# Review of children and young people's mental health services

Phase One supporting documentation:
**Summary of engagement report**

# 1   Introduction

This summary report brings together the findings from engagement activities that have taken place as part of Phase One of the Review of children and young people's mental health services. It identifies common and emerging themes in line with the key lines of enquiry within the review.

# 2   Who did we speak to?

Our engagement activities for Phase One of the review have encompassed three main areas of activity:

1.  An Expert Advisory Group, which brings together people with different types of expertise and experience in the subject matter.
2.  A workshop with our Children and Young People's Advisory Group and Young Experts by Experience, which is made up of children and young people who have used mental health services.
3.  Collaboration with the Social Care Institute of Excellence, who work with children and young people who are in care or have recently left care, and who have also used mental health services.

Through the policy and literature review (see separate supporting document), we also considered feedback already given by children, young people and their families and carers to previous reviews and publications on the subject of children and young people's mental health. Appendix 1 has a summary of the engagement for selected previous reviews, that we considered as part of the policy and literature review.

## Expert Advisory Group

We have held two face-to-face meetings with our Expert Advisory Group (EAG). The make-up of the EAG includes:

- public representative bodies
- young Experts by Experience
- professional and clinical representatives
- provider representatives
- system and policy partners
- commissioning bodies
- government representatives.

The full list of EAG members is:

- Association for Young People's Health
- Association of Directors of Children's Services
- Association of Independent Local Safeguarding Children Board Chairs
- Association of Mental Health Providers
- Association of School and College Leaders
- Barnet Enfield and Haringey Mental Health NHS Trust
- British Association for Counselling and Psychotherapy
- British Psychological Society
- Brooklands Hospital
- Centre for Mental Health
- The Challenging Behaviour Foundation
- Children and Young People's Mental Health
- Coalition
- Children's Commissioner
- Children's Society
- Council for Disabled Children
- Department for Education
- Department of Health
- Education Policy Institute
- Healthwatch England
- Healthwatch Hillingdon
- Healthwatch Rotherham
- Healthwatch Suffolk
- Healthwatch Wakefield
- Involve
- King's College London
- Local Government Association
- Mencap
- National Association of Head Teachers
- The National Autistic Society
- National Children's Bureau
- NHS Confederation
- NHS England
- NHS Providers
- NHS Improvement
- NSPCC
- Ofsted
- Place2be
- Public Health England
- Race Equality Foundation
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists

- STR Humber Mental Health
- University College London
- Young Experts by Experience
- YoungMinds
- Youth Access.

Our first EAG meeting had 25 attendees and our second meeting had 37 attendees.

## Children and Young People's Advisory Group with Experts by Experience

We held one face-to-face workshop with our Children and Young People's Advisory Group (CYPAG), supported by young Experts by Experience. All children and young people had experience of accessing children and adolescent mental health services. The make-up of this group included:

- 12 young Experts by Experience (aged 18 to 25)
- 5 CYPAG members (aged 11 to 18)
- 3 parent carers.

## Workshop with children and young people in partnership with the Social Care Institute of Excellence

We worked in partnership with the Social Care Institute of Excellence to run a face-to-face workshop with children and young people who had experience of accessing children and adolescent mental health services, including Tier 4 services.

There was representation from eight local authorities and the group included 23 young people. All young people were either in care or care leavers.

# 3 What did we find out?

## Identifying and responding to mental health needs

### Access to services
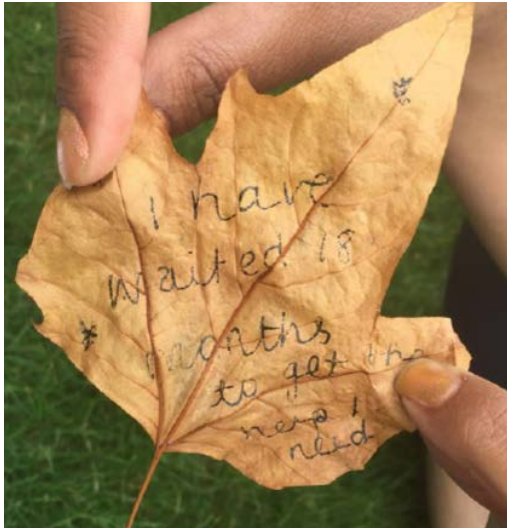


*Young person from the SCIE group*

Most of those that we spoke to felt that services needed to do more to raise awareness of the support available for children, young people and their families so that they knew where to go when they thought they might need support.

Young people particularly felt that services needed to do more to improve their communications, tapping into channels they are familiar with such as social media and school assemblies. The young people we spoke to from SCIE did feel that they knew who to talk to when they needed help – but this may be because of specific specialised support available to this population group.

All young people would have appreciated more information produced on what services are available, how to access them and what they can expect.

> *"Social media like Facebook and Snapchat would be more eye-catching for young people and you can like and follow."*
> **Young person (SCIE)**

All groups were in agreement that diagnosis was important to consider and that it generally took too long for young people to get a diagnosis and for their needs to be identified. For the young people in the Children and Young People's Advisory Group (CYPAG), this was needed for certainty and to enable them to begin accessing services.

The EAG also touched on thresholds and felt that the system had developed barriers to protect services, which meant there were a number of young people with mental health needs who did not meet thresholds, and who were not receiving support.

Waiting times were highlighted as a major concern for all the groups we spoke to. Young people in the CYPAG felt that long waiting lists meant that support was not available when they most needed it. It was felt this often led young people to a point of crisis that could have been avoided. When young people reached crisis point, they often found themselves at A&E where they felt the staff were not adequately trained. It was here that young people at our CYPAG meeting widely agreed that they had their worst experiences.

Furthermore, CYPAG perceived a lack of available support in the prolonged waiting period after an initial assessment and this was a further point of concern. Young people felt that there was a lack of support, information and planning for this period, which led to increased stress levels and which made reaching crisis point more likely.

The EAG suggested implementing different waiting list standards for different sets of problems.

> *"Both my school and my GP had to chase CAMHS as I had such a long wait for the referral to be actioned."*
> **Young person (CYPAG)**

**Schools**

Across our engagement activity schools were seen as one of the biggest issues in identifying and responding to mental health needs.

> *"School is a big one – what pathways to support children and young people to receive help are there?"*
> **EAG member**

The most common theme focused on staff expertise. This stemmed from a belief that the children and young people's mental health system has gradually become "school-led", with the system not equipping schools to hold this responsibility. There were concerns across the board around whether staff in schools had the correct training and skills to work with children and young people with mental health conditions. The EAG also raised concerns about the capacity of staff to retain new skills they may learn.

There were also concerns from children and young people and the EAG around how children and young people in a care placement or residential schools accessed care. This was seen as a particularly difficult situation.

The EAG specifically raised concerns about whether children and young people's mental health is a priority for the education system.

Young people felt that schools were a great opportunity to raise awareness of mental health and the services available to children and young people; it was felt that this in turn may help with identifying mental health needs. The EAG echoed this and felt schools should be presenting more positive health and wellbeing.

**System design**

The EAG raised a number of additional issues relating to how services were designed and the impact this had around how they identified and responded to need. There was a general consensus among members that partners needed to ensure they were "joined-up" and that young people didn't fall through the gaps.

To this end, the EAG also felt that the funding and commissioning arrangements surrounding children and young people's mental health were not enabling services to join up in new and creative ways. There were calls for a joint commissioning pot for children and young people's mental health services and for commissioners to encourage innovation. It was felt that this would enable the development of a more nimble and responsive support service.

Linked to this was a call for to more collective responsibility among services for children and young people with mental health needs. This would also ensure that services were working together to identify and respond to needs.

# Working together

Across all of our engagement activity there was agreement that services needed to be working together in order to support children, young people and their families well. Although pockets of good practice were identified, there was a sense among all groups that this wasn't happening as much as it should be. This was identified as being a particular concern at transition points in young people's lives.

### Working with families

For the EAG and our CYPAG groups, a key area was how services work with the whole family. The young people reported feeling that the current system did not always take into account the whole family. Families were seen as having to manage with issues daily, and most felt that the current system did not offer enough support. There were some reports of excellent treatment for anxious parents. The EAG questioned how young people were supported at home and felt family education was something that should be considered.

### Person-centred care

The EAG felt that services should be working together to ensure that the support children and young people were receiving was child-centred and that it was responsive to their individual needs.

Young people in both SCIE and CYPAG events reported that it worked well when support workers came to work with them in a familiar environment. Examples were shared of counsellors coming into school, or into the home with the family, which helped the young people to feel more relaxed.

## Experiences of care

**Professionals working with children and young people**
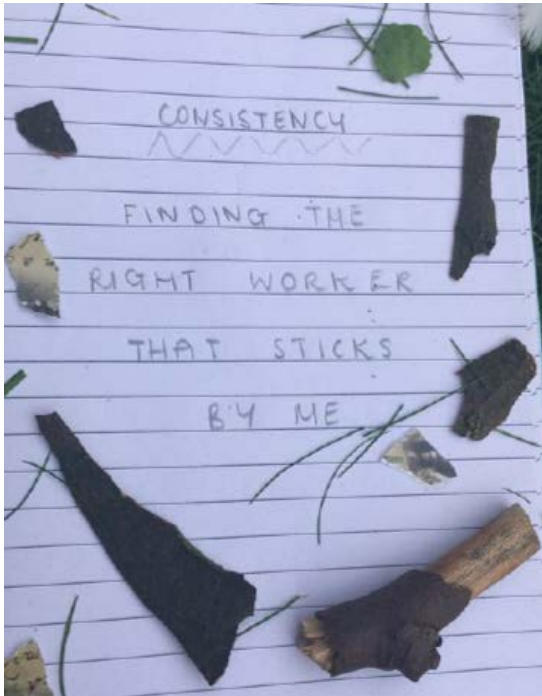


*Young person from the SCIE group*

For children and young people in our engagement activities, the professionals working with them had the biggest impact on their experience of care. This was referenced across all services including schools, hospitals, CAMHS services and GP practices.

Young people felt it was very important that staff had good communication and interpersonal skills. The EAG echoed this sentiment, suggesting that language barriers may pose a challenge to the communication with patients.

> *"I have a looked after children nurse, but I don't have time to develop a relationship."*
> **Young person, SCIE**

Professionals' knowledge and expertise also affected children and young people's experience of care. Young people in our CYPAG group felt that professionals were often inadequately trained to work with children and young people with mental health needs. This was seen as a particular concern for GPs, who were generally perceived to not have adequate training on mental health by most young people in both groups.

> *"What works well is when you get the right people who have the right experience around you."*
> **Young person (CYPAG)**

Continuity of support staff was also reported across both groups of young as being critical. Young people found staff changes frustrating, and did not want to have to establish a relationship with a new staff member and tell their story again. SCIE young people felt that staff changes impacted the ability to build trust.

> *"We have experienced big gaps in cover, when someone leaves; this has a major effect on my wellbeing."*
> **Young person (CYPAG)**

The capacity of professionals was also noted as an important factor. Even when staff were seen as adequately trained and able to work well with children, young people and their families, there was a common perception that they did not have the capacity to work in the way they would like.

> *"Sometimes staff are good. The quality of care can be there but they are overwhelmed and over worked."*
> **Young person (CYPAG)**

The young people we spoke to in SCIE reported some good experiences of the Virtual School (an additional resource to support and challenge all those involved in the education of children in care). All young people from SCIE agreed that having a Virtual Mental Health Lead would be positive. This role would ensure smooth communications, oversight of the system and help advocate for these children and young people.

**Stigma**

Some young people in our SCIE meeting reported that the stigma around mental health had lessened and felt that this was due to there being more help available. However, other young people we spoke to felt that a stigma around mental health still existed and that this impacted their experience of care.

Young people reported that schools often took a view of children and young people as "naughty" or "trouble makers". Some young people felt that the policy of some schools emphasised this – for example, returning to school after a period of being unwell, and placing young people on a restricted timetable.

Young people in our CYPAG meeting felt that a stigma also existed around mental health services. They felt that there needed to be more awareness raising and promotion of positive outcomes in order to lessen the stigma around mental health services and their users.

**Person-centred care**

Person-centred care was also seen as playing a big role in children and young people's experiences of care. It was important to all groups of young people we spoke to that they were treated as an individual. Young people wanted support from a flexible system that met their individual needs.

Many young people felt that more informal options of support were preferable but not always available. For example, young people in our SCIE group discussed how they would feel more comfortable being able to speak to someone over the phone, or even by text. Young people in our CYPAG meeting felt that they had a lack of choice over what therapy they could access; they would have preferred more informal options such as counselling groups, which were often hard to come by.

Young people also reported wanting the care they received to be age appropriate. There were mixed feelings around how the current system addresses this. Some young people in the SCIE group felt that services were age appropriate; others that support could feel patronising at times. Both groups of children and young people reported wanting to be included in decisions about their care, which could change as they grew older.

Our EAG also felt person-centred care was important. The EAG wanted to see that young people were included in the planning of their support. It also felt that commissioning should involve full co-production with children and young people in local areas, which could help with more person centred services.

# Appendix

Summary of the engagement for selected previous reviews and publications, that we considered as part of our policy and literature review.

| Publication | Organisation | Date | Engagement |
|---|---|---|---|
| Future In Mind | NHS England and Department of Health | 2015 | • Taskforce set up with children and young people on board.<br>• 1,600 children, young people, parents and carers were involved in engagement activity led by YoungMinds.<br>• Twitter #youngmentalhealth.<br>• Publication encourages engagement with children and young people with STPs.<br>• Young people were quoted throughout the report, as well as professionals and policy experts. |
| Children's and adolescents' mental health and CAMHS - Health Committee | Parliament | 2014 | • 237 submissions including those from young people, carers and families.<br>• Held an informal private meeting with young people.<br>• Highlighted problems with CAMHS services being experienced by children and young people suffering from particular conditions, or from especially vulnerable groups of society. This includes the engagement of young people with specific conditions included OCD, ASDs, ADHD and eating disorders; vulnerable groups included children and young people in the care system, and those who have been adopted or fostered; homeless young people; asylum seekers and recent immigrants; lesbian, gay, bisexual and transgender young people; and bereaved children and young people. |
| Children and Young People's Mental Health and Wellbeing Taskforce. | Vulnerable Groups and Inequalities Task and Finish Group Report | 2014 | • Brought together professionals from numerous sectors and services with experience of working with children, young people and families with a range of different vulnerabilities. |
| It Turned Out Someone Did care: Childline Annual Review 2015/16 | Childline, NSPCC | 2015/16 | • Findings based on Childline providing more than 300,000 counselling sessions to children and young people in 2015/16. Children contact at all times of day and night by phone, email and 1-2-1 online chat. |
| Progress and challenges in the transformation of | Frith E | 2016 | • Engagement involved a Youth Reference Group |

| Publication | Organisation | Date | Engagement |
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| children and young people's mental health care. | | | |
| Making Sense of Mental health – Lewisham. Children and Young people's mental health Matters in the London Borough of Lewisham. Healthwatch Bromley and Lewisham. | Healthwatch Lewisham | 2016 | • Engagement involved 70 young people aged 11-17yrs, through five workshops held across two schools, one charity, and some outreach |
| Making Sense of Mental health – Bromley. Children and Young people's mental health Matters in the London Borough of Bromley. Healthwatch Bromley and Lewisham: Kent | Healthwatch Bromley | 2016 | • Engagement involved 350 young people aged 10-17yrs, through 15 workshops held across two schools, one charity, and one youth club. |
| Be yourself: Everybody else is taken. Our digital project for young people. | Healthwatch Dorset | | • Engagement involved an online project which received more than 150 contributions in a wide range of media<br>• This was followed by different engagement activities including school assemblies, workshops, focus groups, etc with more than 600 children and young people, volunteer centres and children's centres, colleges and universities, youth centres and others. |
| Future in Mind: Leeds. An insight into the views and experiences of young people, parents and professionals | Healthwatch Leeds | March 2017 | • Engagement involved a combination of surveys and workshops: 126 young people, 59 parents and 120 professionals completed surveys; 6 parents and 9 young people attended workshops. |
| Right Here programme | Mental Health Foundation | | • Four local partnerships – in Brighton and Hove, Fermanagh, the London Borough of Newham, and Sheffield – worked with young people aged 16–25 to co-produce and deliver a range of mental health and wellbeing activities, projects, research and opportunities. |

| Publication | Organisation | Date | Engagement |
|---|---|---|---|
| Report on Children, Young People and Family Engagement for The Children and Young People's Mental Health and Wellbeing Taskforce | YoungMinds | December 2014 | • The views of young people, parents and carers were sought on issues relating to the provision of mental health information and services.<br>• More than 1,100 children and young people and more than 400 parents responded to online surveys.<br>• 800 male respondents completed a poll, 17 discussions groups were held, and 6 telephone interviews. |
| YoungMinds Annual Report 2015-16: Increasing the influence of young people's voice and their families objective. | YoungMinds | 2015/16 | • 64,598 young people pledged support for the YM Vs 'Charter for Change'<br>• A total of 10,420 young people were involved in the project. More than 5,000 young people were more closely engaged in developing the campaign through surveys, focus groups, feedback etc.<br>• The ongoing leadership at YM was provided by a national team of young ambassadors who were connected to local community ambassadors. These local ambassadors led the implementation of the campaign in their local areas and engaged their peers in community campaigning.<br>• 55% of young people involved in the campaign were black and minority ethnic, 18% of campaign participants had a disability, 12% of campaign participants identify as lesbian, gay, bisexual or transgender.<br>• The Parents Say project was started in 2014 with over 600 active parents keen to report on their experiences and give recommendations for improvements. The Participation Toolkit for parents and CAMHS, and has led to a further 250 parents taking membership to over 1000. |