publication from the National Children’s Bureau (NCB), discussed young people’s views of CAMHS in their September 2004 edition. It noted that there is a steadily growing body of literature examining young people’s understanding of emotional and mental health issues and their experiences of health services, including CAMHS. An overview of this literature by the NCB has revealed a number of themes that emerge consistently from such consultations. These themes are summarised in box 2. In addition, the literature has revealed that young people have expressed clear opinions concerning inpatient care and treatment including the daily routine, range of therapies, use of the Mental Health Act and the management of difficult behaviour.

Box 2. Consultation themes identified by NCB

- Importance of information sharing, specifically about treatment
- Importance of young people feeling their views are being listened to
- Having staff who are available, approachable and skilled in engaging with young people
- Placing value on:
 - Young people’s ability to consent;
 - Confidentiality
 - Need for privacy
- Establishing relationships with staff over time
- Services to be age-appropriate
- Transition between CAMHS and adult services
- Timing and flexibility of appointments (evening appointments and drop-in services)

Source: National Children’s Bureau, 2004

How have consultations been carried out to date?

Quite a broad range of methods has been used to consult with CAMH service users and carers. This has included questionnaire surveys, focus group discussions, seminars and individual interviews. The consultation process

implemented by service providers in the London Borough of Kensington and Chelsea represents excellent practice as the links between consultation and policy development have been clearly evidenced. A report produced by the borough describes it as having a comprehensive and co-ordinated CAMHS based on a clear philosophy, sound inter-agency partnerships, effective practical assistance and good planning of service delivery. The services are developed on the basis of understanding needs, consultation and clarity about desired outcomes.

The borough's CAMHS strategy for 2000-2003 was developed in consultation with service user and carer groups and a number of specific projects have been initiated in response to need assessed in collaboration with users/carers and designed with user/carers co-operation and support. An example is the Sure Start project developed in Golborne Ward. An extensive consultation process included innovative methods such as events for parents with complementary beauty and therapy sessions; video boxes at local events; a multi-agency planning day; lunch time meetings for social and health care staff; articles in the local papers. The result was considerable success in eliciting the views of the local community as well as publicising Sure Start and opening a dialogue with all agencies working in the area.

In 2004 The Department of Health published the National Service Framework (NSF) for Children, Young People and Maternity Services. It establishes clear standards for promoting the health and well-being of children and young people and for providing high quality services, which meet their needs. The NSF is composed of eleven standards of which Standard Nine is devoted to the Mental Health and Psychological Well-being of Children and Young People.

Standard Nine acknowledges that it has been challenging for CAMHS to ensure the participation of children and young people and their families at all levels of service provision but that it is clear that a variety of creative approaches are needed to improve participation and user involvement. The overall vision is for "the views of children, young people and families being valued and taken into account in the planning and evaluation of services" (Dept. of Health, 2004, p.87). Specific guidance is given such as:

"Inclusiveness can be promoted by providing a welcoming and responsive environment for discussions with young people, children and their families, and ensuring that meeting times and locations are sensitive to providing local access, travel, childcare and other personal needs."

(Dept. of Health, 2004, p91)

The document also endorses and promotes the principles set out in Learning to Listen: Core Principles for the involvement of Children and Young People (DfES, 2001). Insofar as it has been possible to do so, the current study has attempted to follow the values established in this and other relevant documents.

What can be achieved by a consultation with CAMH service users and carers on behalf of the Bamford review?

The Review of Mental Health and Learning Disability has been clear in its intention to engage consumer expertise as a means for testing out its ongoing work and proposals. The purpose of the present consultation was to attempt to secure significant involvement and a wide discussion among users of CAMH services in Northern Ireland, both young people and adults, about their experiences of CAMH services. Specifically, views are sought on current provision in terms of both its strengths and weaknesses and on how users and carers would like to see services change and develop in the future.

Clearly there are limitations placed on this exercise by the limited time and resources available to complete it. The sample group, for example, is one of convenience and as noted above different, richer information is typically gathered from consultations that involve people in a process rather than a one-off meeting or questionnaire. Nonetheless useful information has been gathered and presented to the Review's CAMHS sub-committee. It is also hoped that the dissemination of these findings and the resources referred to in the current paper will support a developing culture of user and carer involvement in planning, providing and evaluating CAMHS provision in Northern Ireland.

Method

The consultation involved a two-step process of a survey-based open-ended questionnaire and a series of four focus groups. Such qualitative methods have been widely employed in other healthcare settings and generally elicit a more full and complete picture of the needs and wishes of participants than more structured or quantitative methods. Ethical scrutiny and approval was provided by the research ethics committee at the School of Psychology, Queen's University Belfast.

Questionnaire survey

Participants

Questionnaires were distributed to randomly selected sites in the CAMHS network across Northern Ireland. In view of the time and resource limitations on the project, selection of questionnaire sites was largely determined by ease of contact and the preparedness of practitioners and managers to commit staff time to organising the completion and return of questionnaires. This approach results in a convenience sample that is biased towards statutory provision. Nonetheless significant co-operation was provided and questionnaire packs were distributed to sites as indicated in box 3.

Box 3 Questionnaire study distribution			
Area	Tier 2	Tier 3	Tier 4
Northern Board	2 sites		
Southern Board	4 sites	3 sites	
Western Board	1 site	1 site	
Eastern Board	3 sites	2 sites	3 sites*

* Sites hosted in Eastern Board area and including one Youth Justice site.

Process

An open-ended questionnaire was designed which posed three brief questions in order to encourage participants to comment freely in terms of areas of concern and level of detail. The small number of questions increased the likelihood of participation and targetted the core concerns of the investigation. They asked;

- 1) What has been really good about the service you have received?
- 2) What have you not liked about the service and how could it be improved?
- 3) Tell us anything else that you think we should hear about CAMHS.

Each site received a questionnaire pack providing all information and documentation required in order to provide participants with information about

the consultation, collect participant consent, and return completed questionnaires. The pack included the following:

- ❑ Guidance notes for person distributing questionnaires
- ❑ Information sheet: 'What to say to clients about the survey'
- ❑ Information for Directors
- ❑ Consultation information leaflet
- ❑ Questionnaire returns cover sheet
- ❑ Questionnaire returns envelope
- ❑ Cover/consent/questionnaire forms and envelopes

Services were encouraged to distribute questionnaires on a single day between 13th and 15th October, 2004 in order to provide a 'snap-shot' of service users' and carers' views.

Thirty completed questionnaires were received from tier 2, twenty-three from tier 3 and ten from tier 4.

Focus group discussions

Process

A total of four focus groups were conducted during September and October, 2004. The aim of the focus group discussions was to provide a more detailed picture of the likes, dislikes, and concerns of service users and carers. They also aimed to provide a forum for the exchange of information and ideas concerning the future direction of services in Northern Ireland, from users/carer perspectives.

Two focus groups for parent and carer groups were facilitated by an experienced user advocacy worker. In addition, two groups were organised for young people who were service users and involved peer facilitation. The rationale for this was to allow the young people to identify with the facilitators and thus encourage a more open and frank discussion of the issues. The young people who facilitated the groups had been involved in a service provision project in Craigavon and Banbridge Trust and in the course of this project had received training on group facilitation skills. They were provided with further training by staff from the young people's advocacy organisation, Voice Of Young People In Care (VOYPIC).

Participants

Focus group 1 was conducted with a group of eight parents/carers whose children had been seen by CAMHS in the SHSSB area. As well as receiving services from the Tier 3 CAMHS team or Community Paediatric Service, they had completed a ten week parent support programme and were members of the Parenteen Association, a project supported by Craigavon and Banbridge Trust's Young Person's Project (YPP). The YPP is a social work initiative which engages marginalised youth and supports and empowers young people at risk.

Focus group 2 was conducted with a group of six parents and carers. Two had been invited through their connection with the Young Peoples' Centre, as parents of young people who had been inpatients with this service. These parents also had experience of using services at tier 2 and 3. The other four participants were foster carers connected through The Fostering Network, all of whom had had experience of caring for young people who were in contact with CAMH services.

Focus group 3 was conducted with a group of eight 16 to 20 year olds who were all involved with VOYPIC and had been selected on the basis of having had previous experience of using CAMHS services in the Belfast area.

Focus group 4 was conducted with three young people aged between 14 and 16 who had ongoing experience of using services in the WHSSB area. This group suffered from non-attendance by a significant number of previously confirmed participants. Nonetheless it was felt by the two facilitators that the smaller group encouraged participants to engage more meaningfully in the process and considerable depth and detail of information was elicited.

In total twenty-five people participated in focus group discussions. The discussions were audio taped and later transcribed for analysis.

Analysis

Analysis involved two investigators independently reading transcripts of focus group discussions and questionnaire responses. For the questionnaire data 216 individual statements were arranged into categories representing identifiable themes. Readings of focus group material allowed themes to emerge from the transcripts in a similar manner. Themes were then further analysed by the two investigators independently into hierarchically organized categories. This approach to interpreting qualitative data is a recognized form of content analysis known as Interpretive Phenomenological Analysis (Smith, Jarman and Osborn, 1999). Finally the two investigators came together to compare results of their independent analyses and resolve them into models representing the thematic content of the data.

Results

Analysis of responses from the questionnaire and focus group elements of the study produced themes that overlap but also differ in significant respects. Consequently the results of both parts of the consultation are presented independently.

Questionnaire findings

A summary of the questionnaire findings can be seen in the model in Box 4 which presents the derived categories and subcategories in terms of positive comments and criticisms. Around 60% of these categories can be seen to express positive views with around 40% expressing criticisms of CAMH services. More detailed descriptions of the categories are presented below.

Box 4 Thematic content of questionnaire responses

<i>Positive comments</i>	<i>Criticisms/recommendations for development</i>
<p>1. Service presence and responsiveness</p>	
	<ul style="list-style-type: none"> ❑ Information provision ❑ Service flexibility ❑ Accessibility <ul style="list-style-type: none"> ○ Waiting times ○ Resource limitations ○ Practicalities
<p>2. Process and experience of attending services</p>	
<ul style="list-style-type: none"> ❑ Connecting <ul style="list-style-type: none"> ○ Interpersonal skills ○ Solidarity/support ○ Affective engagement ❑ Professional communication 	<ul style="list-style-type: none"> ❑ Connecting <ul style="list-style-type: none"> ○ Interpersonal skills
<p>3. Outcomes</p>	
<ul style="list-style-type: none"> ❑ Endorsements ❑ Advice and guidance 	<ul style="list-style-type: none"> ❑ Advice and guidance ❑ Preferred service models

1. Service presence and responsiveness

Comments in this area refer to the degree to which services are known and understood within the community. Comments also referred to the perceived accessibility and flexibility of services. A number of specific sub-categories were identified:

Information provision Comments in this sub-category were addressed at how well users felt the service was advertised within the community and to what extent they felt they understood what a service had to offer.

Service flexibility These comments refer largely to the degree to which appointments could be offered in a manner that suits users and carers.

Accessibility Comments referring to issues of access to services. Three specific areas were identified:

- **Waiting times**
- **Resource limitations**
- **Practicalities**

2. Process and experience of attending services

Comments in this area refer to how people have experienced attending CAMHS, particularly with reference to their interactions with workers and other users. Two aspects to this emerged referring to the human experience of these interactions (Connecting) and to the experience of receiving and responding to professional or formal communications (professional communication)

Connecting Within this area three sub-categories were identified:

- **Interpersonal skills**
- **Solidarity/support**
- **Affective engagement**

Professional communication This category described the experience of sharing information and formal communication with CAMH service providers.

3. Outcomes

Comments in the sub-categories of this area are evaluative of the outputs of CAMHS services.

Endorsements A large number of non-specific positive evaluations of services were recorded

Advice and guidance These comments identify and evaluate directions given by services that led to or failed to lead to changes or improvements

Preferred service models With these comments, participants have communicated their ideas about what mode of delivering services they feel be more useful to them

Summary and discussion

The category with the highest proportion of positive comments was **Process and experience of attending services**. The majority of responses indicate that participants experienced contact with CAMHS workers as being positive, agreeable and helpful. These similarities suggest that the interpersonal contact between CAMHS workers and users is an important and valued aspect of both parents' and young people's experience of CAMH services. Within tier 2 and 3 responses there was no indication of dissatisfaction in these areas. Particularly notable were the responses of young people who had experienced CAMHS work within a group setting. A significant number of responses indicated that they had found the experience of working alongside other young people particularly helpful.

Responses from tier 4 participants were more balanced in this area. Many comments indicated satisfaction with staff communications and supports and

the helpfulness of experiencing solidarity with other young people in the residential setting. Tensions particular to this setting, however, were also described. A small number of comments indicated dissatisfaction with relationships between young people and staff while a more significant number of comments identified young people's dissatisfaction with the level of control they could exert over practical decision-making within the residential setting.

The category within which most dissatisfaction was expressed was ***Service presence and responsiveness***. Within the sub-categories defined above, responses overwhelmingly indicated dissatisfaction. In summary, participants indicated that they would like CAMHS to be more widely publicised and understood within the community. They would like these services to be more accessible in terms of having referrals made promptly when required and accepted by services. They would like shorter waiting lists, more flexible working practices in terms of appointment times and, in some cases, to have shorter distances to travel to appointments. Many parents/carers also demonstrated considerable knowledge with regard to their young people's specific needs and the type of services that could meet them. Dissatisfaction was expressed that more specialist services – such as for the assessment and treatment of attachment and eating disorders – were not available.

Recommendations for CAMHS developments were also offered within the category defined as ***Outcomes***. For example, some parents/carers identified access to respite as a need to help them cope with their young person's mental health difficulties. Others indicated that they would value access to more literature that they could consult at home. Access to help-lines was also suggested.

Some dissatisfaction with outcomes was indicated among comments that related to frequently changing diagnoses and workers, delays in accessing medication and minimal or no improvement experienced despite input. On balance however, the majority of questionnaire responses were positive suggesting that for this group of participants, who were in ongoing contact with CAMHS, there was a considerable level of satisfaction with the help they were receiving.

Focus group findings

Content analysis of the focus group transcripts revealed a similar overall structure to that derived from the questionnaire data. The tone of comments was somewhat different, however, and extra detail emerged resulting in a slightly different sub-category structure. Some differences emerged between the views of carers and young people, but for ease of presentation the findings from all four focus groups will be collapsed under the headings of ***service presence and responsiveness, process and experience of attending service*** and ***outcomes***. Discussion of differences follows in the summary to this section.

A summary model of the focus group findings can be seen in Box 5, which presents the categories and subcategories in terms of positive comments and criticisms. 12% of these categories can be seen to express positive views with

88% expressing criticisms of CAMH services. The additional sub-categories are described below.

Box 5 Thematic content of focus group discussions	
<i>Positive comments</i>	<i>Criticisms/recommendations for development</i>
<p>1. Service presence and responsiveness</p>	<ul style="list-style-type: none"> ❑ Information provision ❑ Accessibility <ul style="list-style-type: none"> ○ Waiting times ○ Resource limitations ○ Frustration/disappointment ❑ Incomplete services
<p>2. Process and experience of attending services</p> <ul style="list-style-type: none"> ❑ Connecting <ul style="list-style-type: none"> ○ Affective expression 	<ul style="list-style-type: none"> ❑ Connecting <ul style="list-style-type: none"> ○ Solidarity/support ○ Practicalities ❑ Stigma ❑ Professional communication <ul style="list-style-type: none"> ○ Trust ○ Consultation/being heard ○ Perceived indifference
<p>3. Outcomes</p> <ul style="list-style-type: none"> ❑ Endorsements 	<ul style="list-style-type: none"> ❑ Lack of improvement ❑ Resignation ❑ Preferred service models

1. Service presence and responsiveness

Frustration/disappointment Several parent's/carer's spoke of their disappointment with service accessibility. They described frustration and the need to struggle to gain the attention of CAMHS. The concept of being driven towards an attention seeking action to gain help was mentioned.

Incomplete service Several comments were made which focused on additional services the young people and carers would like to see

included and the sense that some participants had of something missing from their experience of CAMHS.

2. Process and experience of attending services.

Affective expression Parent's/carer's expressed both positive and negative sentiments in regard to how they felt during and as a result of contact with CAMHS.

Stigma The young people spoke of their fears and experiences of the negative views held about them as CAMHS users by peers and others in the community.

Trust Comments were made which referred to the parent's/carer's having to place their trust in CAMHS professionals to gain help for their children and of their willingness to do so. A sense of feeling powerless and having no alternative was, however, conveyed in some of the comments.

Consultation/being heard In contrast to comments in the Trust category outlined above, some parent's/carer's expressed a desire to be informed and to have more of a say in their children's treatment. The young people similarly expressed a feeling that at times, they were not being listened to.

Perceived indifference Some parent's/carer's felt that their treatment by CAMHS was at times dismissive.

3. Outcomes.

Lack of improvement A number of Parent's/carer's discussed a lack of progress in their children's behaviour despite receiving treatment. Examples of such comments include:

Resignation A small number of parent's/carer's expressed such frustration with a lack of progress that they looked forward to their responsibility towards their children ending when they reached the age of 18.

Summary and discussion

Out of a total of 16 categories only two referred to generally positive appraisals of CAMHS. These were in areas that related to how services made the parent's/carer's feel about their parenting and how positive changes in the young people's behaviour had resulted from participation with CAMHS. The majority of categories detailed both parent/carer and young people's dissatisfaction with CAMHS provision.

A single core category was found to be consistent across all focus groups. Described in the area of **Service presence and responsiveness**, the desire for easily available, useful information about services, was discussed alongside the need for a greater presence to inform the general public of the function of CAMHS. Among parents, the lack of information provision was accompanied by a strong sense of frustration that they couldn't find what they needed. The young people also commented on its absence, and how their

experiences of mental health services could be improved if they received adequate information.

A number of unique categories were produced which seemed to highlight important perspectives in focus group participants' experiences. Among the parents/carers these included categories such as ***perceived indifference, resignation, lack of improvement, and preferred service models***. The first two of these appear related, in that some parents/carers felt so beleaguered by their child's difficulties that they look forward to the day when they are no longer legally responsible for them. Comments were made which highlighted the desire for more support groups and respite and specifically for more consideration of the needs of carers. Similarly, a lack of improvement in their children's condition moved certain parents/carers to suggest ways in which they would like to improve CAMHS. Among young people, the category of ***stigma*** clearly emphasised how these service users felt about their experiences of mental ill-health.

Described in the area ***Process and experience of attending services***, an important broad theme to emerge from the focus groups referred to the feeling of not being listened to and trusted. Centred around feelings of being 'left out' of decision making, this may reflect that a 'top-down' approach is employed in CAMHS settings when interacting with service users. The similarities in views expressed by young people and adults of CAMHS being expert-led with insufficient regard given to their points of view appeared to contribute to an expressed sense of resentment for some participants. This is clearly an important finding, suggesting that a concerted effort must be made by CAMHS if a widespread culture of inclusion is to be achieved, where the views and opinions of workers, users and carers are valued equally.

Whilst many of the comments gathered from the focus groups tended towards negative appraisals of aspects of CAMH service delivery, most participants acknowledged some beneficial effects and CAMH services appeared widely valued. Some of the comments made may reflect misunderstandings about how services work (eg. the idea that clients should always see the 'head consultant'). Such misunderstandings may evidence the need for better communication about CAMH services. Finally, while some of the dissatisfaction expressed relates to specific aspects of service delivery, lack of flexibility and accessibility were the main sources of dissatisfaction. Many of the critical comments outlined above may best be understood as representing the frustration users and carers feel when unable to access a service that addresses their particular family's mental health issues and support needs at times when it is most required.

Discussion

In total eighty-eight participants provided views on their experiences of using CAMH services, either by completing a questionnaire or taking part in a focus group discussion. An initial conclusion must be that there is considerable willingness on behalf of CAMHS users and carers to take part in consultation exercises. Participants communicated a wide range of views about CAMHS and many of these were consistent with themes identified by the National Children's Bureau (2004)[see box 2].

Some differences were evident in the nature of responses received in the two distinct elements of the consultation. Considerably more detail was captured through focus group discussions. Participants in these discussions were, on the whole, more critical of services than were questionnaire respondents. There may be a number of explanations for this, among them being the differential constraints and encouragements of the two consultation methods. While questionnaires reach more people they inevitably elicit less information. This is a reminder that there are limitations on any consultation process as a result of its methodology. While the current study succeeded in achieving considerable support from colleagues working in CAMHS provision and from within the Review of Mental Health and Learning Disability support team, it was carried out under the constraints of limited available time and resources.

Due to inherent limitations to the scope of this project, delivery of a definitive or fully representative description of CAMHS users' views could not be achieved. The consultation provides a static and limited account of these views; material best used as part of a developing process of user involvement. Many of the views are unsurprising (eg concerns about long waiting lists and difficulty accessing services) and providers will have no difficulty in recognising the frustrations of many people referred to CAMHS. Others may be more difficult to countenance, for example the perception of staff indifference described by some participants or the resignation to irreparable relationships expressed by some parents in view of an absence of appreciable progress with a young person's presentation. The present approach to consultation cannot provide estimation of the extent of applicability of any of these sentiments among CAMHS users, but all of the issues voiced represent a concern for someone.

Findings from the questionnaire study showed that to a large extent service users felt positive about their contact with CAMH services. Clearly the interpersonal contact and communication between users and providers is for many a strength in current provision. However, more detailed responses from the focus groups may provide an indication as to how this strength can be further improved. Many participants stated that they did not feel consulted or heard during their treatment or during the treatment of their children. Perhaps a more explicitly user-focused approach that attempts to integrate the opinions and views of users consistently and transparently into decisions about treatments would help address these concerns.

The issue of a lack of information provision and understanding about the role of CAMHS in the community was something highlighted in both questionnaire

and focus group responses. Participants felt that CAMHS needs a higher profile to contribute to public understandings about mental health issues and to alert families who might benefit from the services. Many stated how they regretted not knowing what CAMHS had to offer sooner as they felt this delayed their receiving help for their children. This may indicate that some level of public health information campaign is required to highlight the mental health needs of children and adolescents. Such a campaign could publicise the role and function of CAMHS in order to reach those families who could benefit from some form of service provision. Such a campaign could also address the stigma and prejudice undoubtedly experienced by young people and their families.

One of the clearest lessons from the consultation is that carers as a group have complex needs and sophisticated views about CAMHS. Research has indicated that professionals can hold confused views of carers, seeing them as resources or co-workers or clients or some combination of more than one of these roles (Twigg, 1992). Despite the type of support offered being inevitably shaped by these conceptualisations, such complex issues are rarely taken into consideration when planning service development. Further detailed consultation with carer groups at local and regional levels would help to clarify carers' needs, what carers can bring to services and what might be the best ways of negotiating around these issues.

Methodological issues.

Perhaps the most significant limitation of the present consultation is in the sample group. In view of constraints this was a convenience sample acquired on the basis of ease of access. Information is not available in terms of the distribution of demographic and socio-economic characteristics in the sample and while it is of a reasonable size and relates to a range of forms of provision, it could not be said to be representative of the population of CAMHS users, particularly in view of its bias towards statutory provision. Moreover, at least with regards to the questionnaire sample, the CAMHS clients surveyed were continuing their contact with services. The views of the significant group who have disengaged from CAMHS have not been accessed and it is possible that this contributes to a positive appraisal bias in the sample.

With regards to the focus group study, consecutive groups ideally should be run with different groups of people until the researcher concludes that no new information is being generated (Chambers, 2000). While there was considerable commonality between the content of the four groups it is not clear that this critical mass of information has been achieved and there may well be views held within the population of people using CAMHS which are not here represented.

Conclusion and recommendations.

As well as indicating satisfaction with many aspects of CAMH services, the users and carers consulted in this project have highlighted much dissatisfaction and offered many suggestions about how their concerns might be addressed. While the present paper does not attempt to provide suggestions about how each concern should be addressed, the following list summarises some major development areas for CAMHS as identified by service users:

- Increase service capacity at all tiers of provision to improve general accessibility and reduce unacceptable waiting times, and to address limited or absent availability of specialist services to specific groups.
- Establish a public health information campaign with regard to child and adolescent mental health and improve information provision to communities about their local services.
- Develop models of treatment and service provision that are increasingly collaborative in terms of developing care and treatment plans and sharing information.
- Implement assessment models that evaluate the needs of carers and other family members as well as identified patients and that utilize the expertise available within families about how help should be provided.
- Establish as standard practice user-focussed evaluation of CAMH services to include investigation of their overall public health impact.

In order to make this consultation genuinely meaningful rather than tokenistic, it must represent a stage in a developing process of involving CAMHS users in setting priorities for CAMHS provision and development; a principle promoted by the Review of Mental Health and Learning Disability Services. A next stage in this process of engagement may be a commitment to quantifying user concerns in areas highlighted by this consultation. Crucially structures should be established to ensure user/carer involvement in the future shaping and monitoring of CAMHS.

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