

Agenda Item 4

Report CT&F 01/01

Reviewing the Child and Adolescent Mental Health Service – eliciting the views of young people Rosie Smithson July 2009

Research Methodology

The research method employed was an adaptation of Grounded Theory¹ – in that it is qualitative and did not begin with a hypothesis to be tested, but rather, through the use of a set of open-ended questions with individuals and small groups, generalisations have been drawn from responses.

Notes were made by the interviewers and read back to the participants to check for accuracy and agreement. No taped recording for transcripts was made as it was important for the interviewees to be as comfortable as possible, given the nature of the research.

The main findings have been drawn from comparisons of all the specific responses, analysing these and extracting general points which have been categorized. However, if a single response was made which was considered to be significant, this has been referenced.

The interviews were conducted largely by adults who were working within the settings – the exceptions being the Prince's Trust groups who were interviewed by the lead researcher. Eighteen interviews were conducted one-to-one, all other interviews took place within small groups (3 to 7 people)

1: Strauss AC and Corbin J (1998) Basics of Qualitative research techniques and Procedures for Developing Grounded Theory

Ethical Considerations

All young people were given an explanatory statement to read which outlined the purposes of the research. An adapted version was available for young people with Special Educational Needs.

Parents/Carers/Guardians of young people under 16 were given a copy of the explanatory statement and were asked to sign an informed consent form. All young people participating were asked to sign an informed consent form – an adapted version was available for young people with SEN.

All young people were aware they could withdraw at any time without prejudice. All were assured of confidentiality and anonymity.

Although it was made clear no promises could or were being made, the young people who participated in this research gave up their time freely, allowing their experiences to be documented, to contribute to and inform debate around developing support services for young people.

Interviewees and Settings

A total of 55 young people aged between 13 and 22 were interviewed between November '08 to July '09.

The young people were involved with a range of Tier 2 services: Two youth centres; Four Princes Trust groups for young people Not in Education, Employment, or Training; One Women's Aid Refuge, One group run by 'Mind' (The Junction) – eight settings in total.

The settings were from across five Essex districts – Tendring, Colchester, Chelmsford, Basildon, Harlow and included four towns (Colchester, Harlow, Basildon, Chelmsford) and two large 'villages' (Dovercourt, Galleywood). Some young people travelled to the settings from rural locations.

The interviewees were a representative sample of males and females. The groups included young people from black and minority ethnic groups and young people with special educational needs. In addition interviewees included young people living in temporary accommodation, 'Children Looked After' and a teenage mother.

Although all these young people were currently receiving support from Tier 2 services, in discussion, a number reported that they had received or were receiving Tier 3 support. No young person reported having received in-patient support or outreach at Tier 4.

Main Findings

Emerging Concerns:

Relationships

- Bullying was raised as a significant issue by young people – particularly for those under the age of 16. Concerns about 'violence' and 'gangs' and 'getting into fights' were referenced by three individuals.
- Difficulties with relationships however emerged as a significant issue across the whole age range – with specific references to parents/families/school.
- 'Peer pressure' and related concerns about 'fitting in' and 'standing out', being 'too small' or 'overweight' were also reported.
- Additional concerns were about 'being judged' and coping with 'prejudice' and being 'stereotyped'.

Housing

- A significant number of young people referenced housing as a real concern. There were several young people who had become homeless due to family breakdowns. Two were, at the time, 'sofa-surfing'.
- Concerns related to the quality of the housing provided given its cost, paying for 'additional' service charges, as well as the difficulty in getting emergency housing or advice and support when needed – in some cases this was because the young people were considered to have made themselves 'intentionally homeless' – which they regarded as unfair given the circumstances.

Health

- A number of young people referenced concerns about their health – physical as well as mental health. Sexual health (specifically SDIs) and 'pregnancy' were referenced as concerns among those young people at the older end of the age range.
- A number of young people who had been made homeless due to family issues sited problems with drugs/drinking as the cause of the family relationship break-down.
- Concerns about weight and food were reported – although actual concern about eating disorders was referenced by a single individual.
- 'Depression' and 'anxiety', having difficulty with 'life' and 'survival' and dealing with 'anger' were reported.

Money

- Not having enough money was a significant issue – particularly for the young people who were living independently of families and reliant on benefits. Getting into debt and/or being evicted were very real concerns for some of these young people.
- A related issue was finding work in the current recession which was the cause of a lot of anxiety.
- Having a criminal record was referenced as a concern in regards to getting a job by one individual.
- Accessing advice about benefits/debt and accessing benefits themselves was the cause of great anxiety for a significant number of young people over 16. Hardship payments were difficult to access.
- A related problem referenced by a single individual was dealing with gambling.

Education-based concerns

- Coping with course work and exams, concerns about competing for college places, finding a suitable course after leaving school, getting the right help when you struggle at school were reported by a significant number of young people.
- Among the Prince's Trust groups, not getting the right help at school for their SEN (dyslexia and ADHD were referenced) and therefore becoming

disengaged, was seen as significant for a number of young people, leading to poor or non attendance in KS4, being excluded and/or leaving without qualifications.

- For young people living in temporary accommodation (Women's Refuge), starting at a new school caused anxiety.

Accessibility of Information/Services

Finding information

There was wide variability reported about the ease in finding information about support services. A small number stated that it was 'easy' to find information independently – these young people sited the internet, posters and leaflets at Connexions and Youth Centres. Television adverts were reported as useful for information about training opportunities: e.g. Learn Direct. The majority however had gained information via significant adults - referencing parents, friends, youth workers, Midwife, Connexions PAs, key worker in refuge or YMCA, mentors, probation officer, mental health nurses, social workers, tutors in school, GPs and key workers in drop-in centres such as The Junction. Many of these offered support as well as signposting additional services. The few individuals who referenced 'school' sited assemblies and information in school library and form rooms – with one comment being 'schools should bring in more outside people to talk to us'.

Additional comments included information was 'easy if you know where to look, 'depends where you live' and 'good ones are hard to find'. 'Word of mouth' was referenced, as one young person reported 'Young people trust other young people'.

Getting information about available support however is just the start – a significant response was that it was not always easy to access the appropriate support at the time it was most needed.

Accessing services

Young people, as reported above, get information and advice from a range of sources, including from people working across different services. All the young people involved in the research were receiving support from Tier 2 services – generally regarded as helpful and supportive – however, getting access to specialist support or accessing advice about specific issues was seen as more problematic. As one young person commented, it was possible to get 'into a chain where you're just moved on' in that they were referred to someone who referred them to someone else with no one really 'dealing with the issue' itself. The consequence of this for some of the young people interviewed was that they were 'fed up with trying places'.

Getting access to timely advice was an issue. A number of young people reported clashes of opening hours of some services with college/work times. The Citizen's Advice Bureau was considered generally very helpful for practical

advice/support relating to debt/form filling/employer disputes, but limited opening times and usually very long queues created access problems.

Many services have town-centre locations which are accessible for those living nearby, however young people who lived outside of the town reported lack of bus routes at the times needed or of travel costs limiting/preventing easy access. A number of young people reported going to their GP, however one young Asian woman said this was not an option for her as a member of her family would always accompany her, therefore preventing her from speaking freely.

Services which were not appointment-dependent were appreciated – e.g. Open Road, Connexions, The Junction, The Townhouse, Youth Centres (including the Youth Bus). However, opening hours for these services vary considerably across the county and not all open evenings and weekends.

Accessing Childline using a mobile phone is not possible without credit.

Experience of Support Services - key issues

The young people interviewed were all positive about the settings they were currently involved in. However variable experiences were reported across a range of other support services.

Consistency/Continuity

One recurring factor in whether a young person reported a positive, as opposed to a negative, experience was the importance of consistency of a key worker/contact. Several young people stated that they had felt 'nervous' or 'embarrassed' about opening up to someone, and therefore when key workers changed, particularly without prior warning, having 'got used to talking' they felt they had to 'start again' and found that difficult. In some cases they simply stopped seeking the support. One young person, who had been in care reported that six months after he'd turned 18 he received a phone call from his 'new' social worker to check he was OK. He hadn't been informed about the change nor introduced to the new person and therefore wasn't interested in engaging.

When only a limited numbers of sessions were offered, these were reported as not continuing long enough to really help. In addition, young people reported that when appointments with mental health nurses/psychiatrists took place every few months or less, this wasn't as helpful as regular contact.

Self-referral

When young people had identified an issue they wanted help with and therefore had directly self-referred or indirectly self-referred via a key worker, this was generally more successful than when counselling had been suggested to them as a response to them presenting with an issue or problem. Young people who had been referred to counsellors at school did not report particularly favourably about their experiences. This appeared to be because the young person had not

really wanted to attend, was not always fully aware of what to expect, the meetings appeared 'pointless' or with 'no direction' or that they simply didn't at the time 'feel ready' to engage. One young person reported that the sessions made them 'feel worse' as if 'everything' was their 'fault'. They reported leaving the sessions feeling 'depressed'.

Relationships

Feeling comfortable with whoever was offering support/advice was considered essential or young people reported that 'you don't want to tell them anything'.

When asked to identify what was or was not helpful, several factors emerged. Young people reported 'being listened to' was essential and that the person offering support should treat them with 'respect' and to be 'on their side' – in counselling, the first meeting was important in establishing this. As one young person reported 'I don't want to be patronised'. In a counselling session, one young person recounted her counsellor talking about her own experiences. This was not seen as helpful: 'I'd gone there to talk about me, not her.' In addition, one complaint which recurred was counsellors not addressing what the young people felt were the 'real issues': 'They talk about your week, but don't talk about the underlying problems which caused you to do what you've done'.

Positive experiences were reported when the person offering support appeared to 'understand' the young person and helped to point them in 'the right direction', giving them 'a helping hand to organise' themselves – such support was experienced across a range of settings, including schools. IPDAS was reported as being very helpful through giving clear messages: 'you get a reality check about side effects'. Support which solely consisted of listening- 'they didn't say anything' - without offering suggestions/advice was seen as unhelpful.

Short-term solutions, for the sake of expediency, often led to time and resources being wasted. Examples of this were young people being put on college courses which rapidly broke down as they did not suit the young person's interests or abilities, but had been set up to enable them to claim or continue to claim benefits.

Time

Time getting to know the young person with no pressure, prior to offering advice/support was seen as beneficial. Some young people reported that counsellors hadn't really built up a relationship before wanting to discuss issues. One young person, who described very positive outcomes from counselling, reported that the counsellor had spent the first few sessions getting to know him, going for coffee and 'chatting'. He was then asked if he 'felt ready' to talk. He was always given a written report to verify, enabling him to make changes if he didn't think the report represented how things had gone.

Practical Support

Services which are set up to offer practical support vary in how they work with young people. The Citizen's Advice Bureau was referenced by a large number of young people as 'very helpful' because they gave practical support in a number of ways without being 'judgemental'. The young people reported they got the advice they had requested. The only complaint was of the opening times.

Job Centres however were frequently criticised. Young people reported that they did not feel supported, well informed or 'listened to' and complained about the 'rules and regulations' and 'pointless' activities. Young people referenced the loss of letters and information by the Centres which led to benefit payment problems. In addition, the opening hours were not considered helpful.

Connexions was generally seen as offering a helpful service. However, one complaint was the age threshold for support stopped at 19, unless a young person had SEN. Young people, between 19 and 22, reported a general reduction in support available to them.

Tier 3 Support and Medication

Some young people reported having received Tier 3 support. Although psychiatrists were generally considered supportive, one young person reported frustration at not being given a 'firm diagnosis'. They wanted to 'know what they were dealing with' and considered discussions were too general.

The issue of medication was also raised. One young person with ADHD reported that once he refused to continue medication after some years, over concerns about long-term effects on his health, his psychiatrist would no longer see him, although he 'checked up' on how he was doing. Another young person reported that in meetings his psychiatrist didn't talk about problems, but asked whether he was still 'smoking weed' then handed out medication.

Help in a Crisis

Although very few of the young people interviewed reported having experienced a real 'crisis', those who did, did not report favourably about outcomes.

One young Asian woman and her sisters had requested to be taken into care, or at least to have respite for a few days from the family home. She reported that they were not listened to, that they were returned to the family home by the social worker, they were checked up on once, but received no follow up intervention or support.

Another young woman, when just turned 16, was made homeless following the breakdown of family relationships. She was placed in emergency B & B accommodation – of very poor quality – and eventually housed in Housing Association accommodation. The Housing Association did make telephone contact with her parents once, but no support was given to try to repair relations.

In addition, this young person did not receive advice about benefits and subsequently got into debt.

Implications of Research

- Dedicated support services need to be open more often at times when young people can access them – evenings and weekends. Some young people reported being particularly anxious about returning to school on Monday, and would like support to be available on Sundays.
- Young people indicated that they like to have the choice of drop-in sessions and appointments. Many like to talk when they feel they need to talk, as one young person reported, they may not ‘be in the mood’ at the arranged appointment time. On the other hand, appointments allowed them to organise travel and not waste time.
- Services need to make clear to young people what they can expect from support offered – to ensure expectations are realistic and support appropriate. Importantly, young people need to feel they are fully engaged in the process, they do not want to be rushed and they need to be listened to. These research findings reflect comments made in the report by the Thomas Coram Research Unit² that the skills support workers have are more important than the profession they come from and that the way young people are treated is more important than the model.
- Medication need should be discussed and explained, with young people’s concerns addressed. Medication may be understood to be of greater benefit if offered as part of a package of support not in place of it.
- Some services may need to consider how they currently meet the specific needs of young people from minority ethnic groups, particularly young Asian women.
- Given many young people’s concerns about housing, perhaps more could be done, earlier, to prevent a young person becoming homeless. Young people indicated drink and drugs were sometimes underlying causes of family breakdown. No young person reported any family interventions in support relating to drugs or alcohol.
- A report carried out by Connexions² in 2007 highlighted the issues around homelessness and the lack of understanding of the consequences and difficulties faced by young people when they made themselves ‘intentionally homeless’. The inclusion of a module in parenting support classes on the implications of homelessness for young people is a suggestion that this research would support being considered.
- Youth workers support some of the most vulnerable young people, they have up-to-date knowledge about young people’s experience of accessing services, the effectiveness of interventions and specific gaps. Their involvement in CAMH commissioning decisions could be particularly helpful.

- The effectiveness of independent counsellors employed by schools would benefit from more robust evaluation – governance arrangements and supervision as well as gaining young people’s views.
- Agencies which offer universal support for adults and young people, such as Job Centres, may benefit from training and advice on how to work with young people.
- A number of young people reported that they would like a specific website for young people, with ‘chat rooms with counsellors’. Several reported that a website signposting different types of support would be really useful. As one young person said, ‘it would be really good to know what’s out there’.
- Young people over the age of 19, who do not have specified SEN, continue to need support services. Several young people stated that there seemed to be a lot of support for under 18s and for older adults, but ‘nothing’ targeted at their age group.
- A number of young people felt the label ‘Mental Health’ in CAMH was off-putting, and suggested the name should be changed as they didn’t want to be thought of as ‘mad’ when they needed support.

2 Mental Health Crisis among Young People: Research Thomas Coram Research Unit (TCRU), at the Institute of Education, University of London, the Mental Health Foundation and Young Minds. 2007

3Connexions Sofa Surfing Audit Report Liz Martlew ECC 2007

How to Gain Young People’s Views about Services

- Many young people said they would be willing to fill in questionnaires/surveys – provided they were relatively short.
- Face-to-face contact requesting views was preferred by a number of young people who suggested discussion or focus groups or conversations.
- A number of young people said they would be willing to text their views about services.
- One young person strongly felt that young people should be invited onto decision making panels, to have the opportunity to read reports and to question decisions and actions.
- Using the internet to gain views was suggested by a large number, either through an on-line survey or ‘facebook’ type facility.

With thanks to the following people:

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The interviewees