



How Many Times Do We Have to Tell You?

A Briefing from the National Advisory Council About What Young People Think About Mental Health and Mental Health Services, by Paula Lavis and Dr Lesley Hewson.

Accountability to service users and the wider public has become a guiding principle for the NHS and a central theme of consecutive pieces of policy that place participation and involvement at the centre of clinical practice and service provision (Day, 2008).

Young people have been telling us for years about what they want services to be like - and the same themes are identified time and time again. The individual experiences and needs of the participants in the various studies are different, but there are common themes that are picked-up time and time again.

Some services do respond to what they hear and improve their services in line with the views of young people but this isn't happening everywhere (Worrall-Davies, 2008). A recent article by Robinson (2010) came to a similar conclusion, and cites an Audit Commission report which states that children and young people are 'consulted but not heard'.

Participation is the keystone of the arch that is the United Nations Convention on the Rights of the Child. It is unique and holds the whole structure together. Without it the framework falls. Without the active participation of children and young people in the promotion of their rights to a good childhood, none will be achieved effectively (Badham, 2002).

True participation work isn't always easy and it isn't always well resourced. Nor is it possible to implement everything that young people want. However, participation needs to be led from the top, be central to the management of services and feed into an ongoing cycle of quality improvement and not be seen as an optional add-on.

The new NHS White paper (2010) again prioritises the patients' experience and puts good outcomes at the centre of service provision. Healthwatch and the Local Healthwatches will be crucial to feeding in children and young people's views about services both locally and nationally, but for this to happen these organisations will need to have a strong voice. For instance every local HealthWatch will need to ensure that what young people say is incorporated into the Joint Strategic Needs Assessment, and the Local Health and Wellbeing Strategy.

There is a growing evidence base for what helps but also evidence that many children and young people are not accessing the services they need because they can't or won't seek help, or they are put off services because of negative experiences (Ford, 2005).

NAC Young People's Reference Group

The NAC prioritised participation at its inaugural meeting and set-up the Young People's Reference Group to inform their work. This small group of young people, with considerable experience of a range of mental health services, told us that the following topics are important to them:

- ❖ Good quality transition from CAMHS to adult services
- ❖ The importance of tackling Stigma
- ❖ Ensuring that the workforce is adequately trained
- ❖ Ensuring that what they say is taken seriously

This briefing is based on the work of the National Advisory Council's (NAC) Young People's Reference Group, and on a short literature review, which looked at papers and reports which involved consultations with children and young people. The reports were all published within the last ten years and look at what young people think about mental health, mental health services, the professionals who help them and other issues such as stigma. The briefing aims to highlight that these issues are not just experienced by a few young people who were involved with one research project, but have been expressed by many young people from different areas of the UK for over a decade. It begs the question of how many times do young people have to tell those involved in developing and providing services what they need before they are taken seriously and this is put into practice.

What Young People Think About Services

The type or range of services that young people want

Many of the studies identified that young people wanted access to holistic services that improved all aspects of their lives. They wanted services that met both their mental health needs, but also provided access to a range of other help and support.

Plus, they wanted the opportunity to take part in activities that were fun and creative, and helped them build a range of softer skills such as building friendships.

Flexible and Accessible Services

Young people say that services should be more flexible and accessible, and built around their preferences - available when and where needed – not '9 to 5' or 'wait until Monday'.

Young people have said that they want flexibility in opening hours; a choice of venue, which included their own home or a coffee shop; referral methods which included self-referral and drop-in services. They wanted to have different ways of contacting the services, such as email or text.

Services need to be in convenient locations that aren't miles away - this is a particular issue for rural areas. Some however prefer to go to a service in a near-by town because people are less likely to know them there.

Many young people wanted to have access to counselling services within their school, but some had reservations because of the stigma associated with going to a counsellor. It was suggested that a universal service such as going to the school nurse was better because people didn't know why you were going there. Another problem is that there are often long waiting times to see a school counsellor.

Sometimes they reported long waiting times. They wanted access to help and support when they needed it. They shouldn't have to wait any longer than young people with physical health problems. For instance, it is often those with a mental health problem who wait more than 4 hours in A & E (National Advisory Council, 2010).

Many young people reported that they wanted quicker access to help during an emergency. They wanted better out of hours, and crisis services, and inpatient units should be easier to access. Many young people reported that they are often forced to create a crisis to get help. How they are treated at times of crisis informs how they view services.

Many Parents/carers described feeling like they had to push to get access to appropriate services for their children such as contacting services by telephone every day to find out what had happened to their child's referral.

***I was on a waiting list for a year or so when was 17, and I was 18 when they got round to it - to see a consultant psychiatrist.
(Laws, 1998)***

***'Services should be flexible about where they see young people, when they offer appointments and about how many you can have.'
(NAC, 2009)***

Service Environment

Young people say that they need services to be friendly and welcoming, have a relaxed and informal culture combined with a homely environment. The attitude of the staff is crucial. Facilities need to be clean and offer a safe environment.

Many preferred a range of services to be in one building as this reduces the stigma associated with accessing mental health services. They also thought that it would help with practical arrangements like cutting down on the expense and time of accessing a number of different services located on different sites.

Services should be age appropriate, for example, in-patient facilities should be for children and young people only. But also, services for children aren't always suitable for teenagers.

Barriers to Accessing Services

Research studies have found that there are a number of barriers which put young people and their families off seeking help for a mental health problem (Gulliver, 2010) (Sayal, 2010).

- ❖ Stigma associated with mental health
- ❖ Concerns about confidentiality and trust
- ❖ Bad experiences of services – the pain of not being taken seriously
- ❖ Lack of knowledge about mental health and mental health services
- ❖ Consequences of seeking help
- ❖ Concerns about service providers
- ❖ Reliance on self, do not want help
- ❖ Fear or stress about the act of help-seeking or the source of help itself
- ❖ Lack of accessibility, e.g., time, transport, cost
- ❖ Difficulty or an unwillingness to express emotion
- ❖ Do not want to burden someone else
- ❖ Prefer other sources of help (e.g., family, friends)
- ❖ Worry about effect on career
- ❖ Others not recognising the need for help or not having the skills to cope

Young people are likely to seek help from a range of different professionals. Young people from the NAC's Reference group have told us that they are often not given enough support when they first seek help (NAC, 2010). They are often referred on to specialist CAMHS without being given any information.

Young people's first experience of seeking help needs to be positive if they are to engage in services. Providing some information about what CAMHS is, what it does and who works there should help reduce the anxieties about accessing these services. In addition providing some information encourages other practitioners to take some responsibility and not leave it all to CAMHS.

Many young people recognised that early intervention is good, but spoke about the difficulties concerned with asking for help. They spoke about feeling embarrassed or of being judged. They worried that the person they told would gossip, particularly if they told a friend.

Many said that they were fearful of approaching CAMHS, and suggested some sort of 'befriending' role would be helpful and peer support as a way of raising awareness.

'BYPASS is the only service I find useful because they don't treat you like a nutter, they treat you like a human being, rather than the usual 'oh you're a victim, you've got problems, let me help you'. A more down to earth approach that works probably for more people...' (Laws, 1998)

Choice and Informed Consent

It is important that young people have the freedom to choose whether to participate in counselling or therapeutic support, and when (or whether) to disclose information. They also need to feel that they have some control, even when there are risks.

They wanted choice about what kind of therapist they saw, and choice about the type of person. If they don't get on with a particular therapist, or don't like the approach, they should be able to see a different therapist or try a different approach. This should be seen as their right, rather than them being seen as difficult resulting in them being denied treatment. Research shows that the relationship between the therapist and the client is as important for producing good outcomes (Green, 2006); this is as important as the type of therapy given.

Young people should be offered a range of treatment options, not just medication. Medication has a place, but it shouldn't be the only treatment on offer. Many young people said that they felt fobbed off if they were only given medication, and weren't offered someone to talk to.

Young people need to be fully informed about what they are being asked to consent to. This means that they need information about the condition or treatment in a way that makes sense to them, so they know what they are consenting to.

***"Young people should choose who they see don't just get sent"
(NE Audit – National CAMHS Support Service, 2009)***

'We want to have a choice of the therapy we are offered.' (NAC, 2009)

There were concerns about whether young people's disclosures would be treated as confidential by the adults. Many young people saw the benefit of talking to an adult other than their parents about their problems, but were careful about who they picked as their confidant. Young people need to feel that any information they disclose is treated confidentially. Services need to tell young people what their

confidentiality policy is, and explain when they need to tell someone else, such as when they are concerned about the young person's safety.

[I felt] betrayed, she'd convinced me to trust her enough to tell her what was going on and then behind my back she went and told some of my teachers and even some who don't teach me so technically didn't need to know!!!...It was the last time I trusted her' (CRAE, 2010).

Information and Communication

A big concern amongst young people is that they have to repeatedly tell a number of different practitioners about their problems. This is because they might have needed to see a number of practitioners, or they have been passed around the system and information about their case has not been appropriately shared amongst agencies. Many young people say that they have to retell their often painful stories far too many times before accessing the right help.

"Not having to tell your story over and over is very hard, it sets you back." (Street, 2005)

Local services need to work together and improve communication to ensure that there is a shared understanding of the role of each agency, and to ensure that young people aren't simply passed around the system.

There is a need for better communication between inpatient services and community services to ensure that young people are adequately supported once they leave inpatient care. This is in relation to their mental health, but also relates to more practical issues such as making sure they have somewhere to live, and can access education and employment.

The young people in one study said that the people who work in CAMHS and the young people who have attended CAMHS would be the type of people they would want to tell them about these services (Paul et al., 2008). They said that the best way to tell them about CAMHS would be to have lessons at schools, articles in young people's magazines, the media, and easily accessible leaflets. They wanted information about the referral process, what to expect at their first appointment, available interventions, and about the different professionals they might meet.

Young people want better information about what services are available and what you can expect from them, what different professionals do and what the treatments options are. This is important to address the power imbalance between practitioners and patients, and ensure that young people and their families can make an informed decision about treatments.

We want Information and advice about therapies, medication etc. so we can make an informed choice (NAC, 2009)

We need to have better information about medication, its side effects and withdrawal problems. (NAC, 2009)

Make sure that we are both listened to and understood. (NAC, 2009)

“It would be good if someone came in at Year 10 or 11 to explain various situations that young people can find themselves in and how and where to get help.” (Street, 2005)

“I didn’t know I was psychotic, I didn’t even know what it was. I didn’t know I was depressed until my mum said. (Svanberg & Street, 2003)

Relationships

The importance of the relationship between the young people and practitioners is an issue that comes up time and time again. Young people say that they need to be able to build a relationship with a practitioner. It is not until they feel that they can trust their practitioner that they will talk openly to them about their problems. Building this trust takes time. Unfortunately the reality is that there is often no continuity of care because of staff turn-over or changes in shifts.

The attitude of the staff was also very important. Young people were more likely to build a relationship with the staff that were able to relate to them, who saw them as a person and focused on them holistically, rather than only on their problems.

“Things need to be given time, adults should ask us how they should work with us”. (National CAMHS Support Service, 2009)

‘ .. You need to build up trust as well... You know it’s someone you’re speaking privately and intimately with, so if you’ve not got that trust then you don’t feel able to talk to them...it’s just not going to work.’ (Laws, 1998)

‘We need someone we can talk to who we can trust’. (NAC, 2009)

‘There should be an open and sensitive conversation about what can and can’t be kept confidential. If we don’t trust you, or you break our trust then we won’t feel that talking is safe.’ (NAC, 2009)

Being Taken Seriously

Related to the importance of a good relationship is the issue of being taken seriously and being shown respect. Many young people feel that they are not taken seriously by practitioners because they were not adults. Being treated as an individual, having your particular needs met and being actively involved in your own care are all

important factors in empowering young people and giving them some control over their own lives.

Many young people report that their problems are not taken seriously until they have become very serious or a crisis has occurred. Sometimes it is because they do not know how to access services, but also it is because they feel some practitioners treat them quite badly. For instance, some young people perceive GPs as lacking in understanding, awareness, empathy and interest, and being reluctant to provide certain kinds of support. Even when young people present to Hospital Emergency Departments because they have self-harmed or tried to commit suicide, they are often treated as time wasters rather than receiving care and compassion.

They couldn't understand why I did it. They wanted to get on with the next patient. They just told me I was wasting their time for doing that sort of thing and there were plenty of other patients that needed help. (Smith and Leon, 2001)

"He was totally insensitive and sent me away, and when I forced myself to go back I got his partner, who said I was on the verge of mania. I was more desperate than ever! He gave me a phone number of Pastoral Care and waved me away." (Smith and Leon, 2001)

Young people from the National Advisory Council's Reference Group told us that they had to stop their therapy for a while whilst their therapist was on leave. They felt that this would not happen if someone with cancer was undergoing a course of chemotherapy. So as well as them being taken seriously they want mental health to be taken as seriously as physical health.

Young people's rights should be respected. They shouldn't have to fight for them.

"Talk with us not at us" (NCSS, 2009)

"I tried talking, but he didn't have time to talk so he just prescribed medication... and once I was on medication that set me off feeling really suicidal. Basically I really wanted to talk and I thought the doctor might have done that but he didn't. Just wrote a prescription and left it at that." (Laws, 1998)

***'Listen to problems, not go through file.'* (Laws, 1998)**

Participation

Participation is important for a number of reasons. Being involved in their own care gives young people a say in what help and support they should receive because they know what helps them and what doesn't. Young people in the NAC's Young People's Reference Group referred to the 'pain of not being understood', and how this made

them walk away from therapy rather than stay; they felt misunderstood by the very staff who believed they were being helpful (NAC, 2011).

As well as giving them a say in their own care, participation can help young people to have their say about the overall service, and to contribute to improving the services thus giving something back, helping others in the future. It also helps them to build skills, make friends and share experiences.

However, participation isn't necessarily easy and to make sure it works young people need to feel that what they have said is taken on board and that their voice is included in decision making. It is important that young people receive feedback and can see how their involvement has changed services.

The YoungMinds Very Important Kids (VIK) identified participation as their 11th Manifesto priority (2010):

“We’re the experts; start listening to us. Don’t do this as a token gesture, but really the outcomes of mental health services. Listen to us because we are the ones who really know what it is like. Make sure we are at the heart of planning, commissioning and evaluating.”

Young people say that participation is important to them because it is their right to be heard and responded to and results in benefits for themselves and the services they receive: (HASCAS, 2008)

- *Increased confidence, personal insight, independence, self-esteem and empowerment*
- *An understanding of the value of their own experiences and ability to use those experiences in a positive way*
- *Improved mental health and wellbeing*
- *Improved and more responsive services.... “Sometimes children and young people do know best what they need- adults don’t always get it right, and should be prepared to learn from us too”*

Young people should be kept up to date on projects and have involvement from the very beginning” (NCSS 2009)

“Young people need to be treated equally and don’t patronise us” (NCSS, 2009)

“It is a positive and empowering experience and provides the opportunity to voice our opinions” (Garcia, 2007)

“Just because we’re young we’re not idiots or incapable of understanding what is going on. Listen to us and treat us with some trust and respect - you will be rewarded. For treatment to really work you need a working two way relationship.” (YoungMinds, 2011)

Stigma

Stigma associated with mental health is often described as a fundamental issue that stops young people seeking help. This can be because they actually experience or believe that they will experience prejudice and be discriminated against. There is often a conflicting desire to seek help coupled with the perceived stigma associated with people knowing that you have mental health problems.

“It was daunting because I didn’t like to think anyone would see me going into the CAMHS, especially as it is very close to where I live. Didn’t want people to think I was mad or weird, it’s a stigma. Telling people in CAMHS about problems was difficult at first, they may have thought I was mad or told other people”. (Street, 2005)

Many young people are put off attending services because it includes the word ‘mental’ in the title. A study by Paul and colleagues (2008) found that the majority of young people preferred the name ‘child and family clinic’ to ‘child and adolescent mental health service’ or ‘CAMHS’.

Who young people would go to for help?

Not surprisingly there are differences of opinion with regards to which professionals young people would go to see if they had problems; but there are some common characteristics that young people looked for in a practitioner.

YoungMinds (2011) recently hosted a consultation event with children and young people concerning the extension of improved access to psychological therapies (IAPT) to cover children and young people. They looked in detail at what makes the ‘perfect worker’. The young people came up with a long list of attributes that grouped into three themes: Heart (values, beliefs and principles); Head (knowledge) and Hands (skills). Issues relevant to the workforce were considered such as how to involve young people in staff training, supervision and how to embed participation into ongoing service development.

Many of these staff attributes are similar to those covered by other studies and the following are some that are common across several studies:

- Non-judgemental, show empathy and genuine interest in listening to you
- Show respect
- See young people as individuals
- Be informed and competent
- Be open minded
- Provide the right help and support when needed and someone takes responsibility for you
- Promote equality between young people and staff
- Ensure that privacy and confidentiality is respected

Some young people reported that they can feel intimidated by mental health professionals and find them unapproachable and inaccessible. So would seek help from a friend or from someone more accessible.

Being able to speak to an adult outside of the family about a problem was seen as useful, but they needed to be sure that they would take them seriously, and could be trusted to keep it confidential; being able to build a good relationship was imperative.

“All I really need is someone to talk to. I think talking to a friend that understands, rather than going to see psychiatrists and doctors and counsellors, because they intimidate you. They sit there with a nice £500 or £800 suit and a Mercedes car outside. They can go into a really nice home at night while I go to a dump. They just purely intimidate. They get this £25 Parker pen out just to write your prescription. Why can't they use a shitty biro or pencil like we have to? That's what really does intimidate me.”
(Smith & Leon, 2001)

“The GP was very much un-clued about the whole anorexia illness, said that I was fine, and maybe should go swimming and walking in the fresh air.” (Smith & Leon, 2001)

Transitions

The transition from CAMHS to adult mental health services (AMHS) can be a very difficult time for young people and their families. This transition is taking place at the same time as many other transitions, so can make a stressful time even more stressful.

Transitions and discharge arrangements should be well planned and happen smoothly. Young people say transitions are often not well planned, with young people sometimes not knowing that they will have to move services, or they don't know when it will happen. The age cut off for CAMHS and entry to adult services usually isn't flexible. Some young people who have problems at the time of their 17th birthday might be told that they will be seen by someone in CAMHS for a short-time before having to transfer to adult services. Or they may be on a waiting list for AMHS and are past the age cut-off for CAMHS so are left with no help and support.

Some young people who are diagnosed with particular conditions such as autistic spectrum disorder (ASD) can find it particularly difficult to access appropriate help. One young person was told by social services that ASD was a mental health problem so was not their responsibility, whilst mental health services said that it was a learning disability and came under the remit of social services.

What young people want is to be informed about what is happening, and the transition should happen at a pace that suits the young person, rather than the services. They want the service to focus on their individual needs and want the help

when they need it rather than being stuck on a waiting list for CAMHS, then one for AMHS, then another one to receive the actual therapy.

Many young people report that negative experiences with services, especially around this transitional time means that they disengage with services. Most serious mental health problems start around this age, so putting young people off accessing service can have a profound affect.

There was a lot of distrust of mental health professionals generally, as this quote from The Track report illustrates:

I'll never be open to any mental health professional like a doctor. If I had serious problems then I wouldn't be open to them because at the end of the day they can lock you up... (Singh, 2010)

Some young people have high expectations for AMHS. They had not got better during their time with CAMHS, so pin their hopes on AMHS and feel let down when AMHS can't provide the 'miracle cure' (Singh, 2010).

Many young people feel that AMHS focuses too much on medication, and that they are not offered any other therapies. They want information about their condition and the medication and therapies that are available, so that they can make an informed choice (Singh, 2010).

"You need something in-between rather than just jumping from child to adult services....you need one specific person who will stick with you and not lots of different people who just pass you on the whole time..." (OCC, 2007)

... you know, like, just go to one and then be passed on to the next one when you're eighteen. That's what it was like, it's like, oh, you're eighteen now, you gotta go... (Singh, 2010)

'The way that we are treated can make us feel worse' (NAC, 2009)

It can be so difficult to access adult mental health services that you get disillusioned and give up trying to access services. (NAC, 2009)

You can get lost in the system. The processes involved make it difficult to access services - there should be clearer protocols so young people are never left without any support. (NAC, 2009)

We want to be treated with respect and have age appropriate services. Relationships and trust are crucial - once this trust is broken it is difficult to mend. (NAC, 2009)

Inpatient and Emergency Provision

Many of the general issues concerning inpatient and emergency provision are covered in other sections of this briefing. For instance, easy access to services when they are first required is an important message to all services, but when a young person is acutely ill or undergoing a crisis easy access to a high quality service becomes crucial.

There is a lot of concern about what it felt like to be admitted on an inpatient unit, and what helped them.

“I was scared. They just said it was a mental health unit so that made it even worse, cos ‘mental health’ it just seems like, if you say someone’s in a mental place it just doesn’t sound very nice” (Svanberg and Street, 2003).

‘I have never been in prison but I can imagine prison being similar - a place where you have to keep your mouth shut and get on with it. You come across people who are pretty frightening in there and you are scared of saying anything. It was like keep your head down, say nothing, do your time and get out.’ (Laws, 1998)

“The most helpful aspect of in-patient care for me was having a keyworker. I was able to build up a relationship based on support and empathy because they get to know you.” (Svanberg and Street, 2003)

Many young people report that being on an inpatient unit seriously interferes with their education. They want education to be available whilst they are on the unit, and for it to be well supported and integrated with education in their locality. This will give them something constructive to do whilst on the unit, and help reduce educational disadvantages once they are discharged.

“There’s only two teachers, you need more support staff for the school.” (Svanberg and Street, 2003).

“It would have been good if there had been more contact with the school and college to prevent losing touch with them – they didn’t understand the seriousness of the problems”. (Svanberg and Street, 2003).

There were mixed views on the discharge process, with some young people having a very positive experience, but this was not always the case.

‘I had to go, no two ways about it. When they told me they were discharging me it was in the middle of a group meeting. I thought I had another week, I didn’t really have anywhere to go. I knew I could stay at my nan’s for a bit but I didn’t want to stay there. He just announced it in the middle of a group meeting ‘Oh.... You’re

going in two days time'. I was like, 'what?' It just bloody freaked me out because I wasn't ready...' (Laws, 1998)

"I think people should know what they need to aim for because for months and months and months I had no clue where I was going. I'd just go by day to day and nothing happened and that is really frustrating because we want to go and you don't know what you have got to do to prove it. (Svanberg and Street, 2003).

"During the first 6 months of my discharge I had regular appointments that were reduced when appropriate. I was supported well and felt involved in my care plans. It was helpful to review my progress and make targets to achieve, concerning school or my health." (Svanberg and Street, 2003).

"I've got friends that've been in prison, and they get out, and they get social workers that get them a flat and give them money ... and I don't get none of that help, and I haven't been in prison, I had a breakdown." (Svanberg and Street, 2003).

Age Appropriate Provision

In the not so recent past it has been known for some young people to have been placed on adult wards for long periods of time, with some being there for up to a year (OCC, 2007). The revisions to the Mental Health Act now mean that young people should not normally be placed on adult psychiatric wards. The quotes below give an idea about what it feels like to be a young person on an adult psychiatric ward.

Many young people say how frightening being on an adult psychiatric ward, with seriously mentally ill people is, and how they can really fear for their own safety.

They might be the only young person on the ward, so feel very isolated, and have nothing constructive to do. They felt that staff generally didn't have any training or experience with working with young people. They felt that the staff were not nice to them; they were neither told about their rights, nor given any information about what medication or treatment they were receiving.

Many young people found the experience of being placed on an adult ward made them worse off; one young person said she needed "treatment to get over her treatment". Confusingly going on the adult ward had resulted in her being given a new diagnosis: prior to admission it was depression, it was then PTSD with borderline personality disorder." Another young person reported that 'during her five months on the ward, she was been abused verbally and physically, came to feel neglected and untrusting of the professionals responsible for her, and was able to abscond'. (OCC, 2007)

“Young people need information and this must be written down and talked through since “you can’t take it all in at once, you needed to sit down and think about it.” (OCC, 2007)

“They just didn’t listen enough...my care plan was just a piece of paper that I signed.” (OCC, 2007)

“Worrying about whether there is a bed for you really makes it worse”. (OCC, 2007)

“They said occupational therapy was available, but there’s a gap between what’s on paper and the reality. People were off sick and there’d be no cover, or the room was being used for something else. But there was no talking therapy and the care was only as good as the staff on duty. I felt it made her problems worse.” (OCC, 2007)

“a lot of aggression between patients and staff” (OCC, 2007)

Equality and Diversity

Many of the relevant issues have been described earlier: easy access to services, and services designed around the specific needs of service users. But in addition professionals need to have a greater awareness of religious or cultural issues and how they impact on people from different communities. These specific issues need to be addressed when designing and delivering services.

“The therapist I was seeing was Asian and so was more aware of Asian community values. A White professional would not have had the same understanding about what the Asian community thinks about mental health” (Street, 2005)

“Staff should be aware of all cultures and needs. Otherwise they do things that are normal for their culture Which are not familiar to people like me.” (Street, 2005)

So What Needs to be Done Now?

Participation has been high-up on the political agenda for sometime and there are good examples of participation work being undertaken, but services are not always putting this into practice. Anne Worrall-Davies (2008) states that much of the participation work that takes place isn’t implemented because there is often a conflict of interest between the various stakeholders, so it becomes difficult to deliver services that meet everyone’s requirements. Managing these competing demands

can mean that children and young people's views end up ignored. Realistically it will rarely be possible to act on everything children and young people say, but services need to be clear about what they are able to do and when and why this is not possible.

Commissioners and providers of mental health services need to ensure that they have the skills and resources are identified to ensure participation underpins all aspects of service planning and development.

There are examples of services that have done just this. A recent conference by the National CAMHS Support Service (NCSS) showcased some of these good examples: http://www.chimat.org.uk/default.aspx?QN=NCSS_OCT2010.

There are also many third sector organisations working to support participation, for example YoungMinds, Rethink and BEAT and many guides and tools to help services develop their participation work. The Participation section on the Mental Health Hub of the ChiMat website is a good place to look for help: http://www.chimat.org.uk/default.aspx?QN=MENT_PARTICIPATION

There needs to be suitable drivers to make this change. The Coalition government's proposals to reform the NHS, specifically the shift to give more power to patients, and the measuring of outcomes may be drivers for change. But staff involved in developing and delivering CAMHS, from the Chief Executive down need to appreciate the benefits that the participation of children and young people can bring. This may be in terms of service development, but also engaging young people in their own care and treatment, and how this encourages young people to access services.

At a recent meeting of the National Advisory Council's Young People's Reference Group (2011), young people spoke about 'the pain of not being understood'. These more recent thoughts and concerns chime with those expressed by many other children and young people. To seek people's views and not act on them is unethical (Worrall-Davies, 2008); so isn't it now time that we show that we have listened and actually do something about this? It is only in this way that 'No decision about me without me' (DH 2010) will become a reality.

National Advisory Council

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