NATIONAL CHILDREN'S BUREAU

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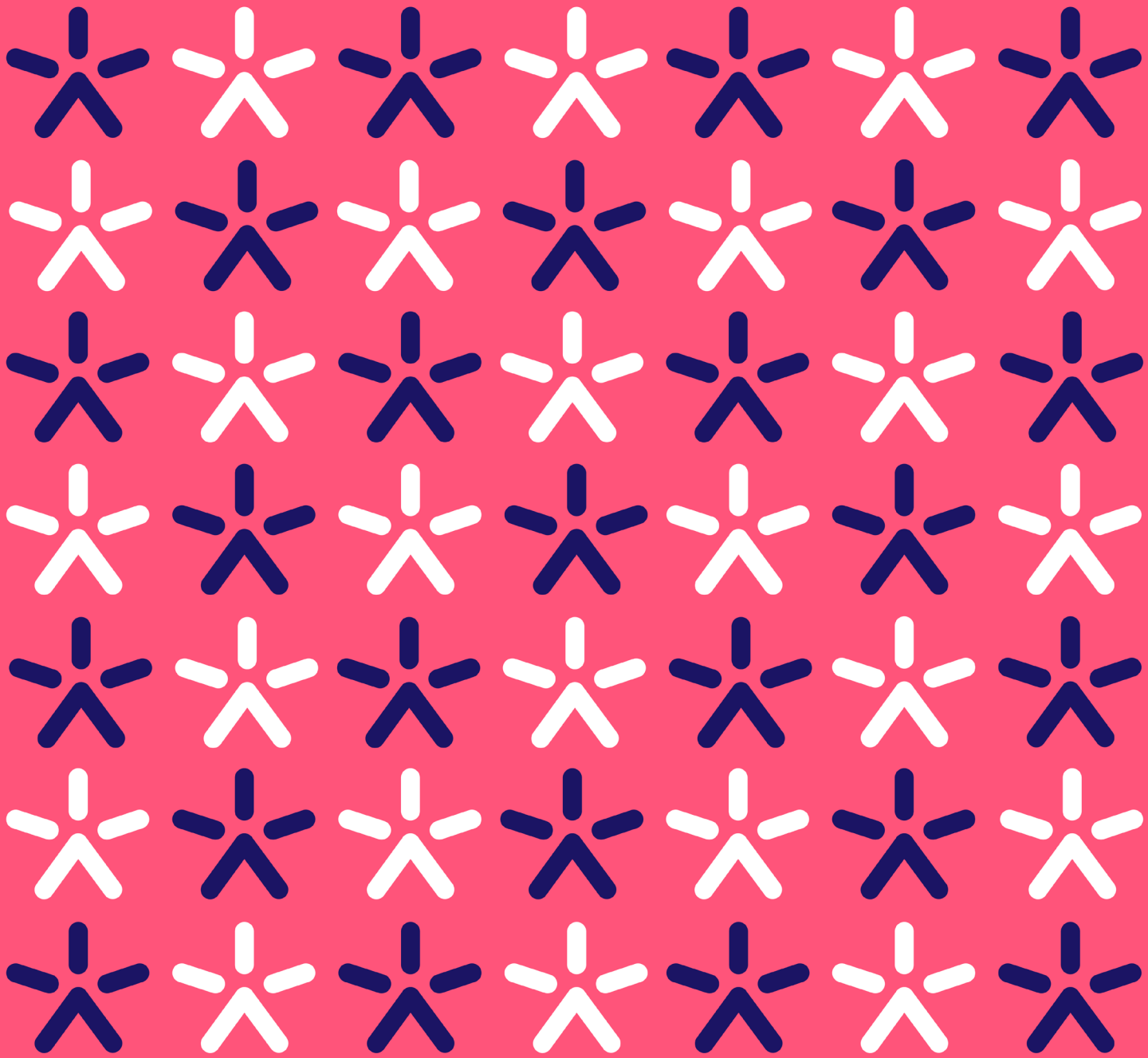
October 2019

A review of children and young people's mental health and its impact on Special Educational Needs and Disabilities Information, Advice and Support Services



UNITED FOR A BETTER CHILDHOOD

Context

The initial intention behind this piece of work was to investigate the following two related areas:

1. To understand the current nature and extent of Special Educational Needs and Disabilities Information Advice and Support (SENDIAS) services' work with children & young people (CYP) experiencing mental health issues.

2. To ascertain SENDIAS services' current level of awareness of and engagement with CYP mental health services in their respective local areas.

To undertake this investigation, a survey was circulated to all SENDIAS services in England. 186 responses were received from over 100 services (respondents were allowed to anonymise their responses). The findings of the survey are summarised and analysed in the sections below.

The impetus behind this piece of work originated from two areas.

Firstly, from anecdotal evidence that SENDIAS services are already engaged in supporting CYP with mental health issues and that this area of work seems to be growing for many services. Accordingly, it seemed useful to seek greater clarity on the nature and extent of their work in this area.

Secondly, mental health has become an area of increasing prominence, both in terms of the Government's policy agenda and within wider public discourse. The publication of the *Future in Mind* report (2015) followed by the *Transforming Children and Young People's Mental Health Provision* Green Paper (2017) moved the issue of CYP mental health to the centre of the Government's policy agenda.

Future in Mind advocated using the example of the changes to the national statutory framework for children and young people with special educational needs and disabilities (SEND) in 2014 to inform improvements in CYP mental health services. It further emphasised the importance of strengthening strategic links between mental health and SEND services.

The Green Paper, meanwhile, set out a series of reforms designed to develop and improve CYP mental health provision both within schools and through service development.

With these considerations in mind, and in anticipation of the full implementation of the Green Paper agenda over the next five years, it would seem that the present moment offers an important opportunity to consider how SENDIAS services can be better positioned to engage with, support and contribute to the changing landscape of CYP mental health provision.

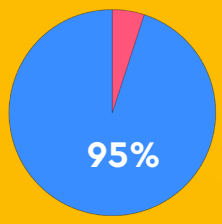
This paper presents the key findings of the SENDIAS mental health survey and concludes by offering some recommendations based on these findings in relation to the Government's CYP mental health agenda.

SENDIAS mental health survey questions

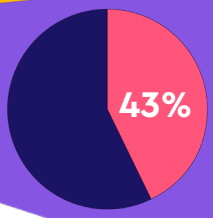
1. Please specify your local area
2. Have you experienced supporting CYP with mental health issues?
3. Have these come with a formal diagnosis?
4. Do you feel as confident in offering support to a CYP with a mental health diagnosis as compared to, for example, a CYP with a diagnosis of ASD?
5. How confident do feel in your understanding and recognition of mental health issues?
6. How confident do you feel in working with and supporting CYP with mental health issues?
7. What CYP mental health services are you aware of in your local area?
8. What CYP mental health services or charities have you experienced working with?
9. Would you feel confident in signposting to the CYP mental health services or charities?
10. Do you feel you and your staff team would benefit from further support and guidance in working with mental health issues in CYP?

Survey results

1. Experience of supporting children & young people with mental health issues



95% of services said they had experience of supporting CYP with mental health issues.



43% of services already have a significant number of CYP in their caseload with mental health issues or have witnessed a significant increase in mental health-related referrals.

Comments

"Increasing numbers of CYP with mental health difficulties are coming through to our service."

"We work with considerable numbers of parents and young people where mental health issues are presenting a problem and a significant number where there is co-morbidity."

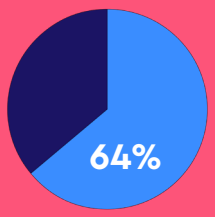
"This number is on the rise. I am coming across more and more CYP that have more complicated mental health such as psychosis or body dysmorphia."

"This area of our work has increased year on year, however, this past 18 months have seen an explosion of young people suffering from mental health difficulties. There are now a lot more boys who are experiencing difficulties in this area – from school refusal, to eating problems, to living in their bedrooms – for a couple of years before support is put in place.

CAMHS are saying that young people with autism do not suffer with mental health problems and these can instead be attributed to their autism. However, parents do not agree with this analysis."

2. Working with children & young people with a formal mental health diagnosis

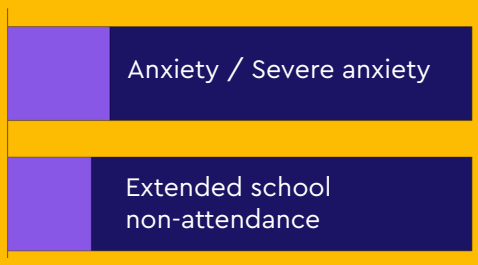
64% of services said the young people they had experience of working with had a formal mental health diagnosis.



Services reported working with CYP who have a formal mental health diagnosis as well as many CYP who experience mental health issues but have no formal diagnosis. Anxiety was indicated as the most common mental health issue suffered by those CYP without a diagnosis.

- Many services connected the lack of diagnosis and/or support for these CYP to long waiting-times and high thresholds for accessing Child & Adolescent Mental Health Services (CAMHS) and, more generally, to a lack in mental health service provision.
- A number of services raised the issue of CAMHS not taking up referrals for CYP with SEN on the basis that they believed their reported difficulties were facets of their special educational needs (SEN) rather than constituting mental health issues. A particularly difficult area in this regard was reported as being the relationship between autism spectrum disorder (ASD) and anxiety and whether anxiety in such instances can qualify as a mental health issue and, accordingly, which service has responsibility for support.
- A further issue raised by services is the question of when social, emotional and mental health needs (SEMH) constitute SEN.

The two most commonly encountered mental health issues were stated as:



- Services also reported working with the following mental health issues and contexts:
  - Bipolar disorder
  - Body dysmorphia
  - Comorbidity/link to SEN
  - "Complex mental health issues"
  - CYP refusing to leave bedrooms for extended periods of time
  - Depression
  - Eating disorders
  - Obsessive-compulsive disorder (OCD)
  - Oppositional defiant disorder (ODD)
  - Psychosis
  - Schizophrenia
  - Self-harm
  - SEMH
  - Suicidal ideation and actions
  - Trauma/post-traumatic stress disorder (PTSD)
  - Young people who have been sectioned
  - Young people in secure units

Comments

"Some CYP come with a formal diagnosis or get one during the time I work with them and their families, but many have no diagnosis and no hope of a diagnosis due to capacity issues within CAMHS and other services."

"Some CYP do but many do not have mental health diagnoses. Many have severe anxiety. If they have an ASD diagnosis they seem to be triaged away from CAMHS and struggle to get any support."

"Some children and young people have a formal diagnosis via CAMHS, others do not. A real issue involves CYP who have an ASD diagnosis and who also have high levels of anxiety which may or may not be related to their ASD."

"Many CYP are not able to access services other than universal services and may have generalised anxiety as a diagnosis."

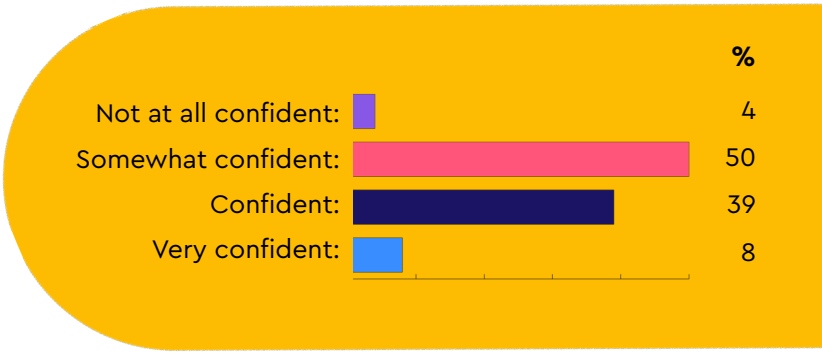
"...the longer waiting times and tougher CAMHS entry threshold makes things very hard."

"Some CYP have a formal diagnosis but many are waiting to be seen by mental health professionals. We usually get calls about CYP with anxiety (including anxiety-based school refusal) or depression and self-harming."

"There is the question as to whether all SEMH constitutes SEN support. This is really a grey area."

3. Confidence in understanding and recognition of mental health issues

Services were asked how confident they feel in their understanding and recognition of mental health issues. Their responses were as follows:



- The majority of services reported feeling somewhat confident in their understanding and recognition of mental health issues while also welcoming the possibility of further development in this area. Services expressed a need for greater understanding of both mild and more complex mental health issues as well as more guidance on appropriate signposting.

Comments

"Our team would value a broader understanding and insight into mental health issues. This would not only help us work with CYP and their families but also with other professionals who may not have such a good understanding of mental health when working with CYP."

"We are beginning to see health service support develop to support education professionals but this needs to be more accessible to meet 'lower level' needs."

"I have a basic understanding, but feel cases are becoming more complex. We also need to consider the impact CYP mental health difficulties have on parents' mental health."

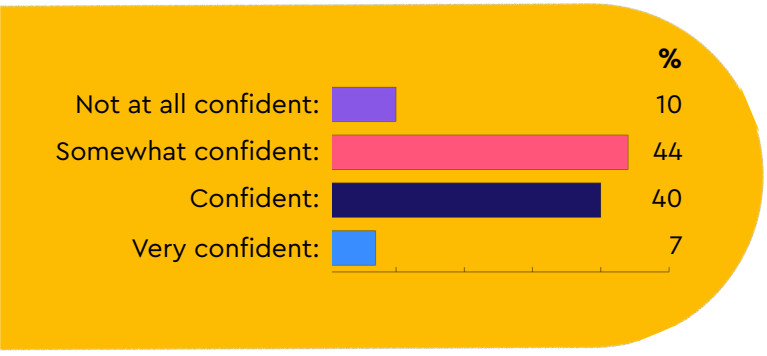
"Our direct work needs to be focused on how best to offer information, advice and support to CYP with mental health issues and their families. We also need to know where to signpost for more direct intervention and support."

"There is a lack of training and support for professionals working with CYP. It is very difficult to access CAMHS as the service has had cut backs."

"Mental health is still more misunderstood by professionals than, for example, ASD. There is still a feeling of 'well the child just needs to get over it/it will go away'. This is particularly relevant in the many cases we have where CYP are refusing to leave the house or where it is a battle for the parents to get them to go to school because of anxiety, depression etc. CAMHS is far too limited with long waiting lists. Schools have no idea what to suggest. The parents are often stuck between physically forcing their children into school and worrying about the impact on their mental health, or keeping them home and risking fines from the local authority."

4. Confidence in working with and supporting children & young people with mental health issues

Services were asked how confident they feel in working with and supporting CYP with mental health issues. Their responses were as follows:



- A significant number of services reported that, while they felt professionally capable supporting CYP with mental health issues, they would nonetheless benefit from further training in this area. Particularly in terms of building trust, rapport and connection.
- Some services qualified their answer to this question by stating that it would depend on the diagnosis or type of mental health issue a child or young person has.
- Some services reported that, while they felt professionally capable supporting CYP with mental health issues, they felt less confident in signposting. Others stated that they felt mental health service pathways were unclear or insufficient.
- Some services reported that referrals are not always taken up by mental health services and that, in general, waiting lists for accessing mental health services are very long.
- Some services reported that educational settings often lack understanding in regard to mental health issues and may often treat them as matters of attendance or of social care.
- Some services highlighted the transition point between CYP and adult mental health services as a particular area of concern.

Comments

"I am confident and passionate about supporting CYP with mental health issues. Sadly, however, there is not always appropriate support available locally either via schools or NHS."

"I feel I understand the law regarding mental health rights (e.g. SEND law, the equalities act, DfE guidance on medical condition). I have a good overall understanding of mental health conditions from previous training but not from SENDIAS related training. I am still trying to understand local pathways for mental health support for students as the CAMHS referral pathway keeps changing and there are lots of gaps in local provision."

"There is no support out there for these young people, CAMHS signpost to SENDIAS and we don't have the training or expertise to properly support these young people. Extra pressure is put on staff to try their best, within their knowledge, to help. However, this often does not prove very effective."

"My main issues have been with lack of coordinated support and moving from CYP to adult services."

5. Awareness and experience of local mental health services

40%

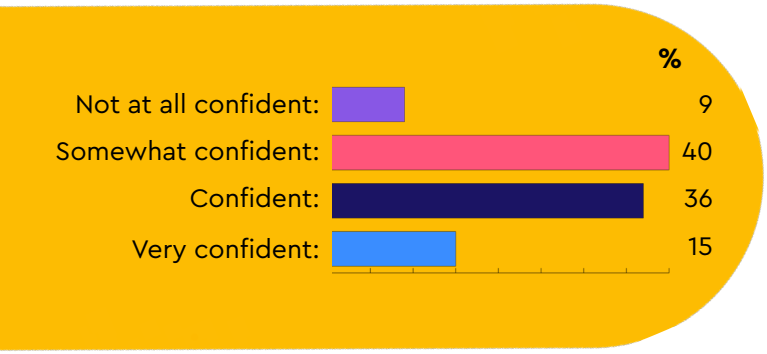
of services had some experience of working with CAMHS.

Many services also reported experience of working with a variety of other mental health services and organisations including:

- Adult Mental Health Crisis Teams
- Anna Freud
- Anxiety UK
- Barnardo's
- CHUMS
- Cruse Bereavement Care
- HeadStart
- Healthy Minds
- Kooth
- Mencap
- Mental Health Matters
- Mind
- No Panic
- YoungMinds
- A variety of different locally-based therapeutic and mental health schemes.

6. Confidence signposting to mental health services and charities

Services were asked how confident they feel in signposting CYP to mental health services or charities. Their responses were as follows:



- The majority of services reported that they felt somewhat confident in signposting. Many also expressed concern as to whether CYP would subsequently receive any support from the mental health services that they were signposted to.
- Many services reported that access to mental health services is variable and waiting times are a problem.
- Some services reported that they felt there were decreasing number of mental health services to signpost to due to funding cuts and that it was difficult to keep up-to-date due to the fluctuating availability of services and provision in this area.

Comments:

"I am confident about signposting, however, there also needs to be understanding that not all charities work in all areas and local authorities may have commissioned specific CAMHS and charity services. I actually feel that there has been enough 'awareness' raising and the focus should now be on providing appropriate pathways and services for CYP, e.g. a child with anxiety and ASD who struggles to engage should not being sent on a group counselling session.

Another big issue is social care, particularly in terms of their querying if even complex mental health issues, such as a child not leaving the house for years due to anxiety, really constitute a disability."

"I feel confident to signpost but not confident in the fact that the CYP will actually receive a service, for example, will they meet the criteria for support."

"Difficult to keep up with this sector and it's providers due to funding cuts and changes to provision and offers of support."

"Referrals are not always accepted and when they are there is often a long wait for services to be delivered."

"It feels a lot harder to find appropriate support for young people whose mental health needs are impacting on their education. The local authority commissions advisory support services for young people with ASD with a clear process structure and lower thresholds for involvement. It can be a time consuming process and challenging to get CAMHS involvement and an active treatment plan in place. This leads

to struggles to get Medical Needs Education services involved. It can be difficult to know where to signpost to in supporting young people back into education when their needs are not at Tier 3/4 level but are still massively impacting upon their access to education."

"Signposting for support is difficult and there have been quite a few incidents where referrals have been made to services but then rejected. We then feel that we are left in a position where we are the only practitioners involved with the children who are self-harming/talking about thoughts of suicide etc."

7. Further support and guidance in working with mental health issues

Comments:

"Yes. As a service, we are encountering increasing instances of mental health issues and increasing confidence in this work would be very beneficial to us."

"Not sure – the main difficulty seems to be lack of access to services, or schools not acknowledging mental health difficulties – e.g. seeing extreme anxiety as 'school refusal'."

"Yes. mental health is a huge area, and a growing number of CYP we work with present with mental health difficulties. The better informed we are, the better we are able to provide the right level of information, advice and support for the CYP and their families, some of whom also have mental health difficulties."

"Yes but at the same time, we are being sent young people who should be receiving support from specialist mental health services, and I often end up feeling that I have taken on responsibility way beyond my role as there is nowhere to signpost these young people to."

"I think the increase in difficulties with mental health for both children, young people and parents has been increasing dramatically and we are in need of more resources to cover this demand more than anything. It may be helpful for us to have more knowledge and training around providing strategies in the interim period while waiting for specific support."

Summary

The majority of SENDIAS services reported already working with CYP with mental health issues and thus having experience and some understanding in this area. Many services reported encountering an increasing number of CYP with mental health issues.

Services are keen to develop their practice and knowledge in this area and feel they would benefit from further training. More specifically, services feel they would benefit from:

- Developing their knowledge and understanding of mild and more complex mental health issues.
- Developing their practical skills in terms of how to build trust and connection with CYP with mental health issues.
- Developing their understanding of mental health services, pathways and thresholds.

Services reported working with a variety of mental health services and organisations, though less than half reported experience of working with CAMHS.

Overall, a common theme is that services feel there is a lack of adequate mental health provision for CYP both in terms of services and within schools. The result is that SENDIAS services often feel unclear where to signpost CYP in need of mental health support.

Many services stated that long waiting lists and high thresholds for CAMHS support result in CYP falling through the net in terms of being able to access appropriate advice and support.

A commonly-reported issue is the lack of clarity in terms of the relationship between SEN and mental health. There are reported instances of CAMHS declining to support CYP with SEN and conversely a question of when SEMH constitutes an SEN.

The findings of SENDIAS Mental Health Survey are in line with those of the Values-Based Child and Adolescent Mental Health System Commission report (2016) and the Care Quality Commission's Review of Children and Young People's Mental Health Services report (2017) and are indicative of shared challenges across local authority areas in England.

These include the complexity and fragmentation of the system that supports CYP mental health and frequent disconnection between services that operate within this system as well as long waiting times for assessment and treatment by specialist CAMHS and the growing frustration when referrals are rejected or considered 'inappropriate' and no alternative offered.

The result of this situation is that GPs, schools and SENDIAS services often struggle to manage growing numbers of CYP with mental health concerns and escalating risk. This situation is further compounded by a lack of awareness of or a lack of capacity in terms of alternative resources available for early help, support, advice and assessment. In many areas, prevention and early intervention provision are underdeveloped with the consequence that those needing help are unable to access it until their condition worsens and they meet threshold for specialist services.

The provision of high quality advice and information, in regards to where to get help and how to access services and support (including digital technology, telephone and face-to-face contact), can play an important role in the promotion of emotional wellbeing.

This is predicated on the workforce having a knowledge of the factors that support emotional wellbeing as well as an understanding of risk factors and the capacity to recognise emerging problems and know where to seek guidance in relation to these problems. It is further predicated on staff having a knowledge of the range of mental services available in their local area as well as access thresholds for these services and appropriate referral pathways.

Services that support CYP mental health, including SENDIAS, health, social care, education and the voluntary sector, need to work effective together in a way that makes sense to CYP and their families. This requires the fostering of stronger links between these services so that a truly collaborative approach is taken while also putting the needs and views of the CYP at the forefront of any decision about support and treatment.

The landscape of CYP mental health provision is changing. With the implementation of the Government's 2017 Green Paper over the next five years, a key initiative will be the development of further provision in this area through the creation of Senior Mental Health Leads (SMHL) in schools and Mental Health Support Teams (MHST)/Education Mental Health Practitioners (EMHP).

As it stands, given the apparent scale of need in the area of CYP mental health and the continuing scarcity of provision, it is hard to foresee what the impact of the implementation of the Green Paper agenda will be for SENDIAS services in terms of increasing or decreasing mental health-related referrals to these services. However, it seems clear that the increased prominence of mental health within the Government's agenda for CYP offers the opportunity to position SENDIAS in a complementary and mutually supportive role in relation to this agenda and particularly in relation to the implementation of the Green Paper proposals. This is even more the case given that SENDIAS services are already providing *de facto* support to significant and often growing numbers of CYP with mental health issues.

Initially, it seems clear that SENDIAS services would benefit from a thorough knowledge and understanding of the structure and content of the Green Paper reforms, particularly in terms of the existence and functions of SMHLs and MHSTs/EMHPs. Similarly, both SMHLs and MHSTs/EMHPs can be envisioned as benefitting from a knowledge and understanding of the existence and functions of their local SENDIAS services.

Building strategic links here could be an important area of development and mutual benefit. This benefit could be further enhanced by the development and provision of a training package to SENDIAS services which enhance their understanding and skills in relation to mental health, particularly in terms of their knowledge of common mental health difficulties and appropriate referral pathways as well as some relevant skills-based content for engaging with CYP with mental health issues. Indeed, significant portions of the content of the learning outcomes specified in the SMHL documentation would also be applicable and valid for SENDIAS services to have an understanding of. Similarly, it can also be envisioned that some reference to SENDIAS services could be included in the curriculum of the SMHL training package and could potentially be supportive of these leads in the performance of their new role.

Accordingly, based on the findings of this survey, a knowledge of the planned implementation of the Green Paper proposals and in accord with the principles of the CASCADE[1] and THRIVE[2] frameworks we propose the following recommendations for SENDIAS services:

- Providing clarity on the roles, remit and responsibilities of partners involved in supporting CYP mental health (including that of SENDIAS services themselves). This would also include a knowledge of the Green Paper reforms, including an account of the roles and responsibilities of the SMHLs and MHSTs/EMHPs.
- Emphasising the importance of SENDIAS services developing agreed points of contact in schools/colleges and CYP mental health services.
- Emphasising the benefits of a representative from CYP mental health services being included on SENDIAS service steering groups and/or the development of partnership agreements between SENDIAS services and CYP mental health services.
- Developing understanding of how to differentiate when the need of the child or young person would be better met by an education or health intervention, specifically in relation to SEND, and how to access the right service.
- Providing knowledge of how to give and seek support to and from existing mandatory roles, such as SENCOs, Designated Safeguarding

1 Available at: https://www.annafreud.org/media/7537/a4-layout-casscade-300518a-spread-view.pdf

2 Available at: https://www.annafreud.org/media/9242/thrive-framework-for-system-change-2019.pdf

Leads, Designated Teachers and Virtual School Heads, to ensure CYP with mental health conditions get the support they need.

- Providing knowledge of statutory and independent mental health service provision in local areas and guidance on planning for how to embed interaction with these services, bringing together education with mental health professionals to make the most of shared resources and work towards the best outcomes for CYP.

  This will include being able to work effectively with SMHLs, MHSTs/EMHPs and the Mental Health Services and Schools/ Colleges Link Programme, where applicable, in order to ensure CYP receive the right support for their mental health needs.

- An understanding of the thresholds for making a referral to CAMHS and guidance on writing an appropriate referral to CAMHS.
- Providing knowledge of common and more serious mental health challenges and an understanding of risk factors associated with mental health difficulties of specific groups, including young carers, LGBTQ+[3] , children and young people with SEND, children in need, and adverse childhood experiences.
- Providing guidance on building trust and rapport with CYP with mental health issues in order to support their engagement with planning and decision-making processes.
- Supporting and empowering CYP voice to inform what support is needed for them.

3 Lesbian, Gay, Bisexual, Transgender and Queer (or Questioning) and others.

Recommendations

1. Guidance

The Council for Disabled Children (CDC) to develop useful guidance for SENDIAS services in regards to working with those affected with mental health issues, in developing strategic links with statutory mental health services and in how service staff themselves are supported.

CDC is part of the National Children's Bureau family.

2. Training

CDC to develop a mixed training package comprising face-to-face and e-learning components.

Training would include details of the 2017 Green Paper structure; guidance on understanding and working with statutory mental health services; knowledge of common and more serious mental health challenges and an understanding of risk factors associated with mental health difficulties of specific groups.

3. Relationships

CDC to facilitate relationships between SENDIAS services, statutory mental health services and voluntary organisations on a local and regional basis.

This would entail consulting with local services and organisations to ascertain the most effective way of achieving this on an area by area basis. Initially, this may additionally involve working with a small number of services i.e. those in the Green Paper first wave trailblazer areas.

4. Oversight

CDC to host a cross-cutting Mental Health Task and Finish Group to oversee and contribute to recommendations 1, 2 and 3 and to present an opportunity for discussion and shared learning which supports CDC and Government and informs policy and practice.

To include SENDIAS Service Managers with experience of working with mental health issues; mental health charities; CDC officials; NHS England and Department for Education colleagues.

Appendix 1: Resources for SENDIAS services

Youth Wellbeing Directory

The Youth Wellbeing Directory provides a list of free local and national organisations for anyone up to the age of 25, along with important information you may find helpful.

https://www.annafreud.org/on-my-mind/youth-wellbeing/

Open Talk

Open Talk is designed to support decision-making between children, young people and mental health professionals in inpatient and community mental health services.

http://www.opentalk.info/

MindEd

The MindEd Core Curriculum is directly aimed at all adults working as professionals or volunteers with children and young people and is not aimed specifically at a specialist child mental health audience. It offers e-learning to inform about the mental health of children and young people, what goes wrong and what can be done to help. It provides a wealth of information on child development, how problems show and will give practical insights into when to be concerned, what to do and when to refer on to specialists.

https://www.minded.org.uk/#

Mentally Healthy Schools

Mentally Healthy Schools is a free website for primary schools, offering school staff information, advice and practical resources to better understand and promote pupils' mental health and wellbeing.

https://www.mentallyhealthyschools.org.uk/

Anna Freud

Mental health resources for professionals, CYP and families.

https://www.annafreud.org/what-we-do/our-help-for-children-and-families/

The Anna Freud Learning Network is a free national network for individuals and organisations which shares the latest research, resources and learning opportunities to those working to transform the mental health of children and young people.

https://www.annafreud.org/what-we-do/anna-freud-learning-network/

Place2Be

These Place2Be resources can help parents and carers to support the emotional wellbeing and mental health of their children and young people.

https://www.place2be.org.uk/what-we-do/parent-carer-resources.aspx

Kooth

Kooth, from XenZone, is an online counselling and emotional well-being platform for children and young people, accessible through mobile, tablet and desktop and free at the point of use.

https://www.kooth.com/

Centre for Mental Health

Mental health resources for CYP and families.

https://www.centreformentalhealth.org.uk/our-work

Moodscope

Moodscope is an entirely service-user-developed online mood-tracking and feedback tool with built-in social support, designed to stabilize and improve mood. It enables individuals to accurately measure and record daily mood scores which are automatically tracked on a graph and, with an individual's agreement, emailed each day to one or more trusted friends who have agreed to keep an eye on the user.

https://www.moodscope.com/

NATIONAL CHILDREN'S BUREAU

United for a better childhood

The National Children's Bureau brings people and organisations together to drive change in society and deliver a better childhood for the UK. We interrogate policy, uncover evidence and develop better ways of supporting children and families.

Let's work together: 020 7843 6000 | info@ncb.org.uk

London: 23 Mentmore Terrace, London, E8 3PN

Belfast: The NICVA Building, 61 Duncairn Gardens, BT15 2GB

Anti-Bullying Alliance

SEX EDUCATION FORUM

Council for disabled children

ni ABF Northern Ireland Anti-Bullying Forum

Childhood Bereavement Network

LEAP

Part of the family
NATIONAL CHILDREN'S BUREAU

National Children's Bureau is registered charity number 258825 and a company limited by guarantee number 00952717. Registered office: 23 Mentmore Terrace, London E8 3PN.