2024-2025

NHS YOUNG RESEARCHERS:

SHARING YOUNG VOICES, CHANGING MENTAL HEALTH SERVICES

Authors:

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TRIGGER WARNING

The contents of this report may be emotionally challenging and potentially triggering as it explores **experiences of mental health crises, with specific reference to suicidal ideation and self harm,** and **traumatic experiences of mental health services.**

If you do require any more support, please access these mental health helplines:

Young Minds:

Text: YM 85258
Website:
https://www.youngminds.org.uk/about-us/contact-us/

Samaritans:

Call: 116 123
https://www.samaritans.org/how-we-can-help/contact-samaritan/talk-us-phone/

Papyrus UK:

Call: 0800 068 41 41
https://www.papyrus-uk.org/

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INTRODUCTION

Young people deserve better mental health support. To understand the real experiences of those who rely on NHS mental health services, we gathered 245 responses from young people across the country. Their voices are powerful, honest, and urgent.

This report reflects their stories—their struggles, frustrations, and hopes for change. It highlights the barriers they face, from long waiting times to inadequate support for neurodivergent individuals. We also offers clear recommendations on how services can be improved to meet the needs of the young people they are meant to help.

This report shows that change is needed now.

Who are we?

We are the NHS England Young Researchers 2024-25 (mental health subgroup) —a group of young people passionate about improving health services for young people across the country. As advocates for change, we believe that young voices must be heard in shaping the future of mental health care.

This report is the result of months of dedication, research, and collaboration. We gathered and analyzed responses from 245 young people to highlight the urgent need for reform in NHS mental health services. Each of us bring our own experiences, insights, and commitment to ensuring that young people receive the support they deserve.

Authors:
Yifan Wong
Susie, 18
Sharvari Patil 22
Megan Kwok
Anna Morton, 20

Together, we hope this report sparks meaningful change. The NHS must work with young people, not just for them.

TIMELINE

1. HOW IT STARTED - WE:

SUB GROUP

Share a passion for mental health advocacy. We chose to work in the NHS Young Researchers' **Mental Health** sub-group.

ONLINE SURVEY

Built a **survey** to gather insights on mental health and assess **what <u>changes to policies</u> and <u>services</u> within the NHS and wider sector are needed.**

2. COLLECTING DATA

We shared the online survey across various channels:

THIS MEANS:

- **SOCIAL MEDIA:**
  - E.g: Instagram stories & TikTok
- **WORD OF MOUTH**
  - Talking to friends
  - Other Youth Groups & Forums

WHY?

TO: REACH A DIVERSE AUDIENCE.

- Our goal was to collect data that is **more representative of the <u>entire population</u>** (England)
- **Not** just a specific demographic group.
- This helps **<u>lower</u> the <u>risk of bias</u>** in our results.

RESULTS:

WE RECEIVED <u>245 RESPONSES</u> IN TOTAL!

3. ANALYSIS & REPORT

AS A TEAM WE:

1. Grouped survey questions **into separate sections**.
2. Assigned a section to each team member to **analyse**.
3. **Worked together** to produce this report!

IMPORTANT NOTES

ANONYMITY

ALL SURVEY RESPONSES WERE COLLECTED ANONYMOUSLY.

No personal details, such as names or contact information, were linked to any answers.

- Survey participants **felt safe,** allowing them to be **honest** and express their **true opinions** without fear of judgment.
- This approach enabled us to gather **reliable** and **genuine responses**.

INDEPENDENT RESEARCH

OUR TEAM PREPARED THIS REPORT ENTIRELY ON OUR OWN, WITHOUT ANY OUTSIDE INFLUENCE.

The NHS Young Researchers programme, supported by Barnardo’s, provided us with resources and guidance. However:

- **Every part of the research** - from designing the survey, collecting responses, analysing the data, and writing the report - **was carried out solely by our team.**
- Our report reflects our **genuine interpretation of the data we gathered.**

DEMOGRAPHICS

This section covers the demographics information collected from our survey participants.

In our survey, we included 9 demographics-related questions:

“What is your age?”
“Region”

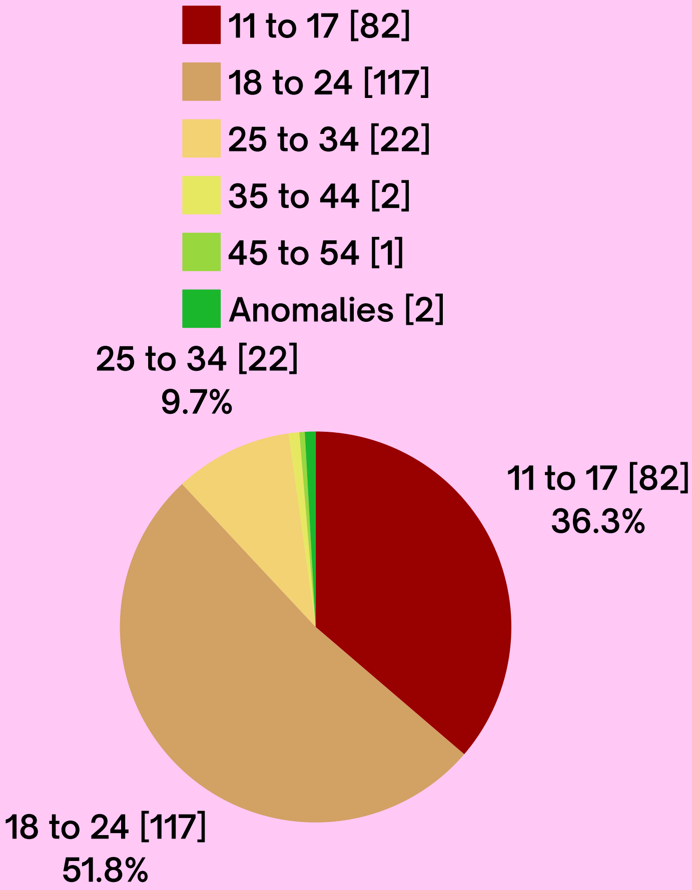
“Ethnicity”
“Religion or Belief”

“Gender Assigned at Birth”
“Gender Identity”

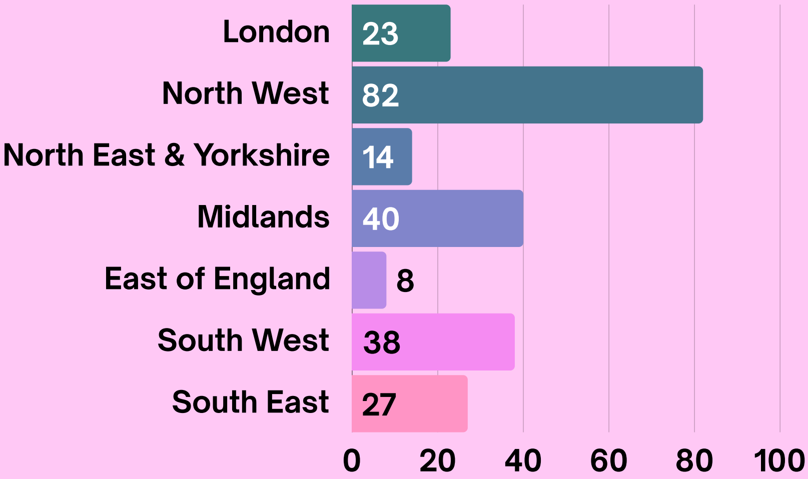
“Sexual Orientation”
“Do you identify as... (tick all that apply)”

“Disability, Impairment, Mental of Physical Health Condition”

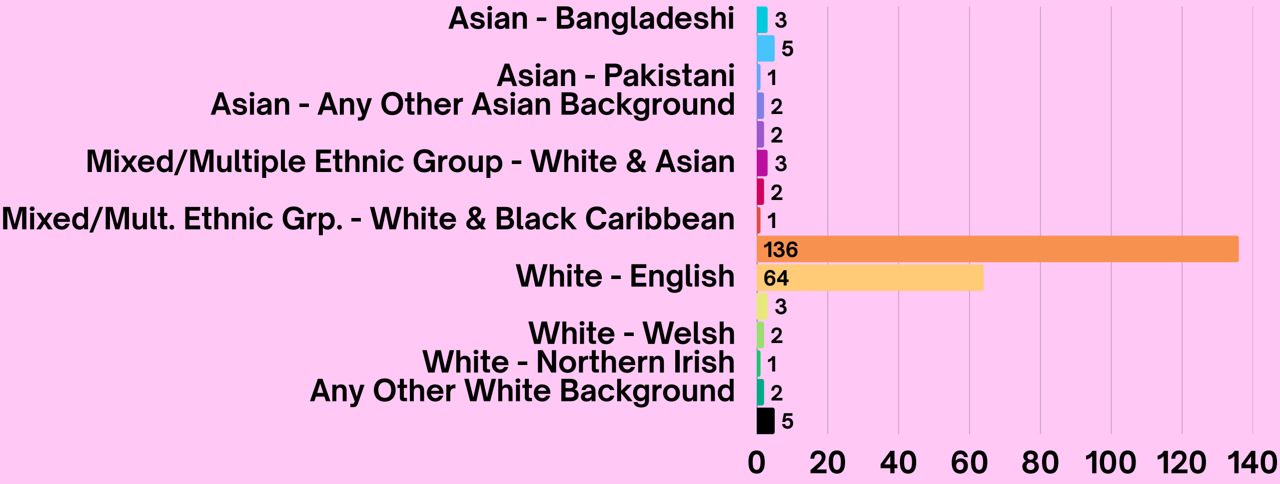
Age:


🟥 11 to 17 [82]
🟫 18 to 24 [117]
🟨 25 to 34 [22]
🟨 35 to 44 [2]
🟩 45 to 54 [1]
🟩 Anomalies [2]
25 to 34 [22]
9.7%
11 to 17 [82]
36.3%
18 to 24 [117]
51.8%

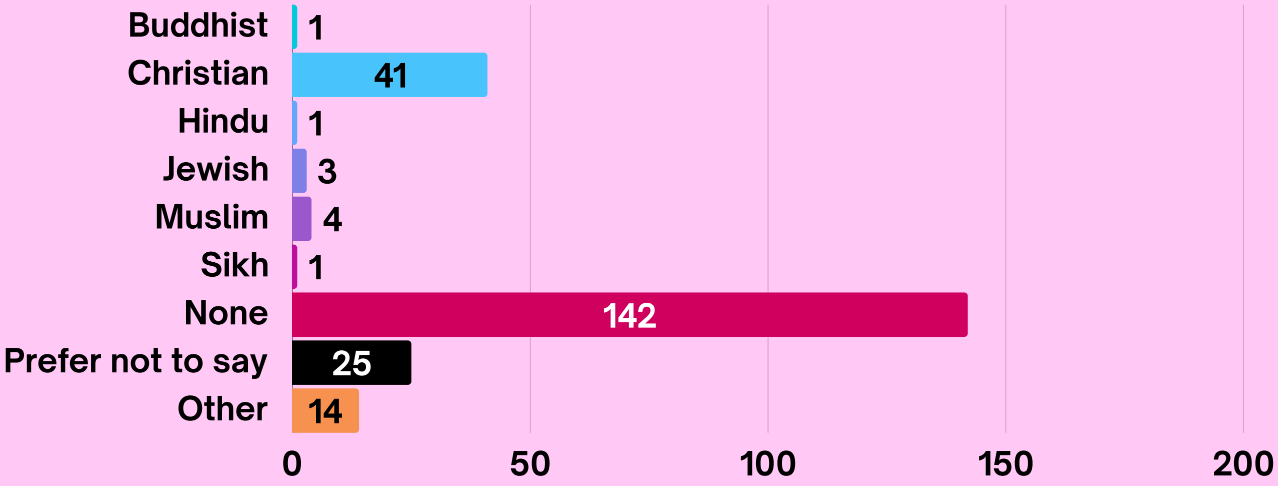
Region:


London
23
North West
82
North East & Yorkshire
14
Midlands
40
East of England
8
South West
38
South East
27
0
20
40
60
80
100

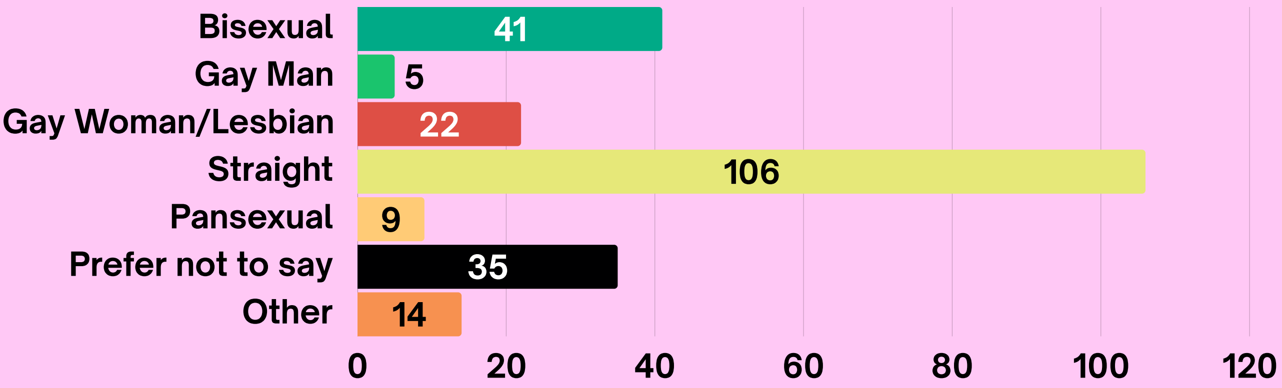
Ethnicity:



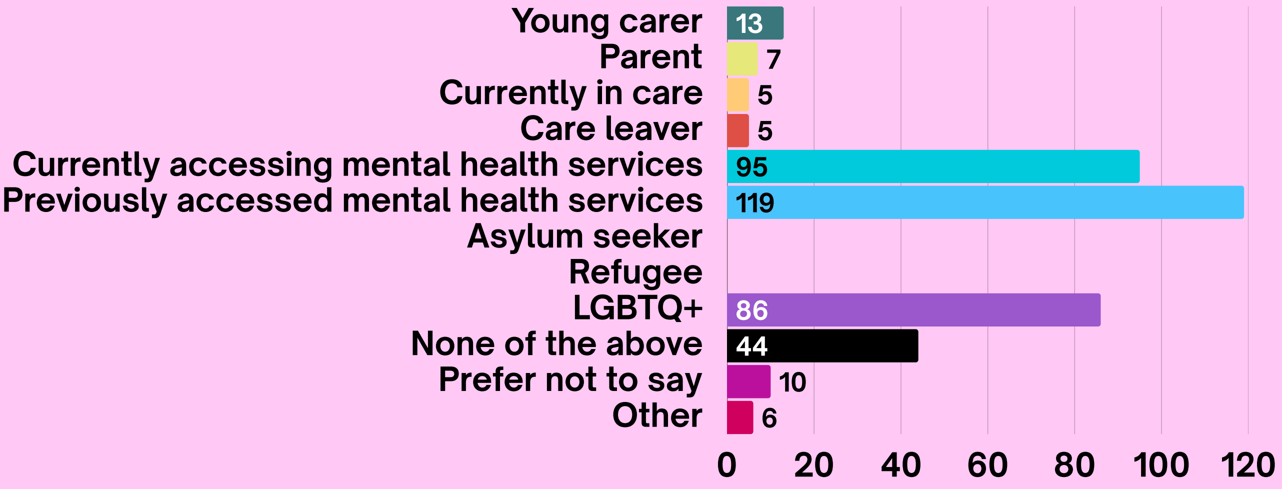
Religion:



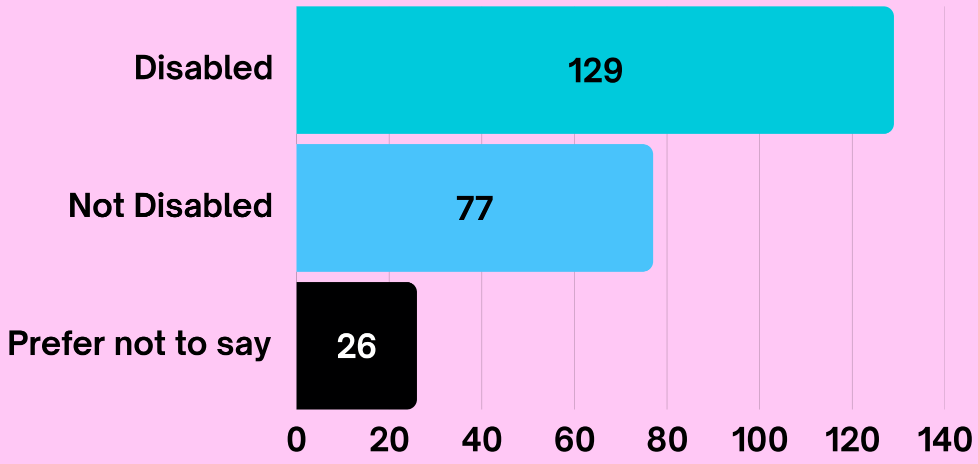
Sexual Orientation:



"Do you identify as (tick all that apply)":



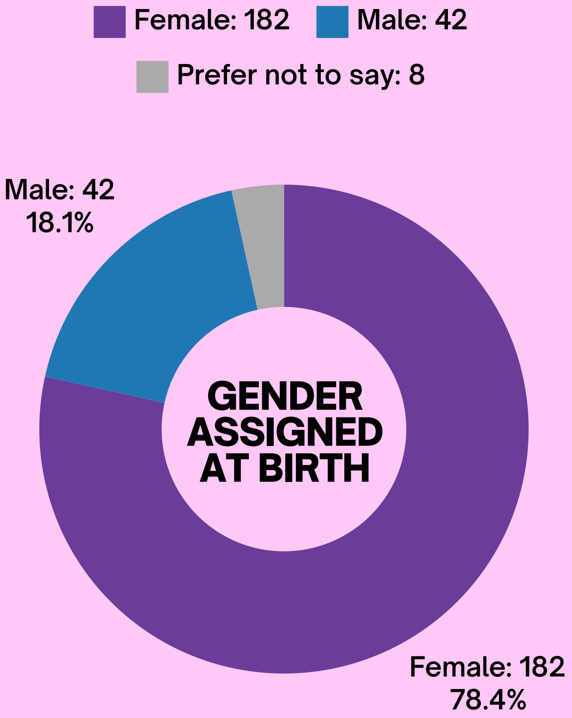
Disability, Disability, Impairment, Mental or Physical Health Condition:

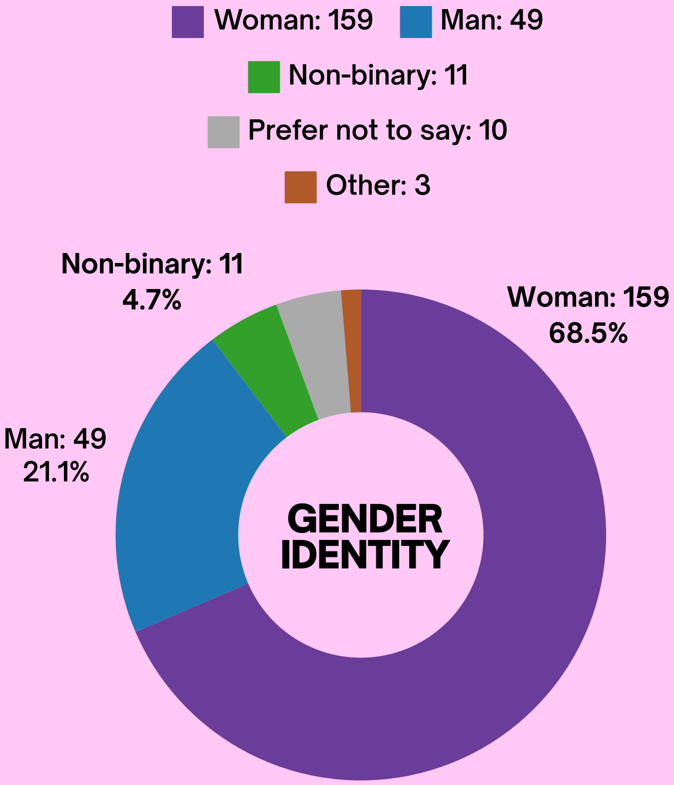


In addition:
185 survey participants (76%) identify as neurodivergent

Description from our survey:
“We use the social model of disability and look to remove the barriers that limit the choices of disabled people. For monitoring purposes, we use the Equality Act 2010 (or the Disability Discrimination Act 1995 in Northern Ireland) definition of disability that includes long-term physical or mental impairments that have a substantial adverse effect on your ability to perform day-to-day activities.”

Gender:





WHAT CAN WE SEE?

There is **a big gap between male and female responses**.

The difference is about: **60.3%**.

The **big gap** we see is **unlikely to have happened by chance**.

WHAT DOES THIS MEAN?

This suggests that there **must be a reason** that far fewer males participated in the survey.

Neurodiversity

In this section we asked young people, who identify as being neurodivergent, to comment on their experiences of mental health services. We obtained 185 responses and were exceptionally fortunate to have such a large volume of young people talk so openly and honestly about their own lived experiences.

Disclaimer- I think that it is important to bear in mind that no two neurodivergent individuals are alike. The themes picked out are specific to the responses we were given. They may not reflect the general consensus. If you wish to educate yourself better on a person's neurodevelopmental condition(s). Speak to them, if you are able, try to understand how they perceive the world, what their struggles and most importantly focus on their strengths.

By Susie

Do you think being neurodiverse has impacted your care?

84%

Believe that being Neurodiverse has negatively impacted their care

Many responses were centred around the lack of reasonable adjustment in mental health services and how the lack of adjustments impedes their ability to access the support they crucially need. Whether this is because the actual environment a young person would receive care is too overstimulating (perhaps lights are too bright or there is a cacophony of background noise) or the young person is unable to leave their home maybe the journey there is too anxiety-inducing or maybe the young person is just unable to engage in the particular type of therapeutic treatment they are being offered. The general consensus is that mental health care, for those who identify as being neurodivergent, needs to be more bespoke; it needs to meet the needs of the individual rather than being a one size fits all model.

‘Bouncing from service to service with no support’

Many young people have been left in a grey area, left to contend with their mental health struggles without any professional support. Frequently, a young persons struggles with their mental health have been attributed to their neurodivergence and consequently mental health services are reluctant to offer support. Many express that mental health care should be allocated based on need; a young person’s neurodevelopmental condition(s) should not factor into whether they are given support.

‘I feel like everything gets blamed on my autism’

Neurodivergence seems to be a get-out-of-jail card for mental health providers. It provides them with an excuse not to treat a young person. Many responses convey a young person being denied access to the correct treatment because their ‘problems’ are down to their neurodivergence. Therefore mental health support teams cannot help them.

‘Came out worse than I went in’

The general consensus from response given is that conventional treatment methods such as CBT (cognitive behavioural therapy) are ineffective for those who identify as being neurodivergent. Many went further to say that these types of treatment are damaging. One recalled having to partake in a ‘role play activity’ despite explicitly clear that they felt uncomfortable. Consequently, the young person left was unable to trust the therapist afterward.

‘I had to educate them on autism myself’

One young person was told by a member of staff, whilst in tier 4 care, that they ‘actively switched off whilst receiving autism training’. Although every neurodivergent individual is unique, a basic level of understanding, which can then be applied to a young person's situation, is needed to ensure every neurodivergent individual receives the correct care.

‘Attention seeking’

Many young people who identify as being neurodivergent struggle to voice their emotions. The responses we received reflect this. Whether this is because they struggle to articulate their own emotions or are constantly masking. Often young people turn to certain behaviours when they are at breaking point, when they cannot cope anymore. Such behaviour should not be labeled as ‘attention seeking’ they should be recognised and actions should be taken to support the young person following them. No matter how trivial their issue may appear; for you are not in the young person's mind (neurodivergent brains cope and respond to different circumstances in a way dissimilar to those who are neurotypical) nor may you be in position of the full facts.

‘Trying to anticipate the correct answer’

Social masking for many neurodivergent individuals is the norm. Putting on a front and hiding their true identity is second nature. This barrier ceases to come down when receiving mental health support. Measures need to be taken ensure that the young person can trust the mental health professions and subsequently open up about their problems.

‘Hard to explain how I feel’

More support is required to better aid young people in articulating their feelings. Often those who identify as being neurodivergent struggle to identify emotions and subsequently communicate those effectively. Expression of emotions, particularly at a time of mental health crisis, is crucial to ensuring a young person's safety is upheld.

‘You feel like an outsider’

‘Feeling like an outsider’ or ‘feeling out of place’ is a recurrent theme from our responses. The world we live in is not designed for those who identify as being neurodivergent. Mental health services are no exception to this. Many young people expressed that they felt failed by mental health services.

When you first received your neurodivergent diagnosis, did you feel that you received adequate support and information about your diagnosis?

81%

Said that they were not given adequate support and important post diagnosis

‘Left in No Man’s Land’

Many recount feelings of abandonment following a neurodivergent diagnosis. Receiving a neurodivergent diagnosis, too many, is life-changing; evoking many questions for the person diagnosed. Many wish they were given the chance to talk to a professional about what their diagnosis means to them and the potential implications their diagnosis may have upon their life. Instead, many are left to figure things out for themselves, navigating their new identity whilst, for many, simultaneously battling mental illness.

‘I felt like I had the title and then was left alone’

‘I got a leaflet and sent home’

‘Left in the dark about what my diagnosis really entailed’

‘‘Left to deal with it and find support myself’

‘I didn’t know what it meant’

‘I still have a lot of unanswered questions’

Acknowledgments can be made that the NHS chronically underfunded and understaffed. However, all these young people wish is to be given the opportunity to talk. To talk to individuals who have similar experiences to them, to talk to individuals who will listen to the hardships they have faced, to talk to someone who will validate them and reassure them that just because they have a neurodevelopmental condition(s) that there is nothing wrong with them.

How could mental health services better accommodate your needs as someone who identifies as being neurodivergent?

‘Access to screening and diagnostic services’

There is clear correlation, found in the responses to this between late/missed diagnosis of neurodevelopmental conditions and poor mental health. Whether this is due to individuals finding particular therapeutic treatments ineffective as mental health professionals don’t fully understand a person’s neurodevelopmental condition or mental health professionals not recognising that a young person has a neurodevelopmental condition and instead treating the young person for something else entirely. Therefore, screening alongside mental health assessment is critical in safeguarding a young person's health and wellbeing.

‘You don’t look Autistic’

Comments such as these can be deeply degrading. It reinforces a stereotype that all autistic people look and act in the same way. This is not true; autism is a spectrum disorder- no two autistic people are alike- this is crucial in understanding and conversing with autistic young people and more widely neurodivergent young people. A one-size-fits-all approach cannot be taken. Service providers need to be better educated on how to address young people.

‘Listen to and don’t judge’

Often there is so much stigma surrounding neurodiversity. Quite often neurodiverse individuals believe that they are the issue, that there is something wrong with them. The best thing that can be done to listen intently to what the young person has to say and make them feel validated.

‘More time in appointments’

Some neurodivergent individuals have spoken about their struggles with slow processing or their difficulties on focusing for prolonged periods of time. This hinders their ability to fully engage in whichever therapeutic treatment they are being offered. If given more time, or perhaps breaks during sessions, may allow young people to get more out of every session.

‘Better explanations’

The world, for those who identify as being neurodivergent, is quite anxiety inducing. Better explanation as well as giving young people advice warning on changes that may occur in their treatment (ie whether their appointment is being postponed or they are going to be seeing a new member of staff) can make the world of difference. It can mean that the young person has a better understanding of what is going to happen and consequently feels more relaxed allowing them to better engage in treatment.

Summary of Recommendations

SCREENING FOR NEURODEVELOPMENTAL CONDITIONS ALONGSIDE ALL MENTAL HEALTH ASSESSMENTS

To ensure that no young person slips under the net and to ensure that every young person receives the support that they require.

MORE POST DIAGNOSTIC SUPPORT (NOT JUST LITERATURE) - SUPPORT GROUPS OR A FORM OF TALKING THERAPY- TO CHAT THROUGH THE IMPACT OF THIS DIAGNOSIS ON THEIR LIFE

To ensure that young people are in possession of all the facts, that they are aware of what their diagnosis means to them, and that they are given all the resources to manage their condition(s). It is imperative that young people receive all the help they require in order to safeguard their mental wellbeing

LISTENING INTENTLY TO YOUNG PEOPLE - GETTING YOUNG PERSON'S VIEWS ON THE SUPPORT THEY BELIEVE WILL BE MOST BENEFICIAL TO THEM (OFTEN CONVENTIONAL TREATMENTS FOR MENTAL HEALTH CONDITION ARE INEFFECTIVE FOR THOSE WHO IDENTIFY AS BEING NEURODIVERGENT)

To ensure that young people are only given support that is going to positively impact their mental wellbeing.

SUPPORT GIVEN TO AID A YOUNG PERSON TO EFFECTIVELY ARTICULATE THEIR THOUGHTS AND EMOTIONS.

Many young people relay their struggles to effectively communicate their core thoughts and emotions. Whether this was due to them themselves not knowing exactly what emotions they are feeling or whether they struggled to explain how they were feeling to professionals. If young people were given support in conveying their true feelings, the mental health professionals will be able to understand their true needs and offer them the correct support and perhaps prevent further deterioration in the young person's mental wellbeing.

MENTAL HEALTH WITHIN THE COMMUNITY

This section focuses on what respondents would like to learn about their mental health and the support they would like to receive within their communties. It also contains practical recommendations for the NHS and community mental health services to implement

WHAT WOULD YOU LIKE TO LEARN MORE ABOUT YOUR MENTAL HEALTH

"How to cope. Baths and cuppas don't help"

Most young people wanted to to know techniques on how to be mentally fit. This includes learning to be "resilient, deal with challenges" , "deal with thoughts and manage emotions" and how to "look after yourself in an attainable way". They felt that current strategies offered are not "achievable for young people". While they had the knowledge to take care of their physical health such as "eat 5 a day and exercise" they wanted to know the equivalent for mental health. This is important as we need to promote a culture of wellbeing and mental fitness rather than simply reacting to mental health issues. Contrary to popular belief, young people are seeking out this knowledge and being proactive so that they can "learn to help themselves" - they are driving force of this change but they need support and knowledge to do this e.g. from schools.

"I'd like to learn more about how I can PREVENT getting into a crisis rather than just reacting to it!"

"I feel like awareness to your peers would be more useful of what it is really like to be mentally unwell"

"Why am I like this?"

No young person should feel that there is something wrong them. We need to continue raise awareness of ALL mental health disorders - not just the ones that are currently spoken about.

"Why I am the way I am"

"What is wrong with me?"

"Know that I'm not bad"

WHAT WOULD YOU LIKE TO LEARN MORE ABOUT YOUR MENTAL HEALTH (PAGE 2)

Knowledge about neurodiversity and mental health

The current healthcare system is designed in mind for neurotypical young people. Young people want knowledge about the intersection between neurodiversity and mental health and what accommodations would help them. They want to learn knowledge that is specific to their disorder such as “rejection sensitivity from ADHD” . Most importantly, they need to receive treatments and coping strategies that are tailored for their specific disorders - not just ones that work for neurotypical young people. Given the high prevalence of mental health disorders within this population, future research needs to look at how to tailor therapies and coping strategies can work for neurodivergent young people.

> **“I want to know how my brain works and learn ways to cope”... “Not just methods that are supposed to work for non-autistics”**

Knowledge about mental health disorders

Many young people wanted to know more about their specific disorders. Most frequently reported include: PTSD, anxiety and OCD. Many expressed interest in knowing about symptoms, causes and treatments for these disorders. They also seeked a better understanding of how these manifest in day-to-day life and how to deal with symptoms when they are triggered.

WHAT SUPPORT WOULD YOU LIKE TO RECEIVE FROM YOUR EDUCATION/ WORKSPACE?

Physical adjustments

Sensory adjustment	Frequency
Quiet space	20
Sensory adjustment(e.g. fidget toys, headphones)	9
Breaks (e.g. mental health sick days, flexible schedules)	15
Safe person	11
Lenient deadlines	6
Check-ins	10

Schools and workplaces need to feel safe. Right now they don't. There is too much stigma and misunderstanding. Young people are angry and rightfully so; they deserve spaces to feel safe. Adults have a responsibility to develop their understanding and promote safety and acceptance of all young people and accommodate their needs.

"I wish it didn't feel taboo to talk about / address my needs. I'm always so worried about discrimination/unfair dismissal against my needs that I don't disclose them to employers, which makes life harder than it should be."

"teachers don't understand and tell us "it's not my job role" okay well you're a trusted adult to me, why aren't you equipped to help? Whether it's your job role or not, I'm with you like 40 hours a week you should at least be supportive."

"I don't really have any support at school, even though I'm been just diagnosed my school is very believing that I am neurodivergent, as I mask quite well which can be really frustrating. "

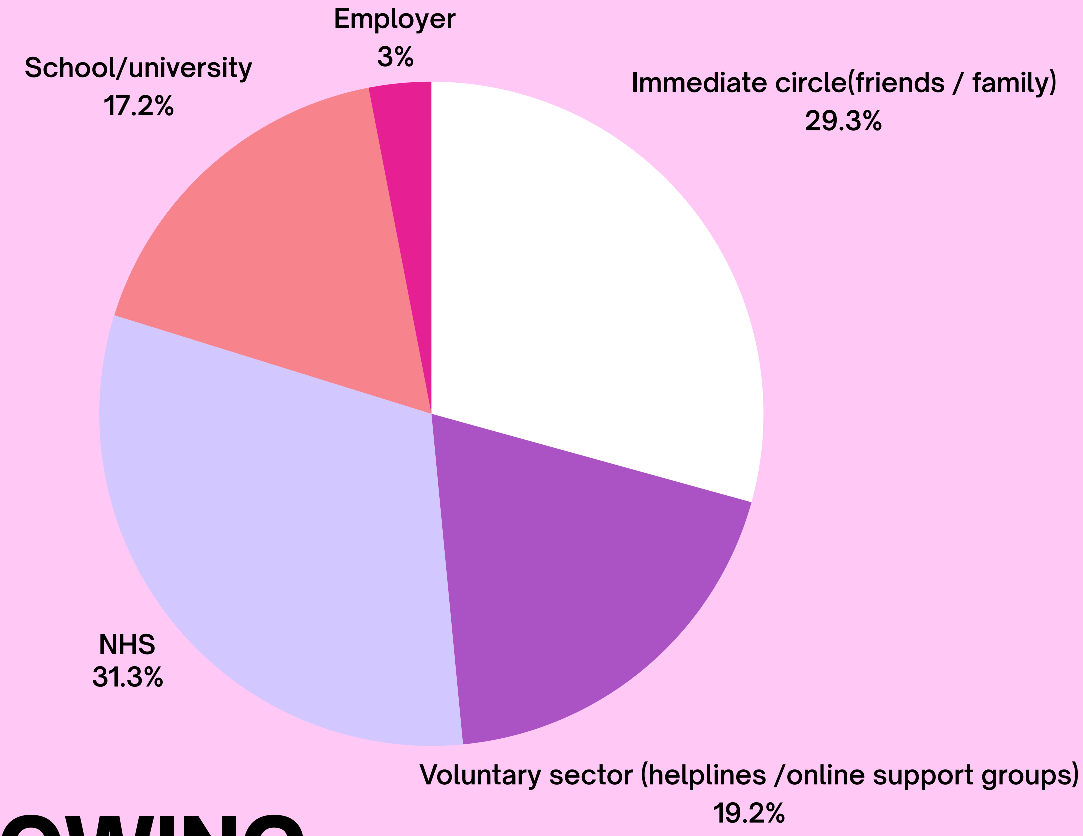
77% of responses centered around needing better awareness, understanding or training for teachers / employers

" i don't want to feel like i have to explain myself in lots of detail when i need assistance because that can be a barrier to getting help when i don't want to explain."

"More mature support in schools, mental health is a very serious and vulnerable thing and it helps to be respected like a young adult eg. No unnecessary yelling, or childish warnings"

"Mental health teams have always adapted to my disability and other problems even if undiagnosed, they notice quirks of mine I show through panic attacks etc and overstimulation especially "

WHO WOULD YOU GO TO IF YOU WERE IN A CRISIS?



> **“KNOWING WHERE TO TURN TO ISN’T THE SAME AS GETTING HELP IN PRACTICE”**

While young people have the knowledge, they find it difficult to access support in the moment. This is due to a variety of reasons such as accessibility (e.g. not feeling comfortable calling). They also felt that while GPs were good for getting referrals, accounting for the large proportion who would turn to NHS workers, they needed long-term support. As they can not access this in schools / NHS, voluntary organisations and friends and family were stepping in. Given the large proportion turning to their immediate circle, mental health first aid and peer support training should be given to everyone in the community.

SUMMARY OF PRACTICAL RECOMMENDATIONS

Safe space

There needs to be a safe, quiet space within each school/ workplace - this can be made safe through sensory adjustments such as sensory toys, headphones etc. This needs to be well-signposted.

Safe person

Teachers need to be trained on mental health first aid, how to respond to crises and safeguarding issues. Training should be practical and involve role play to maximise learning. They should be informed on protocol and dealing with discrimination based on mental health/ neurodiverse identities. While all teachers need training, specific members of dedicated to supporting with wellbeing should be clearly known within schools. This same training should be made compulsory for all employers as well.

Peer support training and parent training

Given the large proportion of young people turning to friends and family for support, young people should be trained on how to support their peers so that they don't feel overwhelmed and can signpost to relevant resources. This can also reduce stigma due to a better understanding of mental health. Parents should also receive training on basic mental health first aid and identifying signs of distress. This has been successfully implemented in Richmond as part of a series of webinars from the MHST in schools.

More education in schools (not just in pastoral lessons)

Education around mental health should be interactive, should focus on a holistic understanding of mental wellbeing and practical strategies for coping and remaining mentally fit. More knowledge on neurodiversity and how it interacts with mental health and tailored coping strategies as well. To encourage help-seeking, information sheets could be designed with phrases on how to talk about mental health and communicate a crisis. Education should extend beyond pastoral lessons e.g. it could be incorporated into form time by trying out new strategies to manage emotions.

EXPERIENCES IN THE NHS

In this section, I (Megan Kwok), analysed the answers quantitatively and qualitatively to see the common themes within experiences in the NHS, whether they were poor or good, and tangible solutions for the NHS to implement to improve.

WHAT ASPECTS OF THE NHS HAVE PATIENTS HAD POOR EXPERIENCES IN?

We analysed all the answers to find the keywords that were repeated in each response to see what were the most significantly poor aspects.

“Waiting list” or “wait times”

This phrase appears in **67 out of 87 (77%) responses**, showing the pervasive issue of lengthy wait times for assessment, diagnosis, and treatment. **40 out of 87 (46%)** respondents reported waiting for a year or longer.

“Listen” or “listened”

Mentioned in **36 responses**, this keyword underscores the frequent sentiment of not feeling heard or understood by mental health professionals.

“Discharged” or “discharge”

Appearing in **41 responses,** these words often describe premature or inappropriate discharge from services, sometimes due to not meeting specific criteria (like being suicidal) or administrative reasons (like turning 18).

“Trauma” or “Traumatic”

Found in **19 responses**, this term reveals the presence of past trauma in many individuals' lives and sometimes points to a lack of trauma-informed care within services.

HOW CLEAR IS COMMUNICATION WITHIN THE NHS' MENTAL HEALTH CARE?

We asked the question: “Within mental health services, do you feel that mental health professionals communicated the steps of your treatment clearly?”. 52 out of 83 (63%) respondents answered "no" to this question, indicating a widespread lack of clear communication about treatment steps.

The three following themes emerged in the answers:

Confusion + Lack of Information

Many individuals expressed confusion about their treatment plans, often feeling left in the dark or not being actively involved in decision-making.

Informing parents

Several respondents mentioned communication primarily being directed towards parents, leaving young people feeling excluded from understanding their own treatment.

Inconsistent communication

Some respondents experienced inconsistencies in communication, with plans changing without their knowledge or inadequate communication between different professionals involved in their care.

WHAT IS THE “LOOP” OF MISUNDERSTAND-ING?

Several respondents describe being trapped in a frustrating cycle, where their neurodivergence is used as an excuse to deny them mental health support, or vice versa, with the result that they are unable to access the services they need. More specifically, **75% of respondents** indicated that being neurodivergent has affected their mental healthcare. This can lead to them being passed from service to service without receiving appropriate care.

Select quotes from responses include:
- "They blame mental health on neurodivergence."
- "I got trapped in a loop where no service would support me at my lowest because I didn't fit their criteria. CAMHs said they didn't support 'neurodivergent' problems."
- "Camhs have said [that] issues are down to autism and not helped."

These quotes demonstrate the following:
- Neurodivergent individuals often find that their mental health concerns are misattributed to their neurodiversity, leading to a lack of appropriate support.
- There is a lack of specialised services that cater to the unique needs of neurodivergent individuals with mental health conditions.
- Many respondents express frustration with the current system's "one-size-fits-all" approach, which fails to address their individual needs.
- Respondents emphasise the need for individualised support plans that take into account their specific challenges and strengths.

The data emphasises that a "one-size-fits-all" approach doesn't work for neurodivergent people. The importance of individualised support plans that take into account their particular needs, strengths, and challenges is highlighted. Many respondents express that they want to be listened to and have their needs taken seriously.

RECOMMENDATIONS FOR IMPROVEMENT

Based on these responses on experiences in the NHS, here are a few recommendations we have compiled to tackle the largest issues.

Improved Training and Education for Mental Health Professionals

- Mandatory training for all mental health professionals, including those in CAMHS and adult services, on neurodevelopmental conditions, their diverse presentations (especially in women and girls), and their interaction with mental health.
- Training should include practical strategies for adapting therapy methods (and focusing on Dialectical Behavioural Therapy instead of Cognitive Behavioural Therapy due to poor reviews of the latter), communication techniques and environments to be more accessible for neurodivergent individuals.
- Training should also include recognising and addressing the specific communication challenges faced by neurodivergent people, especially during crisis situations.

Reduce Diagnosis and Treatment Wait Times

- Increase funding for diagnostic services to reduce waiting lists for assessment.
- Implement a "light touch" diagnosis for mental health professionals to allow them to differentiate care while people are on waiting lists.
- Increase the capacity of mental health services to accommodate the needs of neurodivergent people, including by employing more therapists with expertise in working with neurodivergent people.

Improve Communication + Patient-Centered Care

- Train professionals in active listening skills + encourage shared decision-making.
- Develop standardised protocols for communicating treatment plans to patients, ensuring clarity and patient involvement.
- Improve communication and coordination between different professionals involved in a patient's care to avoid inconsistencies and ensure continuity.

Post-Discharge/Post-Diagnosis Care

- Establish clear and objective criteria for discharge, ensuring patients are not prematurely discharged due to administrative reasons or lack of specific criteria.
- Implement robust aftercare planning to support patients after discharge and prevent relapse.
- Detailed explanations of the diagnosis, access to support groups, and guidance on how to navigate life as a neurodivergent individual.

Waiting Lists
And
Immediate Support

This section is primarily focusing on people’s experiences of being put on waiting lists to access mental health services within the NHS.
It highlights what people need to support them while on waiting lists and how being put on a waiting list affects respondents’ mental health. The section also looks at immediate crisis support and respondents’ experiences of that.

By Anna Morton

WE ASKED THE QUESTION “IN YOUR EXPERIENCE, HOW LONG HAVE YOU HAD TO WAIT TO RECEIVE THE SUPPORT YOU NEEDED WITHIN NHS MENTAL HEALTH SERVICES?”

We had hundreds of responses to this question however, due to respondents not putting exact amounts of time, it was hard to work out the exact results.

Waiting times ranged from a few weeks to some respondents stating they waited 10+ years.

Below are some of the responses directly from our survey:

“NHS Adult Mental Health Service wait times are a joke. The system fails so many people. Getting through to people to check where you are in the waitlist is near impossible and I have been told so many times "we'll call you back" to never receive a follow up.”

“I gave up waiting.”

“Around a year, it took me trying to commit suicide several times before they let me in”

“I'm still waiting for an assessment appointment 4 years on.”

“You feel like your life is being wasted while you are waiting for an appointment.”

“Years which is far too long for someone who is struggling.”

“I've currently been trying to access therapy for nearly 3 years and have been on several waiting lists and either denied for too high risk, taken off without notice.”

“I was on a waiting list for 10 years”

WHAT IMPACT DID BEING PLACED ON A WAITING LIST HAVE ON YOUR MENTAL HEALTH?

We asked the people who completed our survey what impact being on a waiting list had on their mental health and listed below are some of the key responses.

Anxiety About The Future

Many respondents described feeling anxious and uncertain about their future, particularly regarding when or if they would ever receive the help they needed. The lack of clarity on the waiting process and the continuous delays led to feelings of insecurity and fear that they would never get the support they required, sometimes contributing to suicidal thoughts and a sense of losing control over their mental health.

Quotes directly from our survey responses:

“I was terrified about the amount of time that was passing and the years of my life that I was wasting. I felt that I couldn’t get better without the support so the waiting list made me feel stuck suffering as I wasted away years of my life.”

"The issues have only bottled up and got worse. Exacerbated by ongoing stresses and daily life has overwhelmed my ability to stay afloat.”

“I became more aggravated and more anxious”

Negative impact on daily functioning and relationships

Several individuals mentioned how being on a waiting list impacted their daily functioning, including struggles at school, in their relationships, and with managing basic tasks. They felt unable to cope with daily pressures, and many noted that the waiting list further strained relationships with family and friends, as their needs went unmet for long periods.

Quotes directly from our survey responses:

“Waiting lists and inadequate professional support puts strain on family members and friends to look after the mentally unwell individual, this is too much for a person to take resulting in family and relationship break downs and then increasing more people’s mental health to deteriorate. This has happened to me and my loved ones.”

“I never got the help I needed at school and this ruined my high school experience and I ended up being moved multiple times.”

“Relationship breakdowns.”

Feelings of invalidation and hopelessness

Many respondents reported feeling forgotten, and hopeless while waiting for support, feeling as if it will never come and feeling hopeless that their mental health will ever get better. Respondents doubted if their struggles were real or valid which led them to further distress. Many felt that their struggles were dismissed. The waiting list system often left individuals feeling like they didn't matter or were not "bad enough" to warrant quick help which then pushed them to get worse as they felt that this was the only way to access support. This highlights the need for early intervention so that individuals don't feel that they have to get to crisis before receiving support and help.

Quotes directly from our survey responses:

"Made me feel like I didn't matter and what happened to me didn't matter either."

"As the years have gone on I feel invisible, pointless, hopeless. Just treated as a inconvenience when I call. Its been very sad."

"Felt hopeless, that I had done everything within my power to help myself to be failed by the NHS system."

"I was not worth seeing/helping."

Causing individuals to deteriorate to crisis

A significant number of respondents shared that their mental health dangerously worsened while on the waiting list. They described experiencing increased suicidal thoughts, and self-harm. Without timely intervention, many felt that their condition became more severe, sometimes leading to hospitalization or other crises that could have been avoided with earlier support.
This came up significantly in the responses.

Quotes directly from our survey responses:

"Significant impacts. Homelessness, suicide attempts, relationship breakdowns. Made me lose hope that I wasn't going to get the support I needed and ultimately I was scared I was going to end up dead because of how bad my mental health was."

"Mental health deterioration, increased self harm, decreased family wellness as a result."

"Significantly worse, wanted to just kill myself."

"I ended up sectioned on a psychiatric ward."

WHAT SUPPORT WOULD BE USEFUL/HAS BEEN USEFUL WHILE ON A WAITING LIST?

We asked people what support would be/has been useful while on a waiting list to access mental health services. Listed below are some of the key responses.

Clarity and Transparency in the Process/Check-Ins

A number of responses emphasized the need for transparency about the waiting list process. Knowing where they stand on the list, how long they would have to wait, and what to expect next was seen as crucial for helping their mental health so that people know that they are not alone and that they are going to get help. Many respondents want this in the form of regular check-ins, for example phone calls.

Quotes directly from our survey responses:

“Knowing exactly where I am on the waiting list will help me so much.”

“Regular check ins to let me know where I am- helps with my autism.”

“Check up phone calls just quick 5 minute ones maybe so you don’t feel completely alone and know that they are still aware of you.”

“Updates- I need reassurance that I haven't just been forgotten.”

“Clearer communication, a clear pathway.”

Someone To Speak To

A person to speak to, even if not a trained therapist, was a prominent, repeated response to this question. Respondents felt that just having someone allocated to them who contacted them regularly to check in, even informally, would have been helpful to prevent feelings of isolation, anxiety, and abandonment while waiting. A person that will be a listening ear so that individuals don’t have to suffer alone.

Quotes directly from our survey responses:

“1 person, even if they aren’t a trained professional, that you can let your feelings out to and speak to, even if they can’t help, so that you know that you are not alone and someone is listening is what we need”

“Regular meetings with someone to talk to even if it’s not therapy”

“Check in phone calls to see how your feeling and doing.”

"I’ve never had any useful support but this would be: regular sessions with someone to just speak to in the mean time, even if they are not a trained therapist, just someone to speak our problems to.”

“Being allocated someone who understands in the meantime.”

Being given resources and groups to attend

Many respondents also highlighted the need for resources and groups that they could join while they are on a waiting list. Professionals giving them these contacts/resources so that they don't have to find them themselves was seen as important- these include phone lines, text services, local drop-in centres, charities, support groups, participation groups, self help resources and education on what they are dealing with. People often felt that these weren’t advertised or promoted well enough or there weren’t any available. Some felt that these services should include resources like coping strategies, relevant leaflets or booklets, and information about other support options, such as wellbeing programs and groups that they can attend. Respondents wanted support groups with others like themselves or participation groups to help manage waiting periods and feel that they are involved in something and are not alone.

Quotes directly from our survey responses:

“Online services in the meantime, KOOTH, QWELL, is there any groups I can access? Participation groups, face to face, online, alternative to crisis drop ins across the area. None of this is communicated through GP’s or CAMHS, there is not many young people groups set up to be able to access this. But groups would help so much.”

“Mental health resources, links to helplines.”

“Charities outside of the NHS being recommended to me.”

“Written information like leaflets.”

“More information about where to go in the meantime, support ideas that aren't just mindfulness or getting exercise (and if you do suggest exercise, links to groups who do this rather than being expected to find it yourself).”

“Resources, available local services.”

WE ASKED THE QUESTION ‘IF YOU HAVE BEEN IN A MENTAL HEALTH CRISIS, WERE YOU ABLE TO RECEIVE IMMEDIATE SUPPORT?’

Out of the total respondents that answered this question, only **38% said yes, that they were able to receive immediate mental health support in a crisis**. **62% which was the majority, answered saying no, they could not access immediate support.**

38%=yes
62%=no

These figures are scary and heartbreaking.

We then asked a follow on question: ‘If yes, if you're comfortable, can you provide some details about what support you received? If no, please feel free to share more about your experience and how you felt and what immediate support?’

Below are some of the key responses:

Unreliable helplines

In times of crisis individuals are directed to ring/text crisis helplines. However many respondents said that these helplines are often unreliable and have hours of waiting times to be spoken to. Individuals also feel that they don’t give enough suitable advice. This pushes individuals to lose hope and often be reluctant to use them.

“I was contacting [a charity text line] regularly because I was experiencing a mental health crisis and needed someone to speak to often. They then put me on a ban because I had contacted them ‘too often’ meaning that I had lost another lifeline of support. I also know a few friends that had the same experience, they do not let you contact them as much as you need. They should be there whenever we need them but cut people off if they contact too regularly?”

“[A charity crisis line] advertises themselves as a 24hr service but the wait times in my experience are 5+ hours and still no support. There should be more text/online chat options. Particularly at Nightime.”

“When ringing NHS 111 I was told that it was a 4 hour wait to speak to someone.”

Inconsistent appointments and poor follow up support

Many respondents said that when accessing services in a crisis, they were often sent home with no follow up support. This often led individuals to end up back in crisis again and to lose hope within the services as there was no plan put in place to keep them safe and give them the right help that they needed following on from their mental health crisis. Particularly when they left emergency services like A&E departments. Many felt that there should be a plan in place and continuous support when they are discharged preventing them from relapsing and to help them get better. Respondents also noted the inconsistencies with appointments being irregular when accessing services which led them to feel dysregulated in themselves.

“I attended a&e where I saw the crisis team only to be discharged and had to reattend. I did not feel listened to or supported.”

“When I was in intense mental health crisis and was attempting many times a week, I still only got appointments through CAMHS about once every 2-3 months.”

“They sent the home treatment team round. who don't do treatment. They were supposed to do safety plan but didn't. Some of them were good but some upset me and my family more.”

“Crisis Team Support however they treated me poorly. Would cancel appointments without telling me until I arrived at the hospital. Seeing a different person each time and it being luck whether they would treat you with respect.”

A&E

In crisis, the main place that people are told to go to is A&E. Many respondents have highlighted how distressing and unequipped A&E is to be when you are experiencing a mental health crisis. Multiple responses also expressed how they were mistreated there. Resulting in many refusing to go. The wait times are extremely long, waiting rooms are busy and distressing causing further dysregulation to patients. Many have expressed the need for safer, calmer in-person spaces to be available to receive immediate crisis help.

“The emergency department is no place for anyone, especially a child, during a mental health crisis. But that is the only place you can go and receive immediate support by rapid access to the mental health teams. Why is no alternative, permanent pathway in place?”

“Got put in a room in a&e because I was upset after an attempt and was left there for hours and eventually being told to go home and all I got was told to contact mental health services if I needed them.”

“I had to wait in A&E which is more traumatic as they are not equipped to support me.”

Positive experiences

Despite the overpowering poor experiences, some respondents shared positive experiences with specific crisis services. For example, some had supportive interactions with paramedics, hospital staff, or community-based crisis teams. These services were appreciated for treating individuals with respect, offering safety, and providing a sense of immediate care. However there were very little positive responses.

Quotes driectly from our survey responses:

“i called crisis line and i was sent an ambulance who came quickly enough before i did anything worse. the paramedics spoke to me and ensured i was comfortable before going to the hospital. the nurses sat with me and supported me while i waited for the consultants.”

“I was in the hospital with a staff member who was in the ward the whole time. He was very friendly and kind and would treat me like a human rather than a patient awaiting discharge. We played uno which helped settle my nerves.”

My recommendations of changes that the NHS could make to improve waiting lists and immediate support after analysing our survey:

Waiting lists for mental health services cause individuals to deteriorate mentally, lose hope, feel isolated, stuck and sometimes even lose their lives.
This urgently needs to change as it is a crisis and the waiting lists urgently need to shorten. However, I am aware that it is not something that can be easily fixed.

Waiting list worker:

This is my recommendation:
I would recommend allocating individuals on mental health services waiting lists a ‘waiting list worker’ that doesn’t have to be a trained therapist. Just an everyday person with basic mental health first aid training. This worker would call and check in on their allocated patients every so often so that individuals can get things off their chests, have someone to talk to and know that someone is listening. Simply having an outlet for our feelings and knowing that someone is listening to our struggles even if they can’t fix them, can make the world of good. This worker could also risk assess the patient throughout their time on the waiting list to make sure that they are safe. The consistency of the same person every time is also important and why an allocated worker would be beneficial. The worker can also give the individuals updates about their place on the waiting list, making sure that communication is transparent about what is going on to keep the patient at ease. My recommendation is allocating individuals their own ‘waiting list worker’ that is a listening ear who is in regular contact with the patient while they are on mental health services waiting lists.

Communication:

One of the key themes to come out of the survey analysis is the lack of communication between mental health professionals and patients, which deteriorates patient’s trust in the mental health system and causes torment to their mental health.

Communication about every step in a patients mental health treatment is often poor within mental health services and this urgently needs to change.

Communication and transparency needs to be clear and a priority. Patients should know what is happening at every single step of their treatment and know the plan going forwards. They should also be given the correct information as our survey highlighted how they are often misled which causes huge distress. Communication being strong means that patients can then can build trust with professionals leading to them engaging in their treatment more actively. Leaving patients confused and in the dark can be detrimental to their mental health. They need explanations and transparency. If plans change within patient’s mental health treatment they need to be communicated with at the earliest opportunity and it needs to be clear. Often patients have felt let down and left in the dark when communication is not clear and correct.

Other recommendation's:

The two recommendations listed above are my two stand out recommendations that are a priority and are urgently needed.

Here are my other recommendations:

-Better follow-up support needs to be in place for people after they attend A&E in a mental health crisis to prevent them having to reattend.

-More resources and groups to be available and promoted.
I would like to suggest a ‘waiting list contacts/resource pack’ (in written form) to go out to every person on mental health services waiting list which involves helplines/text lines, contacts to charities, contacts to participation/support groups to attend in the area, websites, advice on what to do in a crisis, educational resources etc.

-More appropriate, calm in-person crisis spaces that people can go to when they are having a mental health crisis.

-Better consistencies in appointments.

-More reliable helplines/text lines.

This is a crisis and this report shows real life experiences. Things need to change now.

This is the end of our report. We hope that this report can create real change that is urgently needed.

For more information about the NHS Youth Forum and Young Researchers, visit **https://www.barnardos.org.uk/nhs-youth-forum** or email us at **NHSYouthForum@Barnardos.org.uk**

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