



Children & Young People's Mental Health Coalition

Policy Briefing 3:

Young People Involvement

The Children and Young People's Mental Health Coalition (CYPMHC) is a unified campaigning voice aiming for policy change at the highest level. We have prioritised four key areas of focus and this policy briefing comes under Reaching Adulthood. The briefing presents one of our policy recommendations, the particular problem it is seeking to address and the evidence supporting our recommendation.

What are we asking?

To ensure no decisions about young people are made without their active involvement in the development, delivery and commissioning of services and in defining the outcomes to improve their mental health and wellbeing.

What is the problem?

1. Young people aged 16–25 have high levels of preventable mental ill health and mental health problems.
2. Adolescence is a critical period of development, when young people experience multiple changes in their lives and in their own physiology.
3. Young people today face increasing challenges to their emotional and mental health and wellbeing – particularly in this time of economic downturn. Disadvantaged young people are most affected.
4. Young people lack access to age-appropriate, accessible and acceptable health services, and transitions between child and adult services are often poorly managed.
5. Young people are commonly denied the opportunity to participate in the design, planning and delivery of services intended to meet their needs.

The Government has recently placed user involvement at the heart of its policy agenda, especially in its future vision of the NHS. The CYPMHC is fully supportive of this vision and this briefing seeks to demonstrate how involvement can become a reality for children and young people.

Action points

1. Commissioning standards must include the requirement for commissioners to effectively involve young people in the planning and commissioning of services, and be accountable for any actions that do not incorporate young people's expressed views. Young people consulted must include a range of services users from across the statutory and voluntary sectors, as well as the young people who take part in formal representation and consultation structures.
2. Services tendering for contracts or other mental/health sector funding must have a policy on young people's involvement and be able to demonstrate how this is put into practice, including how they involve young people in the design and delivery; how they work with young people to tailor services to individual need, and how they seek and act on feedback.
3. These services should reflect young people's preferences by being available in non-stigmatising settings outside conventional mainstream health and welfare centres, having a multi-agency, multi-disciplinary, one-stop shop approach, and available at times that suit young people.
4. The Department of Health must work with service-providers to ensure that young people are fully consulted in developing mental health and emotional wellbeing outcomes in the forthcoming NHS, Social Care and Public Health Service Outcomes Frameworks.
5. When established, GP Consortia and local authority Health and Wellbeing Boards must resource the establishment of separate forums for young people – either by linking to existing representative and participation structures or by working with service-providers' user-groups to consider how they will involve young people in designing, delivering and commissioning mental health and wellbeing services.

***Invest today for a
better tomorrow***

The Children and Young People’s Mental Health Coalition (CYPMHC) brings together leading children and young people and mental health charities to campaign with and on behalf of children and young people in relation to their mental health and wellbeing. With a unified voice, the CYPMHC aims to achieve policy changes at the highest level that will directly improve the mental health and wellbeing of children and young people across the UK. This is necessary because at any one time, one in ten children and young people have a diagnosed mental health problem and it is now well established that the antecedents of most adolescent and adult mental illness are in childhood. Addressing issues early will ensure better outcomes for individuals and for society.

The CYPMHC’s 4 key areas of focus are:

- **The Early Years** – To have greater emphasis on the psychological aspects of parenting and providing parents/care givers with the knowledge and tools to improve their own and their children’s mental health and wellbeing.
- **Building Emotional Resilience** – To support all children and young people to meet the challenges of growing up by equipping them with self-awareness and emotional resilience to achieve good mental health.
- **Reaching Adulthood** – To achieve greater recognition that development to adulthood continues to the mid-twenties and demands a responsive and flexible approach across all areas of health and social policy and practice.
- **Seldom Heard Voices** – To give all children and young people timely access to good quality mental health and well being support, with effective outcomes, regardless of their ethnicity, gender, sexual preference, disability or other personal experience.

What is the evidence for the problem?

1. Young people aged 16–25 have high levels of preventable mental ill health and mental health problems.

Mental health and conduct disorders affect significant numbers of young adults aged 16–24. At any one time:

- one in six will have anxiety and/or depression
- 0.2% will have symptoms of psychosis
- 13.3% of young people aged 16–19 and 15.8% of those aged 20–24 have a neurotic disorder
- 1.4% of young people aged 16–19 and 1.5% of those aged 20–24 have an anxiety disorder
- 1.7% of young people aged 16–19 and 2.2% of those aged 20–24 have had depression
- 3.4% of 16–34 year-olds have a personality disorder (YoungMinds, 2006).

Vulnerability to mental ill health increases as the young person enters late adolescence and the early 20s; three-quarters of all lifetime mental disorders are evident in young people by their mid-twenties, and serious mental disorders are most likely to emerge during this period (Kessler et al, 2007). The average age of first onset of psychosis is 22 years (YoungMinds, 2006).

Some children and young people are particularly vulnerable. Around two in three children in residential care have a mental disorder, and two in five of those placed with foster carers. Emotional and conduct disorders are also much more common in this group (Stein, 2005; Meltzer, 2008). Many of these lifetime disorders may be prevented by early identification and appropriate treatment (NICE, 2009).

2. Adolescence is a critical period of development, when young people experience multiple changes in their lives and their own physiology.

The brain remains plastic and continues to undergo significant structural and functional changes throughout adolescence and into the early twenties. This is a period when the young person is also coping with significant emotional, hormonal and behavioural adjustments. Adverse experiences at this time can have a lasting impact on long-term mental health and wellbeing (Kirkwood et al, 2008).

Young people will also be experiencing other major transitions at this time: from school to college or employment (or unemployment), from family home or local authority/foster care to independent living. Exposure to challenges is a necessary part of developing resilience and emotional and social skills (Newman & Blackburn, 2002; Kirkwood et al, 2008). However some young people who lack both emotional resilience and external support networks may struggle to cope. This is particularly true of young people leaving care, who are already at a far higher risk of mental, emotional and conduct disorders (Stein, 2005; Meltzer, 2008).

Case Study 1: The Cabin, Stockton District Advice & Information Service (Youth Access, 2010b)

Stockton District Advice & Information Service, a Citizen’s Advice Bureau, undertook a consultation with young people to review how it could better meet their needs. As a result, it launched The Cabin as a separate young people’s advice service, located in separate premises, where it was better integrated with other young people’s services. Use by young people subsequently increased; the Cabin currently sees some 1,000 young people a month and is looking to expand its services and premises.

Young people played a central role in designing the service, through focus groups and a youth steering group. The young people said they wanted to avoid a ‘doctor’s waiting room’ feel, and they wanted something that was ‘homely’ rather than a formal ‘centre’. The Cabin has two youth advisory groups, one concerned with the premises, the other with marketing the service. It also established a steering group consisting of local partners and stakeholders, with the role of chair and vice chair allocated to young people. The young people in these roles attended training in running meetings and being on a committee.

www.stockton-yas.co.uk

3. Young people today face increasing challenges to their emotional and mental health and wellbeing – particularly at a time of economic downturn. Disadvantaged young people are most affected.

Young people today are exposed to far greater stressors than any other generation (Pugh, McHugh & McKinstrie, 2006). These stressors are likely to be exacerbated in the current period of financial downturn, presenting still greater risk to their mental and emotional health (Youth Access, 2010a). Young people not in education, employment or training (NEET) are most at risk, have higher rates of emotional and mental health problems, and are more unhappy than their peers (Sefton, 2009; The Prince's Trust, 2010).

There are high levels of learning difficulties and mental health needs among young offenders, which the patchy education, employment and training support provided for them as they pass through the youth justice system does little to address (Ofsted, 2010a). This is a significant barrier to changing the expectations and behaviour of young people who offend in preparation for and following their return to the community. Other groups of young people at greater risk include care leavers (Akister, Owens & Goodyer, 2010) and young people from some black and minority ethnic groups (Street et al, 2005).

4. Young people lack access to age-appropriate, accessible and acceptable health services, and transitions between child and adult services are often poorly managed.

There is a large body of evidence highlighting the lack of appropriate, accessible and acceptable mental health and social care services for young people aged 16–25. The transitions between child and adult mental health services are frequently poorly managed; young people of this age group say they are inappropriately placed either in children's services, where the care and resources are designed for a younger age group and the staff are not trained to meet their needs, or in adult services, which are similarly ill-equipped and lack staff with the necessary skills and where they may be exposed to risk from their fellow patients (RCN, 2007; Fraser & Blishen, 2007; Singh et al, 2008; Singh et al, 2005; The Children's Commissioner for England, 2007).

Mainstream, conventional services can struggle to reach disadvantaged young people and those in vulnerable groups. This is largely because the services are not designed and delivered in ways with which young people readily engage (Ofsted, 2010a; Sawtell et al, 2009; Street et al, 2005; RCN, 2007; Youth Access, 2010b).

5. Young people are commonly denied the opportunity to participate in the design, planning and delivery of services intended to meet their needs.

Evidence shows that young people are often not given the opportunity to influence services, but that they greatly value such opportunities.

Franklin and Sloper's review (2005) of children's participation in health care in England found that 'the involvement of children is patchy and requires further development'. Burke (2010), in a recent comprehensive review, found that children and young people continue to feel excluded from decision-making processes in important areas affecting their lives, such as health and medical treatment, adoption and foster care, juvenile justice, immigration and asylum, and child protection.

A review of all health authorities and NHS trusts in England highlighted the omission of young people from trust policy documents on user involvement (Lightfoot & Sloper, 2002). This, the researchers said, led to children and young people's specific needs being overlooked. A systematic review of published research on seeking children's views about their experiences of CAMHS (child and adolescent mental health services) found no evidence of changes in strategy or service delivery in response to the children's or young people's views (Worrall-Davies & Marino-Francis, 2008).

Yet a review of the literature on children in care and other vulnerable groups' experiences of mental health services (Davies & Wright, 2008) concluded that children greatly value participation and want to be included in decisions about their health care. This review found that non-verbal forms of participation could be helpful as children may struggle to communicate their needs verbally.

Outside the health arena, the Youth Citizenship Commission (2009) surveyed over 1,000 young people aged 11–25 and found that nearly half (46%) strongly disagreed that they had any influence over local decision-making.

The Government has recently recognised the importance of user involvement, placing it at the heart of their policy agenda:

"We want the principle of 'shared decision-making' to become the norm: *no decision about me without me*. International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment" (Department of Health, 2010).

The CYPMHC is fully supportive of this vision of shared decision-making and wants to ensure that young people fully benefit from it.

Case Study 2: Right Here, Brighton & Hove

Right Here Brighton and Hove is a health and wellbeing project for young people aged 16–25 in Brighton and Hove, East Sussex. The project is a partnership between Sussex Central YMCA, Mind in Brighton & Hove, Brighton & Hove City Council and NHS Brighton & Hove. It is part of a four-year national programme launched in 2010 with funding from the Mental Health Foundation and the Paul Hamlyn Foundation to explore ways to promote the emotional and mental health and wellbeing of young people aged 16–25, through young people-led projects.

The project is driven by a Youth Panel of 10–12 young people, who decide and devise what Right Here offers, and much of the work is done by young volunteers in its activities, campaigns, health promotion and evaluation teams. It currently has a volunteer workforce of some 20 young people, and three full-time and two part-time staff. Activities will be planned and designed to address the specific needs of the various target groups. These will include black and minority ethnic young people, young carers, young people with physical or learning disabilities and difficulties, young people in or leaving care and young people involved with the criminal justice system.

<http://www.right-here-brightonandhove.org.uk/>;
info@right-here-brightonandhove.org.uk
t 07834 480 725 or find them on Facebook at Right Here BrightonandHove

Failure to address the problem

The likely consequence of failing to provide mental health and emotional wellbeing services planned and designed by young people is that there will be a significant number of young people who graduate into a lifetime of mental ill health (Kessler et al, 2007; Kim-Cohen et al, 2003). Many young people simply won't access or engage with services they do not trust or think will help them, even when they need them.

Setting aside the human costs, the financial cost to the national economy of poor mental health (in health and social care costs, lost productivity and human costs) has been put at over £100bn annually (CMH, 2010). Conduct disorder and anti-social behaviour in childhood and adolescence is directly linked with conduct and criminal behaviour and a range of other poor educational, employment and social outcomes in adult life, and tenfold increased costs in health, social care and criminal justice expenditure (Scott et al, 2001; Barrett, Byford & Chitsabesan, 2006).

Young people who disengage from society and local communities are not only unable to contribute through employment and community engagement; they are also at higher risk of mental ill health, with all its long-term consequences. Poor educational qualifications and lack of skills make it harder for young people to find work; unemployment is detrimental to mental health and wellbeing, and traps people in a vicious cycle of social exclusion, from which it can be very hard to escape (Department for Work and Pensions & Department of Health, 2009).

What is the evidence to support our recommendation?

The United Nations Convention on the Rights of the Child (UNCRC) gives children and young people the right to express their views freely in all matters affecting them and for these views to be given due weight in accordance with their age and maturity. The UNCRC, which was ratified by the UK government in 1991, has subsequently been expanded to recognise explicitly the more recent concept of participation (UN Committee on the Rights of the Child, 2009).

Services achieve better outcomes with young people when they are engaged not just in their own health care and treatment but also in designing and developing services that meet their health and support needs – as contributors as well as consumers (Street & Herts, 2005; Mental Health Foundation, 2007).

Young people have very clear ideas about what they want from services (Fraser & Blishen, 2007; Kurtz & James, 2002; Mental Health Foundation, 2004, 2007; Street & Svanberg, 2002; Street et al, 2005; YoungMinds, 2006). They want services to be holistic, responsive and flexible; multi-agency and multi-disciplinary; able to address all their needs without having to be signposted elsewhere; easily accessible and youth-friendly; be non-stigmatising and culturally sensitive; able to respond in a crisis; and involve young people, both in their own care and treatment but also in the planning and design of services.

Participation leads to increased accountability to, and improved services for, young people in health and education settings (Local Government Group & National Youth Agency, 2010). Ofsted (2010b) found that the impetus created by youth participation work had a positive impact on other council services and departments, for examples on the development of sexual health services and on play spaces.

Participation is of itself a protective mechanism for mental health and wellbeing and an essential element in the accumulation of mental capital (Kirkwood et al, 2008). For young people, the benefits from participation derive not just from the opportunities to give feedback on services (good and bad), but also from knowing that their views and ideas are valued. This can boost their confidence, self-esteem, experience and skills and help them become more independent; it can also prepare them for active participation in society in adult life (Street & Herts, 2005). Young people who have developed these skills and confidence are more likely to make a positive contribution to society both now and as they grow into adulthood (Kirkwood et al, 2008; Adamson & Poultney, 2010).

Similarly, a review of local authority youth work provision from 2005–2008 found that the most effective youth services are those that promote active citizenship and involve young people closely in tackling local issues. This review also spelled out the considerable benefits. Young people were enabled to develop an understanding of social and political affairs by taking part in voluntary work or community action projects, and gained confidence and leadership and organisation skills (Ofsted, 2009).

A review of specialist targeted youth support (TYS) (O'Mara et al, 2010) found the approach was highly successful in reducing emotional and behavioural problems, including delinquency/offending, school exclusion and truancy, and improving the emotional wellbeing and confidence of young people as well as their participation in education.

A companion review (Adamson & Poultney, 2010) identified clear benefits from young people's engagement in organised, structured leisure time activities. Among numerous benefits, it helps young people to develop personal, social and emotional skills; it can also directly benefit local communities through building social capital and community cohesion. The review found that effective strategies aimed at getting young people to participate include involving them in all aspects of the provision and promotion of activities.

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Children and Young people's Mental Health Coalition core members:



Mental Health Foundation



For better
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The voice for young people's mental health and wellbeing



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In partnership with:



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