Children's COMMISSIONER

Children's Voices

A review of evidence on the subjective wellbeing of children with mental health needs in England

OCTOBER 2017

Acknowledgements

This report was commissioned by the Office of the Children's Commissioner. It was written and researched by Kara Apland, Hannah Lawrence, Jeff Mesie and Elizabeth Yarrow at Coram.

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Contents

Introduction

This report explores findings from an evidence review of the views, perspectives and experiences of children with mental health needs, on matters related to their subjective wellbeing.

This report forms part of a series of studies examining the subjective wellbeing of vulnerable groups of children in England. This series was produced as part of a larger project focused on improving evidence about childhood vulnerability.

Objectives of the rapid review

The main objectives of the rapid review were as follows:

1. To identify, appraise and synthesize published qualitative evidence on the subjective wellbeing of children with mental health needs in England;
2. To draw out key findings and conclusions from the evidence, as well as identifying any important gaps.

Scope

The review was limited to the exploration of qualitative evidence concerning the subjective views and experiences of children in England, published from 2007 and beyond.

The review focused on studies that captured and presented the direct voices, and first-hand accounts, of children. Adult perspectives on childhood experiences, and studies with excessive mediation and intervention by the author interrupting children's accounts, were avoided or deprioritised. The team considered accounts by children of their own personal experiences, as well as their perceptions and reports of the experiences of their peers.

The review only considered literature containing evidence on the experiences and views of vulnerable children ages 17 years or under. Retrospective accounts of childhood, provided by adults from 18 years onwards, were generally avoided, due to the methodological limitations of such studies; however, decisions regarding the inclusion of studies containing retrospective accounts were made on a case-by-case basis (see Appendix 2: quality appraisal tool).

Methodological criteria for the inclusion of studies were broad and flexible (see Appendix 2: quality appraisal tool). There was no minimum sample size threshold for the inclusion of a study in the review; given the qualitative, personal and subjective focus of the research, diary studies of a single young person were considered eligible for review.

Finally, the review prioritised studies which entailed the collection of primary data: secondary literature based on analysis of pre-existing data was generally avoided, except where this information was necessary to fill important gaps in evidence.

Methodology

Rapid review approach

The 10 week timetable for the project demanded the use of rapid review methodology. Whilst the review aimed to be as comprehensive as possible, strict time constraints necessitated placing limits on the numbers of articles reviewed, such that either:

- 13 items/ publications were reviewed, or
- Saturation was achieved and two or more researchers agreed that continuation was unlikely to yield any new insights.

Search strategy & terms

A mixed search strategy was adopted, which included both manual and automated methods. Automated methods involved entering combinations of relevant search terms into databases, digital libraries and search engines. Given the rapid nature of the review a 'guided' approach was adopted to conducting automated searches: rather than systematically reviewing all hits resulting from a certain combination of search terms, researchers scanned search results for relevant papers to review, and ran additional targeted searches when it appeared that all relevant papers had been retained. In addition, sources were accessed through bibliographies and works cited pages of shortlisted publications. Finally, particularly given the focused nature of the literature search, an independent expert was asked to identify any key papers that related to the subject.

Automated searchers were conducted primarily on Campbell Collaboration, Google, Google Scholar and JSTOR. Searches included combinations of: a context related term (i.e. England), a population related term (i.e. child), a methodology related term (e.g. qualitative) and a relevant indicator (e.g. mental health). Researchers experimented with different combinations of search terms to obtain the most relevant set of results. The search terms and operators used were adjusted according to the requirements and restrictions of specific databases.

Search terms used

Context related terms: England, UK, Britain

Population related terms: child*, young*, juvenile*, girl*, boy*, infant*, toddler, minor*, adolescent*, teen*, youth*, pre-pube*, pube*.

Methodology related terms: perspectives, views, voice*, qualitative

Relevant indicators: "mental health", anxiety, depression, CAHMS, and "mental health needs".

Researchers conducted an initial scan of titles and abstracts to discard all immediately irrelevant hits. Items which appeared to meet basic relevance requirements were retrieved as full texts, and retained for further review.

Quality appraisal

Quality appraisal criteria (Appendix 1) were developed to evaluate the relevance, coherence, methodological suitability, objectivity and ethics of each retained study. Those studies that failed to meet key quality criteria were excluded from the review.

14 studies were identified as potentially relevant, 6 of these were excluded during quality appraisal and 8 studies were finally retained. Details about retained studies are included in Appendix 2 below.

Synthesis of evidence and drafting the report

Subsequent to quality review, the team embarked on a process of extracting and coding data on children's subjective experiences and wellbeing from selected studies. This was done through the use of NVivo software.

Wherever possible, researchers prioritised coding direct quotes from children (rather than focusing on the language and analysis of study authors), in order to foreground children's own articulations, views and perspectives of relevant matters.

Ethics

The study was shared with the chair of Coram's Research Ethics Committee. The chair judged the project to be outside of the criteria for a full ethical review (for example there are no human subjects included in the study and no personal data will be accessed).

The study has been delivered in line with Coram's safeguarding and data protection policies. The staff allocated to the review have enhanced disclosure and barring service (DBS) checks.

Limitations in the literature

The primary limitation of literature containing the perspectives of children with mental health needs is its scarcity. Literature searches suggest that quantitative methodologies are more prevalent in mental health research; most literature takes a psychological approach (sociological studies are harder to locate), and applies methods designed to measure and quantify various aspects of mental health and wellbeing. Where studies sought to capture the experiences and views of children with mental health needs through qualitative approaches, they often drew on the perspectives of parents and service providers, rather than children themselves. This may be due to ethical restrictions on conducting primary research with children with mental health needs given their vulnerability.

A more detailed discussion on limitations is including in the 'profile of literature' contained in Appendix 2 below.

Definitions / subgroups

The group 'Children with mental health needs was defined as including any children who needed additional support with aspects of their mental health (defined below). Mental health was conceptualised as a continuum, recognising that a child's mental health is constantly evolving, and is influenced by numerous congenital, environment, family and health related factors.

The Health Advisory Service (1995) defines child mental health as comprised of:

- The capacity to enter into, develop and sustain mutually satisfying personal relationships;
- The continuing progression of psychological, emotional, intellectual and spiritual development;
- An ability to play and learn, with attainments that are appropriate to age and intellectual ability;
- A developing moral sense of right and wrong;
- And, the degree of psychological distress and maladaptive behaviour being within the normal limits for the child's age and context.

A similar definition of child mental health from the Mental Health Foundation (1996) includes:

- The ability to develop psychologically, emotionally, creatively, intellectually and spiritually;
- The capacity to initiate, develop and sustain mutually satisfying personal relationships;
- The ability to use and enjoy solitude;
- The ability to be aware of others and empathise with them;
- The ability to play and learn;
- The capacity to develop a sense of right and wrong;
- The ability to be able to face and resolve problems and setbacks, and learn from them.

Children included in this group included children with mental health needs whether or not they were receiving support from Child and adolescent mental health services (CAHMS).

Child and adolescent mental health services (CAHMS) is a term used to refer to all national health services in England provided to children and young people who have emotional, behavioural, and mental health difficulties.

Findings

Children's conceptualisation of "mental health"

> "I didn't think I was mentally ill, as such, I just thought…mentally ill for me is like…that gives me a picture of someone who's really screwy in the head…." (Plaistow et al., 2014).

Findings from the studies indicated that whilst children were often aware that they had some emotional and behavioural problems, they did not typically associate these with concepts of "mental health" or "mental illness" (Gale, 2006a). Across studies children appeared to have highly negative and stereotyped ideas about mental illness, associating the word "mental" with people with bizarre and unpredictable behaviour: those acting in a manner that would be considered "out of control", frightening, aggressive and violent:

> **Researcher**: What do you think "mental" means?
>
> **Child**: Crazy!
>
> **Researcher**: So you if you saw somebody that was mental, what do you think they would be doing?
>
> **Child**: Smashing bottles! ("Solomon", male, age 5).

Words that children associated with having mental health problems included: "crazy", "evil", "horrible", "angry" and "criminal": "people who are mental are horrible" ("Martin", age 7); "they could…go and do things that are illegal" (child, age 9) (Gale, 2006a). In one study children "acted out" their impressions of how a person who is mentally ill might behave, including through pulling frightening faces, pretending to punch and kick out, rocking back and forth, pulling at their own hair, and running manically around the room (Gale, 2006a). In other studies, children expressed similar stigmatising notions of mental health problems: "someone who wuz a bit of a fruit loop that's what it meant. That's what I thought it meant"; "yeah I think it's jus' scary sayin' mental health cuz it doesn't sound very nice really" (Plaistow et al., 2014).

These findings suggest two things: firstly that the development of fear and stigma around mental health issues starts in the very early years; secondly that children's conceptions of mental health are focused on highly stereotyped representations of particular types of extreme psychosis and psychotic conditions. Other types of mental health issues appear to be less well known and understood by children. Even in studies with older adolescents, the only mental health symptoms that respondents could identify were those associated with psychosis: "[mental health is] like voices in the head and stuff, and like people telling you to do things that … you don't wanna do and things" (Girl, 16 years) (Walsh et al., 2011).

The concept of depression appeared to be particularly difficult for children to understand, describe and classify: as one adolescent explained:

> "Well everyone gets depressed once in their life, don't they? It's just … I dunno, it comes and goes, it's not really a mental health problem … like, I dunno, if a family member dies you get depressed, or if somebody calls you, like a really nasty name, you get depressed because of it, it's not a mental, well it's like, it could be, but I don't see it as mental … you can't stop it, but you can … mental health problems you can stop – mental illnesses you can't … cos if somebody calls you something, you can just let it blow over your head and not get depressed about it … but if some, like, you could take it all in, and they get depressed" ("Alan", male, 17 years) (Walsh et al., 2011).

Even when young people were told by a professional that they might be experiencing depression, and/ or when they had attempted to seek out information and support about depression (e.g. online), they appeared to struggle to link descriptions of the condition as a "mental health" difficulty, problem or illness, with their own experiences of feeling depressed (Walsh et al., 2011).

One study suggested that children's reluctance or inability to classify their problems as "mental health" conditions was related to their understanding of "mental health" as not only something frightening, and "other", but also (and by extension) a condition that they associated exclusively with *adults*. The author writes: "In essence, [children] seem to struggle to connect the words 'child' and 'mental' as being two words which could be used in conjunction with one another. Children's reflections appeared to be describing a concept of mental illness which related solely to adults, and would not be applied to children, or indeed to people that they knew" (Gale, 2006a).

Children's lack of accurate knowledge and understanding of mental health issues, and their inability to relate information that they had received about mental health to their own personal problems, was found to influence their help seeking behaviour: "I didn't even know what it was. I didn't know I was depressed until my mum said" (Plaistow et al., 2014). Furthermore, their associations of mental health with something grave and frightening, further disinclined them to label their problems in these terms, and led them to fear the interventions that might be imposed on them if they were to be diagnosed with a mental health condition: "well you think of a….like a mental home….like of loonies don't yer?" (Anna, female, 16 years) (Walsh et al., 2011); "I thought if I said anything to anyone, I thought I was going to end up at [the local psychiatric hospital] having electric shock treatment." (Plaistow et al., 2014).

Children's experiences of mental health services

Awareness

Children's limited awareness about mental health issues extended to a lack of awareness of the types of services and support available for children experiencing mental health problems. Children often reported being unaware of the availability and purpose of mental health services, even those available in their own schools: the following interaction between a group of 12 – 13 year old classmates is illustrative:

> **Interviewer:** "Do you know much about the counsellor?"
>
> **Child 1:** "I wouldn't know where to go, I think you go up to the Personal Guidance Centre, I think."
>
> **Child 2:** "Who is the counsellor? "
>
> **Child 1:** "I don't know much about it" (Kidger, Donovan, Biddle, Campbell, & Gunnell, 2009).

When asked about how access to mental health services could be improved, children often suggested that it would be useful if more information were provided to children about how to access help: as one eight year old boy who had been referred to CAHMS services suggested, "[we need] something that tells you what number to call if you are feeling really depressed or something like that" (Gale, 2006b). Respondents also emphasised the need for information about mental health itself: including the types of difficulties children and young people may face, and what it's like to experience these: "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" (Services, Lavis, & Hewson, 2010).

It is particularly revealing that several studies included testimony from children with mental health needs who delayed seeking help because they didn't realise their experiences warranted treatment. As put by one child with severe depression: "I didn't think it was that bad. I didn't think it was worth wasting their [the doctor's] time…" (Plaistow et al., 2014). A child who was hospitalised after engaging in self harm told researchers: "It had in no way occurred to me that I might be ill. I hadn't even thought of depression being involved, never crossed my mind […]. Going to the doctor didn't even enter my head" (Plaistow et al., 2014).

Lack of awareness about mental health issues and the availability of services was found to be a particular issue for children from minority ethnic communities, with several studies concluding that BME children were less familiar with the types of support that someone with mental health needs might receive: "I didn't know who or how to get help" (Plaistow et al., 2014).

Finding on young people's awareness of mental health and mental health services are consistent with children's conceptualisation of mental health, explored at the beginning of this section. When children see 'mental health issues' as conditions that are extreme, and abnormal, they are unlikely to see information about services as relevant to their lives or (wish to) associate with their own lived experiences with having a mental health need.

Barriers and accessibility

In addition to lack of awareness, studies found a consistent pattern of children and families delaying or avoiding treatment due to anxiety and uncertainty around accessing services. Children often described the idea of accessing services as intimidating or even frightening, particularly where they lacked a specific or detailed understanding of what access to services would entail. Without specific information, children tended to rely on their own negative and frightening assumptions about mental health services:

> **Child1 (Age 10):** Will it be a Doctor?
>
> **Child2 (Age 9):** I'm not sure what is going to happen. Will it be a hospital?
>
> **Child1 (Age 7):** It's not going to be a nice place…
>
> **Child3 (Age 9):** Yeah, well. I might have to spend a million hours there! (Gale, 2006b).

Indeed, many children reported that they weren't provided with sufficient information or guidance about mental health services, and several studies concluded children referred to CAHMs services are rarely properly informed. Even very young children were able to recognise that more information would make services more accessible:

> **Interviewer:** Maybe do a leaflet or something to explain where you are going, something different?
>
> **Child (Age 11):** Yes. It would make sure that children aren't scared or anything!

Children were also hesitant to access services for fear they would be seen, or where they had doubts about whether confidentiality would be maintained; as one young person who had experience accessing mental health services explained: "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" (Services et al., 2010).

Similarly, a group of 12/13 year old boys recognised that it would be helpful to establish support groups for vulnerable children in their school, but explained that stigma would prevent students from using such groups:

> **Child 1:** People will use it against you and like cuss us or something and say "ah you have to go to your stupid emotional health thing".
>
> **Child 2**: You'll feel like you're special needs and they'll say like "well at least I'm not dumb and at least I'm not special needs" (Kidger et al., 2009).

Several studies emphasised that a single negative experience can create significant barriers to children's future access to mental health services. As a National Advisory Council Briefing exploring young people's views on mental health services concludes, 'Young people's first experience of seeking help needs to be positive if they are to engage in services' (Services et al., 2010). This barrier appears to impact in particular on BME children's access to services; a study exploring the mental health of minority ethnic populations found that the failure of mental health services to meet their particular needs or communicate effectively with them discouraged access (Memon et al., 2012).

Confidentiality and trust

Children and adolescents reported that establishing trust in mental health professionals, and feeling certain that confidentiality will be respected is an essential precondition for accessing services. One young woman explained how she felt when her counsellor shared information that she had shared in confidence with teachers at her school:

> "[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" (Services et al., 2010).

A number of children echoed this point, and emphasised that violation of confidentiality constitutes a betrayal of trust, which would damage their relationship with a service provider irreparably:

> "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" (Services et al., 2010).
>
> "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" (Services et al., 2010).
>
> "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" (Services et al., 2010).
>
> It is concerning that several young people participating in studies expressed extremely low levels of confidence in mental health professionals: "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, 2011).

Studies exploring the experiences of children and young people from BME backgrounds found that these young people demonstrated particularly low levels of trust in service providers, which likely stems from negative experiences accessing what are often insensitive or culturally inappropriate services, or experiences of discriminatory and adversarial treatment by authorities more broadly. As one young boy from a BME background explained to researchers:

> "And so people don't trust psychiatrists particularly. I'm not saying this is general for everyone but from my own experience in my own community their trust is about the same as for the police. And that's not a great deal of trust" (Memon et al., 2012).
>
> Other children explained that they were hesitant to develop a trusted relationship with professionals didn't respect them, 'looked down' on them, and were temporary; "not like, someone who's always gonna be in your life" (Walsh et al., 2011).

Participation and meaningful engagement

Across studies, children expressed acute sensitivity to the authenticity of their interactions with mental health professionals. It was important to children that they felt acknowledged and respected by professionals, and treated as active agents in their treatment and care:

> "Young people need to be treated equally and don't patronise us" (Services et al., 2010).

> "Things need to be given time, adults should ask us how they should work with us" (Services et al., 2010).

> Children felt strongly that they should be kept informed and enabled to participate actively in decisions about their mental health service:

> "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" (Services et al., 2010).

> "Young people should be kept up to date on projects and have involvement from the very beginning" (Services et al., 2010).

> When recounting their experiences of mental health services, young people who didn't feel that they had been 'listened to' or that their needs had been adequately considered lost confidence that treatment had the potential to help them: as one child put it; "[I] could not be arsed with a doctor saying nothing is the matter" (Plaistow et al., 2014).

Other children felt poorly served by professionals who addressed their needs with medication, rather than providing them with therapy and counselling. Children perceived medication as a quick and easy fix, and described being 'fobbed off with medication', rather than have their problems meaningfully addressed:

> "[. . .] I've sat in front of him before and sobbed because I was upset and he just did another blood test" (Plaistow et al., 2014).

> "I was pleased that he had done something but really I didn't want to be put on antidepressants. I would have preferred to have just been able to talk to somebody. I think that's what I needed, rather than just take tablets or something" (Services et al., 2010).

Continuity of care was also found to be essential to children's experience, as it allowed children to develop a meaningful relationship with a service provider and make cumulative progress addressing their need; children who had moved from one professional to the next reported that this undermined their treatment and progress:

> "Each change was disruptive. I was continually having to get to know different people and to tell my story, and it takes a whole load of time to build up trust in someone" (Plaistow et al., 2014).

> "Not having to tell your story over and over is very hard, it sets you back." (Services et al., 2010)

> "See someone, and then it stops. See another person. You need someone continuously or it's not going to work" (Plaistow et al., 2014).

Wellbeing

Self-esteem and subjective experiences of (self-)stigma

> "I didn't want people to say I was a psycho" (Plaistow et al., 2014).

The stigmatising ideas that children associated with mental health conditions, were not only found to affect young people's service seeking behaviour, they also appeared to significantly impact on children's feelings of self-esteem and self-worth, after being diagnosed with a mental health condition. Children emphasised their desire to feel and to be seen by others as "normal", and feared the label of mental illness, which they were afraid would lead them to be labelled as abnormal and weird by others. Children explained:

> "It's like you don't want to be treated differently, you want to talk about it but you want to be treated the same anyway. You want to be normal basically, everybody wants to be normal" (Kidger et al., 2009).

> "[I] didn't want people to think I was mad or weird - it's a stigma" (Services et al., 2010).

> "[My] friends would probably take the mick if they found out" (Plaistow et al., 2014).

Children's fear of being judged even extended to mental health professionals: "telling people in CAMHS about [my] problems was difficult at first, they may have thought I was mad or told other people" (Services et al., 2010).

Children who had been diagnosed with a mental health condition spoke about feeling ashamed of themselves. They also appeared to have a range of negative ideas and perceptions of themselves, including feeling like they were different from other children, "bad children", "out of control", "stupid", unusually angry, aggressive and "naughty". One child explained:

> "I feel ashamed and I can't talk about it… I have a dark secret – being mad. If you are mental you can't control yourself" ("Will", age 10) (Gale, 2006a).

Feelings of guilt, and that they were "not like" other children, appeared to dominate children's low opinions of themselves: "I would like to be like everyone else" (Will, age 10) (Gale, 2006a). One child explained how he wished he could be like his cousin 'Jamie' who, by contrast to him, was a 'good' child.

> **Child**: [I want to] just be like the other children really.
>
> **Researcher**: What do they do? That's different to you?
>
> **Child**: My cousin, I'd like to be like him - .Jamie.
>
> **Researcher**: What's Jamie like?
>
> **Child**: He's very good ("Colin", age 8) (Gale, 2006a).

In one included study, conducted with relatively young children, the author expressed surprise that child participants were so willing to speak openly about their feelings of guilt and shame in relation to their mental illness, concluding that these results (which appear to differ from studies conducted with older adolescents) may indicate that younger children have "less sophisticated" ways of protecting themselves against the invasive effects of stigma associated with mental illness, compared to older children (Gale, 2006).

Children's negative feelings about themselves were reinforced by the feedback that they perceived themselves to be receiving from others, including adults, about their behaviour: often feeling that their mental health condition had resulted in others labelling them as 'bad' children:

> "I wish people would notice that I'm, like, behaving well, but most people concentrate on [my] bad behaviour" ("Salma", age 10).
>
> "the headmaster just thinks ADHD means we're violent" (Singh, 2011).

Interestingly, in one study, children with mental health needs were asked to describe how they perceived other children and adults who had also been diagnosed with a mental health condition. Tellingly, children saw other children with mental health needs as "weird", "sad" and "different", and appeared to disassociate these others from themselves, and their own experience of mental illness. Children noted:

> "Jade – she is a different girl from the whole class" ("Emily", age 7);
>
> "Everyone calls him 'crazy boy'… it make him angry" ("Teddy" age 9) (Gale, 2006).

Children with mental health problems, therefore, experience both "self-stigma", as a result of their perceived feelings of "difference" and "abnormality" compared to other children, and they also experience the effects of public stigma, being subject to the prejudicial ideas emanating from their peers, family, community and professionals around them; as one child explained: "I don't like the word [mental]. I don't like the way it is used" ("Callum", age 8) (Gale, 2006).

Relationships

> "You never know who you can trust … you never know, you can always fall out with someone, and they think … get your own back … there you go, there's something against yer … people can be quite spiteful." "Cathy", age 16 (Walsh et al., 2011)

Findings across studies included in the review indicated that experiences of bullying, discrimination and punishment, and feelings of social exclusion and isolation, are common experiences of children with mental health needs: "that is when I get sad… somebody injures me, sometimes really hard…" (Child, age 8) (Gale, 2006a); "someone at school…don't know… they beat me up" ("Marcus", age 7) (Gale, 2006a).

Children described the impact that bullying had on their wellbeing: often leading to a worsening of their mental health condition, and driving them to aggression and retaliation, which in turn was liable to land them in trouble with adults: "[This boy] he keeps pushing me, pushing me to be, make me angry. And he hits me, he bribes me, he takes money from me. He does anything to annoy me. He knows I'm easy to wind up and he knows I'm easy to get my anger up. I just start hitting him like he hits me" ("Charlotte", age 11, suffering from ADHD) (Singh, 2011).

The need to retaliate was found to add volume and intensity to children's problems; leading to a cycle in which the more children were bulled, the more they became excluded, ostracised and singled out from their peers:

Last week, Friday…I walked through the dining hall, yeah, dining room hall door, bumped into this year six kid, he grabbed me and put me up against the wall, and I punched him right in the nose… Yeah, yeah. That kid lashed out as well and it was only a year four, he lashed out on me as well, got me back on the nose and chucked me onto the floor. I felt embarrassed then… ("John", age 9) (Gale, 2006).

As well as feeling shunned and excluded from their peers, children also reported having troubled, turbulent and conflictual relationships with adults in their lives. In one study children reflected that their problems were preventing them from joining in with family activities: ranging from basic things like going shopping to more unusual and special occasions, such as family parties and holidays (Singh, 2011). Children reported feeling withdrawn from others around them, including from their families: "people don't understand me" (Walsh et al., 2011). One participant explained:

> "I've been a very depressed person for a very long time and it's like the relationship I had with my mum. It's not like I could go and talk to her and it's like you don't mention certain things, you keep them to yourself.(…) And sometimes you just don't want to worry your family, you know" (Memon et al., 2012).

Finding it difficult to talk about their emotions, fearing they would be laughed at and lack of trust in others were all factors affecting children's willingness to speak to adults in their lives:

> "I just never have, I've never turned to my mum or my dad, or anyone in the family … if, if my mates can't help me, I just deal with it myself" ("Alan", age 17) (Walsh et al., 2011).

Some young people also reported having problematic relationships with professionals working with them, including teachers and mental health professionals, reporting intimidating, unhelpful, unfair and humiliating treatment:

> "Teachers are not effective. They don't help. They're always shouting. About half of them forget that you've actually got ADHD when you're in their classroom;" (Singh, 2011).
>
> "She [teacher] says like "I'll pick you up by your sidies [sideburns] and throw you out of the window" (Kidger et al., 2009).
>
> "Sometimes if things are happening outside of school that teachers don't understand and then they have a go at you anyway it just makes it worse" (girl, 13 years) (Kidger et al., 2009).
>
> "Things will happen at home with me and then I come to school and the teachers will shout at you and you feel so frustrated and you tell them what's happened at home and they still wouldn't, oh that's no excuse" (Girl, 14 years) (Kidger et al., 2009).

Power differentials between children and the professionals working with them were also found to impact on their ability to build a trusting relationship, and many children emphasised that they would rather speak to their friends about their mental health issues:

> "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" (Services et al., 2010).

Not all findings were negative, however. A number of children spoke about their relationships in positive and happy terms: identifying these as some of their most important sources of coping and support. Importantly, children who identified positive relationships with at least one parent or carer, emphasised that these caregivers would be the first people they would speak to when they became symptomatic, emphasising the importance of caregiving relationships for early intervention and management of mental health and emotional problems amongst children (Walsh et al., 2011).

Peer relationships were also found to be important: children in one study, which focused on the subjective experiences of children with attention deficit disorder, spoke about how their friends helped them to cope with their disorder, intervening to stand up for them in a fight, or to prevent them getting in to one:

> "My mates look out for me. If I'm running toward somebody they would either tackle me or hold me down or something. That's what good mates do for each other. They know what I'm like. I'll see them after school sometimes. Depends on whether I think I should do my homework. [My friends and I] play X-box and sometimes we'll get out to a field to play footy" ("Shaun", age 12) (Singh, 2011).

> [My friends will] jump on me and hold my arms back and just restrain me, a bit. And in the end I just end up just calming down. But sometimes I can't and I break away." ("Pat", age 11) (Singh, 2011).

The author of this study interestingly notes how these accounts of young people's relationships and interactions are illustrative of how behavioural self-control amongst adolescents in spaces where groups of young people interact is rarely a matter of autonomous decision-making, but rather a collective effort amongst peers. The author writes: 'sometimes fights can be prevented. Sometimes they cannot be. It depends on medication. It depends on mood. But it depends most heavily on friendships; and on what the bullies say' (Singh, 2011).

Self-efficacy and coping (strategies)

> "I end up turning to drugs and alcohol. It's the only thing, you know…"- Adolescent girl, (Memon et al., 2012)

Some of the studies included in the review explored children's strategies for 'coping' with mental health needs, particularly given low awareness and access to professional help and support amongst children with mental health needs (as explored above).

Self-reliance

Many young people, particularly older adolescents, emphasised the importance of working out their problems, and learning to cope, autonomously and "alone". Seeking or accepting interventions from adults, particularly those in positions of authority, was considered pathetic, and associated with a loss of personal control, autonomy and power. For example, one boy explained how he tried to avoid those in positions of authority from "interfering" in his personal life, because he didn't want them "seeing" he "was weak" (Walsh et al., 2011). Another child claimed he was seeking to "keep" his mental health problems to himself, "to stop others getting involved" (Walsh et al., 2011).

Interestingly, the author of one study noted that the conceptualisation and image that many young people had of "mental illness" as being a "problem in your head", reinforced their ideas that they ought to be able to "sort things out" and manage on their own (Walsh et al., 2011).

Turning to others

On the other hand, some young people spoke of the sense of relief that they felt in circumstances where they had asked for help and support: "the best thing was that I [told] someone how I felt and what was bothering me" (child, age 14) (Plaistow et al., 2014). They spoke about the practical support that others were able to provide them, and emphasised that support from adults had actually helped to improve and encourage their sense of self-reliance and efficacy:

> "I wouldn't go to the doctor's on my own, I couldn't . . . and so she [mental health coordinator] would come with me just to make sure, keep me at ease [. . .] That increased my confidence and made me able, like, to go to the doctors whenever now" (Plaistow et al., 2014).

> "When she [mental health professional] helped with my problems I feel just like this dinosaur . . . I can go over my problems and solve them myself and she can help me and the appointments have helped me because I can tower over my problems and look at it another way" (Plaistow et al., 2014).

Throughout the interviews there was a tension between children wanting to be independent, autonomous and 'grown up', and also recognising that they sometimes needed to seek out help and support from adults (Walsh et al., 2011).

Drugs and alcohol

A consistent theme throughout studies that focused on older adolescents and youth was the use of drugs and alcohol as a means of coping, self-medication and stress relief. Young people explained:

> "I was led into this whole partying circuit, smoking and drinking. It just became really detrimental to my health" (Memon et al., 2012).

> "I had an addiction to Valium and things like that" (Memon et al., 2012).

> "You know, let's be honest…when people cannot cope most people's first refuge is alcohol. Drugs. Yeah, that's my experience. I don't know if I'm living in a special world or if everybody's experience that [group makes agreeing noises]" (Memon et al., 2012).

Self-harm and suicide

Young people cited self-harm and suicide as other "strategies" and "methods" of coping:

> "It goes all the way to self-harm and suicide. That should also be logged in. It doesn't have to stop at feeling bad. People go all the way and I have friends who have" (Memon et al., 2012)

Sports and outdoor activities

On the other hand a number of studies revealed evidence of a range of other more healthy and positive strategies by coping used by adolescents experiencing mental health difficulties. Children consistently mentioned physical activity and sport as one of their most important outlets for relieving stress. The following group interaction between children in illustrative:

> **Child 1**: You can build up anger in the day something might have happened and say you've got a rugby match after school you can let all your anger out then
>
> **Child 2**: And you feel good about it… (Voices): yeah
>
> **Child 3**: It's like relaxation, even though you're getting munched (Kidger et al., 2009).

Creative lessons

Creative lessons such as English, Art, Dance and Drama were also raised as forums in which children were able to express their emotions through imagination and in hypothetical, impersonal and unreal ways, avoiding the risk of stigma and stress associated with sharing personal, real-life experiences with others; as young people explained: "The whole creative side like English, Art, Dance, Drama 'cause you can all express yourself through that sort of thing, but it doesn't necessarily have to be about you and people can't guess if it's about you or not so it's like expressing yourself without others knowing, that's what I find really good about it" (Kidger et al., 2009).

Young children

Gale's (2006) study, revealed evidence on a range of strategies utilised by particularly young children with mental health needs; these included reading and listening to music, meditation, and crying:

> "being sad and crying are ok, as long as [it] don't last long…" (Boy, age 9).

Emerging themes

Several themes emerged from the literature on children with mental health needs:

Children conceptualise 'mental illness' in highly stereotyped, negative and limited terms: associating mental illness with people with bizarre and unpredictable behaviour and those acting in a manner that would be considered "out of control", frightening, aggressive, violent or criminal. They view mental illness as abnormal, and tend not to relate it to their own identities or experiences.

Children have limited awareness and understanding of mental health, including the types of metal health difficulties that people experience. They also tend to be unfamiliar with the types of help and support that are available, or how to access them. As a result many children with mental health needs are delayed in accessing or receiving support.

Fear of being seen accessing services and insecurity about the confidentiality of the service also emerged as important barriers to young people's ability to address and overcome mental health needs. Young people see trust and confidentiality as essential elements of service provision; whilst young people's relationships with professionals vary, troublingly, many young people lack trust in mental health professionals, and feel misunderstood and unheard. Services are most helpful to children where they are participatory and children are given agency in decisions about their care.

Mental illness is perceived by young people as attracting significant stigma, which in turns impacts on feelings of self-worth and self-esteem amongst children diagnosed as having a mental health need. Children with mental health needs tend to see themselves as different from other children, feel guilt and shame in relation to this difference, and aspire to normality. Children's 'self-stigma' is often reinforced by the way they are perceived and treated by the people around them.

Experiences of bullying, discrimination and punishment, and feelings of social exclusion and isolation are common experiences of children with mental health needs. This often leads to a cycle, in which bullying compounds children's mental health difficulties, leading them to retaliate and/or self-isolate, which in turn leads them to be bullied and singled out from their peers.

Where children have strong relationships with family and peers this is experienced by children as some of their most important sources of coping and support. Meaningful and supportive relationships, both with friends and family, and mental health professionals, can lead to improvements in the wellbeing of children with mental health needs, however it is important for children, particularly older children, to maintain a sense of autonomy and independence.

References

Gale, F. (2006a). Children's and parent's/ carer's perceptions of mental health and stigma: a thesis submitted for the degree of Doctor of Philosophy.

Gale, F. (2006b). CHILDREN ' S AND PARENTS '/ CARERS ' PERCEPTIONS OF MENTAL HEALTH AND STIGMA Thesis submitted for the degree of Doctor of Philosophy at the University of Leicester by Department of Child and Adolescent Psychiatry School of Medicine University of Leicester, (March).

Kidger, J., Donovan, J. L., Biddle, L., Campbell, R., & Gunnell, D. (2009). Supporting adolescent emotional health in schools : a mixed methods study of student and staff views in England, *18*, 1–18. https://doi.org/10.1186/1471-2458-9-403

Memon, A., Mohebati, L. M., Collins, V., Campbell, M., Porter, A., Hope, E., … Collins, V. (2012). A Qualitative Study of BME Mental Health and Wellbeing in Brighton and Hove, (February).

Plaistow, J., Masson, K., Koch, D., Wilson, J., Stark, R. M., Jones, P. B., & Lennox, B. R. (2014). Young people's views of UK mental health services. *Early Intervention in Psychiatry*, *8*(1), 12–23. https://doi.org/10.1111/eip.12060

Reilly, M. O., Vostanis, P., Taylor, H., Day, C., Street, C., & Wolpert, M. (2013). Service user perspectives of multiagency working : a qualitative study with children with educational and mental health difficulties and their parents, (4), 202–209. https://doi.org/10.1111/j.1475-3588.2012.00674.x

Services, H., Lavis, P., & Hewson, L. (2010). 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, 1–19.

Singh, I. (2011). A disorder of anger and aggression: Children's perspectives on attention deficit/hyperactivity disorder in the UK. *Social Science and Medicine*, *73*(6), 889–896. https://doi.org/10.1016/j.socscimed.2011.03.049

Walsh, J., Psychol, C., Scaife, V., Cqsw, G. S., Notley, C., Dodsworth, J., & Walsh, J. (2011). Perception of need and barriers to access : the mental health needs of young people attending a Youth Offending Team in the UK, *19*, 420–428. https://doi.org/10.1111/j.1365-2524.2011.00991.x

Appendices

Appendix 1: Quality appraisal tool

Summary Information	Criteria	Possible fields	Inclusion criteria (where applicable)
	Citation	Author, year, title, publisher, journal & issue, page numbers.	n/a
	Is the source publically available (published)?	Yes/No	Exclude if not publically available
	Publication year		Exclude if published before 2007
	Peer reviewed	Yes/No	n/a
	Did the study involve the collection of primary data?	Yes/No	Exclude if no
	Does the study contain information about children within England?	Yes/No	Exclude if no (unless the study contains information of significant relevance that is not identified elsewhere. If study is to be retained state reason.)
	Geographical scope of study	Multi-country; national; regional; sub-regional; single case	n/a
	Study type	Qualitative/quantitative/mixed methods	Exclude if study is exclusively quantitative

Relevance	What is the research question/purpose of the research?	[Open]	n/a
	Does the study/ source include information about the subjective wellbeing of one of our 'primary groups'?	Yes/No	Exclude if no
	Which primary group does the study address?	List primary group	n/a
	Does the study capture and present the views and experiences of children under the age of 17 years?	Yes/No	Exclude if no
	What is the age range of vulnerable children participating in the study?	[Open]	Exclude if none were 17 or younger Proceed with caution if studies include a mixed age group above and below 18 and comments are not attributed to ages
Methodology & methods	Are there any potential conflicts of interest? (I.e. related to the funding interests?)	Yes/No [Provide details]	Consider exclusion if yes
	Is it clear from the data source through what means evidence/ information/ data about children's views were collected?	Yes/No	Consider excluding if no
	Are the study design/ methods used appropriate to support the evidence, analysis and	Yes/No	Consider exclusion if no (unless there is a compelling reason to retain the article and state the reason for this.)

	conclusions presented in the source?		
	Does the methodological approach appear to have been consciously adopted with awareness about the methodological choices made, and the implications of these?	Scale 1-5 with 5 being highest level of awareness	Consider excluding if score is 2 or below.
	How inductive/observation-based is the methodological approach?	Scale 1-5 with 5 being the most inductive approach (e.g. grounded theory), and 1 being highly deductive.	Consider excluding if score is 2 or below.
	Were the methods of data collection used appropriate to ensure that children were given an opportunity for genuine self-expression, (e.g. non-directive opportunities to say what is on their mind, free from pressure/ coercion etc.)	Yes/ No/ not enough information about methods	Exclude if no Consider exclusion if 'not enough information about methods'
	What is the mechanism through which the views of children have been documented and recorded?	[Provide details]	N/A
	What is the context in which children were expressing their views, and the purposes for which the views were expressed?	[Provide details]	N/A (see inclusion criteria below)

How direct and authentic do you consider the presentation of children's voices to be?	(score from 1-6, 6 being the most direct presentation of children's views) Scoring criteria: 6. verbatim narrative 5. edited account 4. question and answer 3. use of selected quotations 2. paraphrasing/ interpretation of children's views 1. children's views are implied through secondary accounts, theoretical analysis and other means	Consider excluding if score is 2 or below.
How were children accessed for the study?	[Open]	N/A
What is the population from which children are drawn	[Open]	N/A
Was the sample method appropriate to the purpose of the study	Yes/ No/ unclear	Exclude if no or unclear
Is the study based on retrospective accounts of childhood by adults?	Yes/No [Provide details]	Consider exclusion if yes
How many children are included in the study? (Sample size)	[Open]	N/A

	Are limitations discussed?	Yes/No [provide details]	Exclude if limitations are so significant that the evidence becomes highly questionable.
Ethics	Did the article undergo an ethical approval process? And was this approval granted?	Yes / no	Consider exclusion if no (and there is reason to believe there are ethical concerns)
	Do you have substantial concerns about the ethical implications of the research (effects on participants, researchers, etc.)?	Yes / no	Exclude if yes

Appendix 2: Profile of included literature

Profile of the literature

After an initial scan for relevance, 14 papers were shortlisted and the full screening/quality appraisal process was applied to these. 6 studies were excluded during the quality appraisal process, largely due to concerns related to their relevance, and the research methods applied:

- In several cases on closer examination the study was determined to be out of scope for the review, due to the geographic region where study was conducted, the respondent group, etc.
- The remaining studies were excluded to methodological concerns or because engagement with children's voices was overly mediated.

After the quality screening was complete, 8 studies remained, and data was extracted from these.

Three of the studies were mixed methods studies, which involved the collection of both qualitative and quantitative data, three were purely qualitative, and two were systematic reviews of existing literature, which included direct quotations of children and young people. Children's voices were captured through a diverse range of qualitative and participatory techniques, including focus groups discussions, semi-structured interviews, and participatory research methods. In the majority of the studies, interviews/group discussions were complemented by additional techniques, including case file reviews, and semi-structured interviews with key informants, such as practitioners working with children.

Two of the studies were grey literature, one was a PhD thesis, and the remaining five were peer-reviewed articles appearing in academic journals. The grey literature included a Briefing from the National Advisory Council exploring young people's views on mental health and mental health services, and a qualitative study in the mental health and wellbeing of BME populations conducted by the NHS in Brighton and Hove. Whilst the second study does not focus on children's experiences in isolation, analysing the views and experiences of a population aged 15 – 35 together, findings from this article have only been included where they address gaps in other included literature regarding the unique experiences of BME persons in relation to mental health needs. A brief description of each piece of literature is included below:

Literature on children with mental health needs

- **Gale (2006)** was a PhD thesis exploring the perceptions of children with emerging mental health problems (and their parents/carers) of mental health and stigma. The study drew upon semi-structured interviews conducted with 20 children (aged 5-11) and 23 parents/carers. Whilst this study was completed in 2006, and is thus technically beyond the scope of this review, it contained one of the richest, most extensive presentations of the direct voices of young children, and was included in the review for this reason.
- **Kidger et al (2009)** was a peer reviewed journal article exploring student and staff views on the effectiveness of methods to promote adolescent emotional health in schools. The study involved the distribution of a survey to 296 schools in order to establish levels of services, as well as 27 focus group discussions with 154 students (aged 12-14) and interviews with 15 staff members at 8 schools with high levels of service provision.
- **Lavis et al (2011)** was a briefing from the National Advisory Council for children's mental health and psychological wellbeing on young people's views about mental health and mental health services. The briefing draws upon the NAC's Young People's Reference Group, and a short review of papers and reports that involved consultations with children and young people.
- **Memon et al (2012)** was a qualitative study on the mental health and wellbeing of BME groups residing in Brighton & Hove, undertaken by the Public Health Directorate and mental Health Team at the Brighton & Hove NHS. The study included focus group discussions and a community survey. Whilst the study didn't focus on the experiences of children and young people in particular, because of the lack of other sources containing information on the subjective experiences of children with mental health needs from BME backgrounds, this study was included in the review.
- **O'Reilly et al (2013)** was a peer reviewed journal article examining the experiences of children attending CAMHS for mental health and educational difficulties, and their parents, and exploring children and parents' views of those services. The article focussed in particular on the aspect of joint working between schools and CAHMS. Interviews were conducted with 11 children aged 8 – 12 (9 boys and 2 girls) and 14 parents.
- **Plaistow et al (2014)** was a peer reviewed journal article which involved a systematic review of published literature on young people's views of mental health services in the UK. Thirty one studies were included in the review, which captured the views of 13,605 young people including 625 young people who had experience of mental health services. All studies included qualitative methods and several applied mixed methodologies.
- **Singh (2011)** was a peer reviewed journal article investigating social and moral dimensions of Attention Deficit/Hyperactivity Disorder (ADHD) diagnosis, asking 'what ADHD means in UK children's everyday lives', and how children process and respond to their diagnosis. The study draws upon data collected for the VOICES study[1]: 150 in-depth interviews were conducted with children ages 9-14 in the US and the UK.

[1] An international research project exploring the social and ethical impacts of ADHD diagnosis and stimulant drug treatments for children.

- **Walsh et al (2011)** was a peer reviewed journal article drawing on mixed methods to explore the mental health needs of young people attending a Youth Offending Team in the UK. The study included the distribution of a standardised questionnaire with questions for young people (aged 10-18) about their levels of mental health needs, behaviour, preferences, and evaluation of support. In-depth interviews were conducted with six of the surveyed young people.

Limitations

The primary limitation in the body of literature on children with mental health needs in England is the scarcity of literature which contains the voices and perspectives of children themselves: whilst numerous academic studies have been conducted on topics relating to mental health and mental health services, these rarely involved the collection of qualitative data from individuals with mental health needs and particularly children. Instead, literature searches suggest that quantitative and positivist methodologies are more prevalent in mental health research, much of which has been undertaken in the discipline of psychology (sociological studies are harder to locate), and draws upon various tools designed to measure and quantify various aspects of mental health and wellbeing.

Where studies sought to capture the experiences and views of children with mental health needs through qualitative approaches, they often drew on the perspectives of parents and service providers, rather than children themselves. This is likely due to ethical restrictions on conducting primary research with children with mental health needs given their vulnerability. Literature addressing the subjective well-being of young children (primary school aged and below) appears to be a particular gap, as was noted by several authors. Literature on the subjective wellbeing of children with mental health needs from diverse (BME) backgrounds also appears to be limited.

Finally, the majority of studies accessed participants through institutions; either mental health service providers or schools. This means that children with mental health needs included in the studies tended to have access to services and support; it was (perhaps inevitably) very difficult to obtain the perspectives of children with mental health needs who had more limited access. Of course young people's descriptions of their difficulties accessing services provide insights into the types of barriers which these children face.

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