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| Community Mental Health Transformation Program |
| IMHN Co-production and Community Engagement  Detailed Report |
| January 2023 to March 2024 |

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# Summary

As part of the Community Mental Health Transformation Programme (CMHTP), Surrey Coalition of Disabled People were commissioned to employ three Co-Production & Community Engagement Officers to work within the Independent Mental Health Network (IMHN), to utilise their direct lived experience expertise to support the improvement of community-based mental health services, including development and delivery. This contract ran from January 2023 to March 2024.

The purpose of this project and community engagement was to find out how suitable health and wellbeing services are, what barriers people face when seeking and accessing support, experiences and needs of specific demographics, and how the existing mental health support offer in Surrey and North East Hampshire can be improved.

Community engagement focused on the adult population of Surrey and North East Hampshire with particular focus on Older Adults, Neurodivergent people, the LGBTQ+ community and Men after these four demographics were flagged as unseen/unheard from groups. The project expanded to include carers and young adults/university students as additional focus areas. Learning from existing projects between Surrey Minority Ethnic Forum (SMEF) and the Independent Mental Health Network were also taken into consideration.

The online survey launched 17.04.2023 to review people’s experiences accessing health and wellbeing support in Surrey and North East Hampshire. It collected 255 responses and ran until 05.11.2023. The survey was anonymous, with an option to submit contact details should a participant wish to be further involved in the future co-design work to improve services and support available.

The report *Exploring the ways Community Connectors in SABP’s GPimhs and MHICS services map their clients’ needs* produced eleven recommendations based on interviews with seventeen VCSE colleagues about their experiences working within the GPimhs and MHICS services.

The team organised demographic specific focus groups to expand on the topics being raised and facilitated working groups that included both lived experience experts and system colleagues to refine recommendations.

The Community Mental Health Transformation Programme will take the learnings from this project and the 57 recommendations into account as the programme moves forward.

**Project in statistics**

* 15 months (January 2023 to March 2024)
* 3 Co-production and Community Engagement officers with lived experience.
* 255 survey responses
* 400+ Surrey and North East Hampshire residents engaged
* 24 participants involved in focus groups
* 11 lived experience experts involved across 5 working groups
* 57 co-designed recommendations

(Note: numbers after quotes in this document refer to the survey identification number)

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# Project Overview

## Context

In 2019, the NHS England Long Term Plan was published. The plan describes a:

“new community-based offer [that] will include access to psychological therapies, improved physical health care, employment support, personalised and trauma-informed care, medicines management and support for self-harm and coexisting substance use…and proactive work to address racial disparities.”

Local areas will be “supported to redesign and reorganise core community mental health teams to move towards a new place-based, multidisciplinary service across health and social care aligned with primary care networks.”

The new place-based community mental health model focuses on meeting unmet need and breaking down barriers to accessing support, and will enable people with mental health problems to:

* access mental health care where and when they need it.
* manage their condition or move towards individualised recovery on their own terms.
* contribute to and be participants of their community.

It intends to modernise the existing Community Mental Health Services by integrating primary and secondary care to increase the amount of mental health care you can get from the NHS within a GP or community setting.

When NHS England published the Community Mental Health Framework for Adults and Older Adults in 2019, twelve sites were awarded funding to be test sites. Surrey and Borders Partnership NHS Foundation Trust (SABP) was selected to lead two early implementer sites in Frimley South and Surrey Heartlands, with the vision to provide people with mental health needs with the right care when they need it.

The Community Mental Health Transformation Programme covers residents aged 18+ in the Surrey Heartlands Integrated Care System (ICS) and Frimley Health and Care Integrated Care System (ICS) catchment that Surrey and Borders Partnership NHS Foundation Trust (SABP) covers.

A place-based approach is a way of collaborative working with local people and organisations to effectively use the combined resources available within a local area. In most cases, the term ‘places’ is based on local authority boundaries, otherwise known as boroughs.

Diagram, text

Description automatically generated

You can learn more about the Community Mental Health Transformation here:

* [Community Mental Health Transformation | CCAnimation Studio - YouTube](https://www.youtube.com/watch?v=cBex7ZXL_Qw)
* <https://www.youtube.com/watch?v=AsVdmkEfO3I&feature=youtu.be>
* [The Transformation of Community Mental Health Services : Surrey and Borders Partnership NHS Foundation Trust (sabp.nhs.uk)](https://www.sabp.nhs.uk/aboutus/our-trust/services-and-site-developments/transformation-community-mental-health-services)
* [NHS England » The community mental health framework for adults and older adults](https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/)

## IMHN involvement

Surrey Coalition of Disabled People were commissioned by the Community Mental Health Transformation Programme to employ three Co-Production & Community Engagement Officers to work within the Independent Mental Health Network (IMHN).

These officers were employed to utilise their direct lived experience expertise and the network’s existing community links to support the improvement of community mental health services, including development and delivery.

The contract ran from January 2023 to March 2024.

## Project focus

Understand how suitable health and wellbeing services are, what barriers people face when seeking and accessing support, experiences and needs of specific demographics, and how the existing mental health support offer in Surrey and North East Hampshire can be improved.

## Target demographics

Community engagement focused on Surrey and North East Hampshire residents aged 18+ alongside more detailed engagement with the following unseen/unheard demographics:

* LGBTQ+ community
* Men
* Neurodivergent people (Autism, ADHD, Dyslexia, Dyspraxia etc.)
* Older Adults (65+)

Work expanded to include Carers and Young Adults/university students as additional focus areas and learnings from existing projects between Surrey Minority Ethnic Forum (SMEF) and the Independent Mental Health Network (IMHN) were taken into consideration. Each Co-production and Community Engagement Officer had an assigned demographic to focus on.

Findings from this project will support the Community Mental Health Transformation Programme to understand how well services are working and how they can be improved to better meet the needs of everyone in the community.

## Report: *Exploring the ways Community Connectors in SABP’s GPimhs and MHICS services map their clients’ needs*

In February and March 2023, engagement took place to investigate the experiences of community connectors with a comprehensive report published in May 2023.

Community Connectors are specialist voluntary sector partners who work within the integrated mental health services. They work with their clients to access the local support they need. This can include:

* Drug and alcohol support groups.
* Debt and housing support via organisations such as Citizen’s Advice.
* Social networks to combat loneliness and isolation.
* Volunteering opportunities.
* Activities to enhance wellbeing.
* Employment support from Individual Placement and Support (IPS).

The report produced eleven recommendations based on interviews with seventeen VCSE colleagues about their experiences working within the GPimhs and MHICS services.

The report identified challenges with maintaining up to date lists of services, the sharing of relevant information, and the use of digital tools.

See ‘Additional Information’ for where to find the full report.

**Survey**

*Data collection*

The online survey aiming to understand resident’s experiences of accessing health and wellbeing services was conducted from 17th April 2023 to 5th November 2023, and gained insights from 255 respondents.

The survey was anonymous with the option to leave contact details should the participant wish to be involved in additional focus groups and co-design work.

See ‘Additional Information’ for where to find the plain text version and pdf version of the survey.

*Questions asked:*

Section 1 - Demographic Questions (age, sexuality, gender identity, ethnicity, disability, neurodivergence, if they care for someone, area they live in)

Gender identity and sexual identity are separate categories in data analysis. Sexual identity is referred to as LGBTQ+, whereas as gender identity is labelled as a separate entity.

*Graph shows the location of survey respondents.*

Section 2 – Accessing support in the community.

Question 1 (Q1): Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

* 65% - Friends, Family, Partner, or Spouse
* 50% - GP
* 15% - Safe Haven
* 18% - Charity Services
* 12% - Peer Support Groups
* 4% - Community Leaders
* 7% - Emergency Services or 111
* 10% - Crisis Line or Single Point of Access
* 18% - No-one
* 10% - Other

Question 2 (Q2): What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life? (text box)

Section 3 – Experience of Support in the Community

This question asked people to select from the following: strongly agree, agree, neutral, disagree, strongly disagree, with an option to provide more information.

* Statement 1 (S1): I feel listened to and respected when discussing my needs with organisations providing support.
* Statement 2 (S2): I feel that organisations providing support will understand my individual needs.
* Statement 3 (S3): I feel that organisations are well-informed about issues relating to diverse needs. For example, age, ethnicity, gender and sexual identity, disability, and other characteristics
* Statement 4 (S4): I feel that organisations are well-informed about what other services are available to meet diverse needs. For example, age, ethnicity, gender and sexual identity, disability, and other characteristics.
* Statement 5 (S5): I am concerned that I may experience discrimination, prejudice, or assumptions being made by organisations that provide support services.

Section 4 – Final Comments

Question 3 (Q3): What would make accessing health and wellbeing support easier for you? (text box)

Option to leave any additional comments.

Section 5 – End of Survey

Respondents were asked to select whether they’d be happy to be contacted by a member of our team to speak more about their thoughts with a text box to enter contact information.

**Data analysis**

Analysis employed a mixed methods approach:

* Qualitative Data: analysed in 1 month increments throughout the data collection period. In the first 3 months analysis took an inductive approach to coding, then moving onto deductive coding. Reflexive thematic analysis produced over 60 codes categorised into 10 key themes.
* Quantitative Data: response trends from different demographic groups were compared to identify variations with how satisfied different groups were with the services they had accessed.

**Data findings**

Over 60 topics emerged, grouped into ten themes:

1. Diversity & Assumptions
2. Communicating the Issue
3. Access & Availability
4. Bounce
5. Mental Health Stigma
6. Crisis & Prevention
7. Holistic Needs
8. Lack of Information
9. Choice & Autonomy
10. Connected Systems

## Community Engagement

Demographics were assigned amongst the team and officers headed out into the community to talk with people and dive deeper into the topics being raised in survey responses.

Throughout the project, officers actively engaged with groups, events, and meetings to broaden their understanding and perspectives, including but not limited to:

* Pride in Surrey
* Lunch clubs
* National Autistic Society gatherings
* Wellbeing walks
* University fairs
* Men in Sheds
* 1:1 meetings with the workforce

Feedback shed light on the distinctive needs, experiences, and barriers faced by diverse populations, including considerations for age, gender, sexuality, ethnicity, disability, neurodivergence, and caregiving responsibilities.

## Focus Groups

To contextualise survey findings, officers facilitated seven demographic targeted focus groups with interested survey respondents, delving deeper into their experiences and needs.

Four focus groups took place in August 2023 dedicated to the experiences of neurodivergent residents. Three focus groups took place in September, two dedicated to the experiences of carers, and one to older adults. 24 people in total were involved (3 carers, 5 older adults, and 16 neurodivergent people).

The questions were also taken to other engagement groups in October.

## Working Groups

Recommendations underwent refinement in dedicated working groups scheduled between November and January.

11 lived experience representatives from the focus groups and 12 professionals from across the system were invited to come together to co-design recommendations informed by all the data gathered to make sure that recommendations were practical, realistic, didn’t repeat existing work, and reflected the needs of the residents in Surrey and North East Hampshire.

Working groups were held via Zoom.

November 2023

* Introductory session to introduce the project to the group.
* Working group 1 covered information before and after appointments, information about the service and about you.

December 2023

* Working group 2 covered GPimhs/MHICS access, self-representation, and how to keep people updated.

January 2024

* Working group 3 covered diversifying services offered, peer support, and targeted communications.
* Working group 4 reviewed recommendations as a group.

## Project Outputs

1. Project Overview
2. Plain text version
3. Detailed report (this document)
4. Presentation
5. Recommendations
6. *Exploring the ways Community Connectors in SABP’s GPimhs and MHICS services map their clients’ needs* report.

# Theme 1: Diversity and Assumptions (183 coded responses)

All demographics have experienced assumptions being made about them based on diagnosis, lack of diagnosis, appearing ‘well’, or struggles that providers don’t understand (e.g., caring responsibilities or neurodivergent symptoms).

Residents felt that training about diverse needs was lacking and impacted by high workforce turnover. They want services to prioritise individual needs instead of assuming needs based on an individual’s demographic.

Age (9 coded responses)

**Survey:** A few residents cited age as a factor that affected how they were viewed by services and the decisions that were made about their care. Some felt that their concerns were dismissed because of their age. Working aged residents felt that practitioners assumed that because of their age, they should be able to do more. See the topic ‘Young Adults’ for data regarding the 18-25 demographic.

An older women felt that she had been lumped into a loneliness category rather than having her concerns listened to. She commented that older practitioners can have lingering patriarchal biases about women’s roles and needs, and that services don’t address/consider the social conditioning and restriction that older women have experienced in their lifetime, making current services inappropriate. Another older person said that they felt services are made for younger people.

**Quotes**

“Potential barrier is that being an older woman, I would be lumped under a generic heading of “old lonely person” rather than an individual with specific mental health issues. I am (hopefully) the last of the generation who have to cede to our husband and society’s tacit demand that we should have sole responsibility of housework/gardening etc and that our expectations and needs should always come after his” *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*

“My age often goes against me; my fluctuating health and mobility goes against me and so does how I react to certain situations. Nothing is put in place to try and prevent crisis situations from happening. I am told the standard things that there are only a limited amount services - all of which do not cater for my needs” *(Disabled Female aged 35-54, Waverley) 101*

“My age group is the hardest age group to find things to do as I am not elderly or a child/youth/young person. If you fall in between you are expected to be working so they do not feel there is a need which is wrong”. *(Disabled Female aged 35-54, Waverley) 149*

**Focus group discussion:** Participants raised that career women with poor mental health aren’t supported by current service provision.

Appearing well (11 coded responses)

**Survey:** Assumptions are made about people’s mental health needs based on how they present (masking, put together), especially for carers and neurodivergent people. They felt that their experiences were minimised, and they weren’t being listened to when they asked for help.

**Quotes**

“Because I speak well and appear confident this can often be viewed that I don’t have an anxiety and stress related illness.” *(Female aged 65+, Guildford) 11*

“I have reached out to a couple of charities for my mental health, but they've never had space for me, and I fear that I’m not mentally ill/autistic/ADHD/OCD enough" to go to a GP and have help and a true diagnosis. I'm really not sure what's wrong with me" *(Neurodivergent LGBTQ+ Female aged 18-25, Epsom and Ewell) 14*

“Assumptions are made about carers without the understanding of just how much strain carers are under while they struggle to do their best for the person they care for. So, if you appear to be coping, it's taken for granted that you will continue to cope without support, or with inadequate support.” *(Female aged 65+, Carer, Guildford) 22*

“As a woman who has complex physical health needs and disabilities combined with subtle and poorly understood neurological issues, but who also lives independently, has post-grad level education, and works part-time, I don't fit into many of the 'boxes' used in the current system, and so often services are unable to respond in a manner appropriate to my specific needs” *(Disabled Female aged 35-54, Guildford)* *5*

Assumptions (8 coded responses)

**Survey:** When assumptions are made, it can affect how well people are listened to. These assumptions include appearing well, mental health stigma, heteronormativity, and assumptions based on diagnosis (for example, neglecting to listen to an autistic person’s lived experience and instead focusing on textbook knowledge).

**Quotes**

“No one listens, no one helps - just make assumptions” *(Female aged 65+, Carer, Tandridge) 179*

“I've had many assumptions made by support providers about how autism affects me. It appears that instead of asking me how autism affects me with the understanding that there's a wide spectrum, they instead draw from references in pop culture or social media.” *(Disabled and Neurodivergent Male aged 26-34, Waverley) 184*

“I am likely to be viewed as anxious and lazy when asking for help with practical issues.” *(Disabled and Neurodivergent Female aged 35-54, Waverley) 186*

“Being an older lesbian - many organisations just assume heterosexuality” *(LGBTQ+ Female aged 65+, Waverley) 228*

“Because I drive and can go out, they assume I'm fine and not struggling. They are not listening to what my head is doing inside.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 236*

“Sometimes people do make assumptions, especially in the medical area, by not listening to the patient or not having a fuller understanding or information regarding the person's health problem.” *(Disabled Female aged 65+, Epsom and Ewell) 31*

**Focus group discussion:** Participants raised that there is a fear that people will be stereotyped and put into a box if they disclose their neurodivergent conditions. It is important to take a learning approach when it comes to interacting with autistic people as everyone is individual.

There was a positive mention of an ear doctor who put a communication flag on a resident’s file after they disclosed that they have ADHD. Each interaction with that provider has been positive since, however it is worth noting that they were dismissive up to the point of disclosure.

Comments were made about how staff shouldn’t assume what people need and how things will affect them.

Carers (42 coded responses)

**Survey:** Carers felt that assumptions are made about them, only a few organisations are informed about carers rights, and there is a lack of appropriate support. Carers wanted people to understand them, offer flexibility with appointments, have drop-in support and/or proactive support from those supporting their cared for person. Carers praised Action for Carers, and a carer for a husband with physical health concerns said physical health practitioners have been a lifeline.

*Graph shows survey respondents’ answers to whether they care for someone or not. If they asked ‘yes’, they have been referred to as a carer in our data.*

**Quotes**

“I cannot praise Action for Carers enough.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

“I’m usually very busy with my family responsibilities and other things during the day. I go to a carers group one evening a month, but there is very little else available in the evenings when I’m free to think about myself and my well-being.”  *(Female aged 65+, Carer, Guildford) 11*

“No one is interested in the carer and their wellbeing … Everyone assumes you are happy to do whatever it takes to care for the person regardless of our own needs and or other responsibilities i.e. kids” *(Female aged 35-54, Carer, Spelthorne) 78*

“Easy access appointments with a doctor who understands the whole family.” *(Female aged 35-54, Carer, Runnymede) 83*

“More available for people who care and work - a lot of the support is in working hours and this means I can't access it as I also work full time. All the things offered are during the day ... yoga, groups etc. 'drop in for a cuppa' activities. I can never access these due to having to work but I'm also a carer.” *(Female aged 35-54, Carer, Runnymede) 88*

“I am being supported at the moment for caring for my husband by SALT, neuro Physio’s and OT’s. They are fantastic and nothing is too much trouble, they have been my lifeline since my husband returned home.” *(Female aged 65+, Carer, Waverley) 97*

“Struggled to get help from community team when my child has been very ill. Certainly no help for me as carer.” *(Female aged 55-64, Carer, Waverley) 133*

“Carers are largely invisible. Their needs secondary to the patients … Information for carers very limited and inaccessible. You’d have to know you were a carer in the first place, most don’t” *(Disabled Female aged 55-64, Carer, Guildford) 147*

“An understanding of the multiple issues involved in being a carer of someone with autism, not someone with learning disabilities.” *(Female aged 55-64, Carer, Waverley) 154*

“Organisations which offer support for carers are generally sympathetic, but the professional services can be very hostile and resentful when you ask them for help or advice and make you feel you are being a nuisance. E.g. the community mental health service, the Eating Disorder Clinic, at times even the GP” *(Neurodivergent Female aged 55-64, Carer, Waverley) 250*

**Focus group discussion:**

* Carers for people with physical health, mental health and neurodivergence have different experiences, challenges, and skills, with mental health being less visible, more stigmatised, and unpredictable.
* Many carers feel they get no support and rely on friends and family members to help combat isolation and loneliness.
* Carers want help balancing the admin of managing their own lives and their loved one’s care, and actionable next steps that are easy to access and don’t add to their existing workload.
* Carers may experience trauma from the act of caring and from historical trauma being triggered by seeing their own cycles of struggle repeat themselves, for which they need mental health support.
* Many professionals appear to lack training in mental health awareness and carers rights.
* Carers assessments must consider the wider context of each case without judging the parent or carer, considering how behaviour is impacted by neurodivergence, transitions, the time of day and the presence of strangers in the home.
* Carers have found a scheduled 5-minute weekly phone call with the nurse helpful.

**Notes:** Carers were not originally a demographic this project focused on, but due to the level of responses from carers in the survey the project was expanded and dedicated carer focus groups were held in September 2023.

Discrimination (33 coded responses)

**Survey:** Many residents said that they had not experienced any kind of discrimination in healthcare settings. However, several residents said that assumptions and judgements are more common, especially regarding disability or diagnosis. A small number of autistic people described experiencing prejudice or infantilisation. A small number of women suggested they had experienced prejudice. A small number of survey respondents used the survey as an opportunity to voice their options about biological sex/gender binary in the ‘Gender Identity’ demographic question. One person used the free text boxes to comment on how there are only 2 genders and that mental health services denying this is a celebration of mental illness, how gender reassignment surgeries are butchering bodies, and is sick and twisted. Another said that services don’t meet their needs but if they identified as a mermaid then they would.

**Quotes**

“As a person of colour, you never know how you will be received.” *(Black British Female aged 35-54, Guildford) 66*

“I have come across individuals within organisations who have their own views, sometimes they are biased. The organisations role/values and the individuals can be so very different.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 94*

“In my experience too many folk are too ignorant of the fact that us AuDHDers actually know what we need often and we get treated like infants far too often; even the standard practice of using ABA and/or PBS removes agency from us. I worked in Adult Social Care for over 6 years and despite their "specialising in Adults with LD, the senior staff clearly knew less than I know. There is such a reluctance to give any credence to our lived experiences.” *(Neurodivergent Male aged 35-54, Woking) 185*

“I am not concerned for myself, but I think people with learning disabilities / autism may experience discriminatory attitudes” *(Female aged 35-54, Reigate and Banstead) 217*

“This sometimes happens, so I don't trust that it won't happen when I engage with a new service” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 26-34, Surrey Heath) 232*

“I am now 65 so feel some services are for younger people.” *(Disabled Female aged 65+, Guildford) 107*

“I think some organisations experience unintentional age bias as well as some lingering patriarchal bias about women’s roles”. *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*

**Focus group discussion:** Participants mentioned discrimination against men and LGBTQ+, and that there is no adequate wellbeing support for either demographic.

Diversity (21 coded responses)

**Survey:** Overall, residents felt that current diversity training was insufficient at promoting understanding and awareness of diverse patients, especially intersectional identities. Residents wanted services and workforce to have a better understanding of different cultural backgrounds and how culture related to mental health and caring. Residents suggested that focusing on individualised support would improve people’s experiences and help avoid assumptions. One person highlighted the needs of older women and how they are often outside of diversity categories or training.

**Quotes**

“Organisations tend to be well-informed on one aspect they are not so aware of intersectional identities and how this may affect a person's experience.” *(Disabled and Neurodivergent Black Caribbean Female aged 18-25, Runnymede) 102*

“More virtual services. More celebration of diversity. More awareness of protected characteristics.” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 26-34, Carer, Surrey Heath) 127*

“Specific groups are useful for specific differences” *(Disabled and Neurodivergent Female 35-54, Carer, Hart) 157*

“More understanding of culture and challenges” *(Disabled Asian British Female aged 26-34, Carer, Runnymede)* 86

“Some organisations have strong awareness, culture, and competence regarding diversity. Others lack these features, and it shows in outcomes for minorities with particular characteristics” *(LGBTQ+ Disabled and Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

“Not sure there are specific services tailored to individual 'groups of needs' - only to individual personal needs - trauma-informed approaches should always take into account cultural backgrounds” *(Female aged 35-54, Mole Valley) 220*

“My culture is not understood and the roles of expected carers … When I talk about my culture and the caring role, I feel like I'm judged but I don't see this as a negative thing” *(Disabled Asian British Female aged 26-34, Carer, Runnymede) 86*

**Notes:** Surrey Minority Ethnic Forum and the Independent Mental Health Network produced the Pathways to Change report, see ‘Additional Information’ for where to find the full report.

LGBTQ+ (7 coded responses)

**Survey:** LGBTQ+ people experience lots of discrimination and assumptions. LGBTQ+ issues aren’t discussed or included in signposting unless people disclose, however, there is a fear that practitioners won’t respect LGBTQ+ identities. Comments included issues being overlooked like coming out and gender identity, no local services for LGBTQ+ people, and how lots of groups are in religious settings which is not always appropriate. 13% of survey respondents identified themselves as LGBTQ+.

**Quotes**

“My experience has been relatively good, and where knowledge is lacking support staff have been willing to listen and learn, however, I think a lot of LGBT+ specific issues tend to get overlooked (such as coming out, or issues that arise with gender identity not matching biological sex), and staff don't have much knowledge of it all prior to being told.” “The places I get regular support from are genuinely brilliant. However, I would be concerned changing counsellor or GP for worry that the new person may not respect my identity in the same way,” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford) 130*

“Most are religious groups places. More equality and inclusion groups places.” “Being gay is difficult and feel there no support for LQBTQ plus in Runnymede” *(LGBTQ+ Disabled and Neurodivergent Male aged 26-34, Runnymede) 122*

“I need to speak to someone about my sexuality, friendships, and relationships however due to how I present we don’t speak about that stuff.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Waverley) 126*

**Responses to the banner at Pride in Surrey 2023 asking “What is the biggest issue affecting LGBTQ+ people in 2023?”**

1. Identity politics.
2. Being bullied at school and online.
3. Disapproval from some elderly members of society.
4. The biggest issue is wilful ignorance.
5. Discrimination, blaming all thing on mental health “it’s just anxiety”, societies view that we are dangerous.
6. Policing LGBTQ+ venues!
7. Loneliness!
8. Lack of information about the support available.
9. Coming out!
10. Bullying.
11. The Tories.
12. The rumours and false truths.
13. The people feel young people are only LGBTQ because of “influence”.
14. People taking away our rights.
15. Intersectionality.
16. Acceptance.
17. Fear of acceptance.
18. People are trying to test for Autism before trans healthcare.
19. Extreme media/political focus on anti-trans policies, giving them a platform.
20. People are not being taught about it.
21. Stale male pale (straight) Tory MP’s!
22. Tories.
23. All the support is for 18-25.
24. Being turned against one another.
25. Negative stereotyping.
26. Ignorance.
27. Dehumanisation.
28. Stigma/acceptance.
29. Judgement from loved ones or those you thought you could trust. Also, ableism.
30. Uneducated people with bias views.
31. Inaccessible healthcare.
32. Climate change.
33. Feeling socially isolated.
34. Stop trying to “fix” me.
35. Accept people for what or who they are.
36. Drug usage + impact on mental health.
37. Divergence.
38. Worry about support by NHS for Gender Dysphoria.
39. Resources for queer youth.
40. Lack of education/understanding outside of the LGBTQ+ community.
41. Lack of schooling around gender and gender binaries.
42. Isolation and loneliness.
43. The rapid ride of fascism and anti-LGBT+ violence over the last decade.
44. Anxiety and fear of being accepted.
45. Trans rights!
46. Anti-trans activism.
47. Freedom of information and support network.
48. Safety when in crisis.
49. Acceptance and finding a safe environment.
50. Tories out!
51. The government.
52. Be true to yourself.
53. Cutting back of services!
54. Conversion therapy still being legal in the UK.
55. Fear for self, for family, for friends, for future!
56. Rishi (Sunak).
57. Legal inequality.

**Responses to the banner at Love without Labels event by End Stigma asking “What is the biggest issue affecting LGBTQ+ people in 2023?”**

1. Asexual Invisibility (x2)
2. Politics
3. Growing up in ignorant religious family (x2)
4. Lack of services for children and young people
5. Ever-growing public transphobia (x2)
6. Lack of kindness
7. Expectation to conform.
8. The government!
9. Not being taken seriously
10. Lack of acceptance
11. Feeling excluded with intersectional identities, i.e. disability, being a person of colour
12. Not being respected as queer/trans people at work
13. The UK government!!!
14. Not enough services/representations in schools for young people or in workplaces
15. Culture, religions, feeling unsafe at work but still having to work.
16. Political climate
17. Culture and religion
18. Transphobic people in power
19. Negative media and misinformation
20. Need more orgs!
21. LGBTQ+ ethnic minorities not belonging in queer white spaces.
22. Trans healthcare lacking support.
23. LGBTQ+ intersectional identities not acknowledged.
24. Workplaces still not having LGBTQ+ inclusion polices and having to advocate for and write these yourself.
25. Legislation only just having been overturned for not being able to teach LGBT in schools.
26. Being disowned when they came out.
27. Young adults out of employment
28. Young adults going back into the closet at work.

**Notes:** There is a lack of established groups in Surrey that are set-up to receive community engagement (e.g., attend meetings and present the project and ask focus questions) making it difficult to find LGBTQ+ people to engage with due to the lack of provision.

Physical disability (discrimination) (10 coded responses)

**Survey:** Residents felt that some disabilities are prioritised over others, that there is poor understanding of the impact of physical disability, and that there is a lack of accessibility and reasonable adjustments. Some disabled people felt patronised and discriminated against.

**Quotes**

Potential barriers to seeking support: “Understanding of sensory loss and the impact. Understanding of, and compliance with, the accessible information standard (which includes contact methods). Locations available and times also feel discriminatory at times. E.g. no counselling assessment appointments available in the evening etc.” *(Disabled and Neurodivergent Female aged 26-34, Carer, Epsom and Ewell) 67*

“Poor understanding of sensory loss and sometimes actively and directly discriminate through inaccessible service offer and methods of contact” *(Disabled and Neurodivergent Female aged 26-34, Carer, Epsom and Ewell) 67*

“Some disabilities seen as being more important or deserving than others. With little or no sensitivity given to how those disabilities affect the patient and 1:1 carer. Physical disability will lead to mental health issues somewhere along the line.” *(Disabled person aged 65+, Carer, Runnymede) 20*

Potential barriers to seeking support: “Physical things like ramps/toilets etc. Understanding not patronising” *(Disabled and Neurodivergent Female aged 18-25, Carer, Waverley) 211*

Prejudice (6 coded responses)

**Survey:** Comments were raised about prejudice and ignorance to neurodivergence, culture and mental health symptoms, and women having their concerns dismissed. These experiences were influenced by some unconscious bias from staff.

**Quotes**

“Medical professionals do not understand my difficulties. The most I get is reassurance that it will be OK, with no help to overcome the actual problem. They think I am lazy because I have executive functioning difficulties and think I am just too lazy to do the tasks, so they encourage me that I can do them, but when I try, I can't. And realistically, there is simply nothing available for them to refer me to anyway so what's the point.” *(Disabled and Neurodivergent Female aged 35-54, Waverley) 186*

“Well, I might say that awareness on such issues has improved in recent times, both in terms of how it is discussed publicly and how it is diagnosed. But this change isn't exactly universal, and regrettably there are still prejudices and ignorance surrounding the disorder that exist within all sorts of people- Up to and including people who work in the mental health field professionally.” *(Neurodivergent Male aged 26-34, Rushmoor) 187*

“Only by age and/or gender - like, if I was an older man I would be listened to, but as a woman it's hormones or stress” *(LGBTQ+ Neurodivergent Female aged 26-34, Mole Valley) 195*

“I think unconscious bias if not active prejudice is widespread across many services” *(LGBTQ+ Disabled and Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

Serious mental illness (SMI) (9 coded responses)

**Survey:** Residents struggle to get treated when they have both a SMI and Autism/neurodivergence. SMI episodes aren’t handled well by the system and residents voiced they can have assumptions made about them based on their diagnosis. Symptoms of SMI can also prevent people accessing support (e.g. isolation).

**Quotes**

“They seem to be focused on people with depression and anxiety whereas those with disabilities such as bipolar or schizophrenia are less well known in terms of awareness” “A lack of fully understanding how the condition impacts the routine of daily life” *(Disabled Female aged 65+, Tandridge) 17*

“I have on multiple occasions experienced prejudice by professionals because I have the label of personality disorder and have been made to feel a nuisance. I have also been rejected from services (IAPT) for the same reason, even when seeking help with something not relevant (grief counselling)” *(Disabled and Neurodivergent Female aged 26-34, Elmbridge) 34*

“I have only just been diagnosed with EUPD in 2019 but before that, [there was] 10 years of being told I had depression and anxiety” *(Neurodivergent Male aged 35-54, Epsom and Ewell) 103*

“It can be very hit and miss. I feel my depression and anxiety have been handled well, but psychotic episodes definitely not as well.” *(Disabled and Neurodivergent Female aged 35-54, Hart) 110*

**Focus group discussion:** Neurodivergent participant had been told she had an ‘underlying mental health condition’ before being finally diagnosed with a Personality Disorder by a psychiatrist. After this confirmation, she felt that they were finally being honest and treating her ‘like a grown up’. There is a feeling that having a diagnosis helps people to understand themselves and their needs better.

Understanding Neurodivergence (35 coded responses)

**Survey:**

There is a lack of awareness and understanding of neurodivergence and its impact on people’s day to day lives, alongside very little specialist support for conditions such as ADHD.

Some neurodivergent women felt that due to masking (suppressing neurodivergent presentation to present as neurotypical) the symptoms they spoke to professionals about weren’t understood or taken seriously. Others (that didn’t mask) were concerned about judgement or misunderstandings due to their differences in communication (facial expressions, tone, and other autistic traits).

A lack of specialist training has led to discrimination and judgement.

Residents wanted neurodivergent and sensory friendly spaces and adaptions to communication such as visual aids, notes being provided after appointments, and being able to provide information beforehand.

Many autistic residents felt that there was poor understanding of Autism and associated traits like Pathological Demand Avoidance.

Comments were made about how Cognitive Behavioural Therapy (CBT) rarely works for autistic people and there is a lack of pro-active accommodations for communication differences.

**Quotes**

“Knowledge is either limited or very by-the-book, meaning they often aren't aware of any symptoms or characteristics that fall outside the standard" and can end up dismissing things as a result." *(LGBTQ+ Disabled and Neurodivergent White/Black Caribbean Female aged 26-34, Mole Valley) 24*

“Support for dyspraxia and ADHD weak” *(Disabled and Neurodivergent Middle Eastern Male aged 35-54, Guildford) 44*

“There is an issue when you have BPD and ASD. Professionals think you are attention seeking due to bpd or that you don’t have a mental health problem due to ASD. The actual symptoms are not considered the label is instead” *(Disabled and Neurodivergent Female aged 35-54, Carer, Rushmoor) 69*

“I feel that there needs to be more training on girls who present with autism and learning difficulties.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Waverley) 126*

“I consistently hear stories from other non-neurotypical people about their difficulties in feeling understood, being listened to, or accessing services relevant to their specific needs. Some Autistic people are met with resistance trying to access mental health support.” *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

“There is very little knowledge on sensory difficulties” *(Disabled and Neurodivergent Male aged 35-54, Spelthorne) 188*

“Lack of understanding in regard to autism and also communication with unknown people and using telephone. Locality of services can also be a problem.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 166*

“I feel people see my diagnosis and not me. They expect me to fit into certain boxes of the diagnosis, but I don't. I'm me. I'm different to the next person. Therefore, they don't listen to me and my opinions. However, my GP on the other hand I feel listens to me all the time. Throws away the diagnosis and sees me for who I am that day.” (*(Neurodivergent Female aged 35-54, Mole Valley) 167*

“I am high functioning and autistic. Services see the first so overlook the second. … Sometimes people do not understand the needs of autistic people, but usually they are doing their best” *(LGBTQ+ Disabled and Neurodivergent Female aged 35-54, Guildford) 170*

“Surrey does not seem to provide therapy that an autistic person can access. I cannot attend groups and it takes me a long time to be able to trust someone and open up.” *(Disabled and Neurodivergent Transgender Male aged 18-25, Reigate and Banstead) 253*

“Organisations simply do not understand autism, and will pin everything on mental health, so you end up with inappropriate support which is unhelpful and leads to additional frustration and isolation. Sometimes encouragement is offered instead of the practical support needed.” *(Disabled and Neurodivergent Female aged 35-54, Waverley) 186*

**Focus group discussion:** Neurodivergent participants discussed:

* The need for clearer communication without people asking for it every time, especially if someone’s record shows they are autistic.
* People reported being unwilling to seek an Autism diagnosis as they fear losing the mental health support they have been accessing. Many people report being discharged from mental health services and denied support following an Autism diagnosis, even though they still have the same mental health conditions and needs. More awareness is needed about co-occurrence between neurodivergent conditions and mental health, in particular anxiety, depression, and trauma.
* It is important to recognise which difficulties are caused by mental health and which by neurodivergence, as neurodevelopmental conditions cannot be “cured”, and people can be put under pressure and made to feel like failures for not “recovering”.
* Some participants have been told their “problem” is their Autism and they should seek support for that, despite there being no Autism specific support for adults who do not have an associated learning disability.
* Neurodivergent lived experience practitioners and peer support groups can validate and empathise with challenges such as sensory issues, burnout, and loss of routine from a place of understanding which clinicians may lack.
* Standard mental health interventions may be inappropriate for neurodivergent people, such as CBT which can be harmful unless adapted appropriately, especially if the person has difficulty recognising emotions or has reduced cognitive capacity due to burnout, and behavioural activation for depression could exacerbate autistic burnout.
* Group therapy may be inaccessible for people who struggle to communicate with others or find the environment and the presence of strangers overwhelming.
* Stimming should not be discouraged, as it helps people to focus and remain calm.
* More understanding is needed of communication differences including masking and tone of voice, sensory differences, comorbidity of conditions, and how bullying and difficulty functioning in a neurotypical world can cause trauma.
* ADHD can make emotions more intense, frequent, and chaotic than for neurotypical people.
* Pathological Demand Avoidance can make it difficult to prepare for appointments.
* Professionals need to view each person as an individual with unique needs and challenges, such as recognising that traditional methods of parenting may not work with neurodivergent parents and carers.

**Notes:** See Case Study under Young Adults for more information about the neurodivergent experience.

Young Adults (5 coded responses)

**Survey:** One resident said that young adults are seen as though they should be able to do more at their age and that their condition is dismissed because of this assumption. Another said they wanted more spaces for young adult recovery. Another said that they needed extra support in helping to identify what needs they have and what services they want to choose.

11% of survey respondents were aged 18-25.

**Quotes**

“Some people don’t understand for me personally I really struggle to make decisions and need help to make those decisions, so people see it as me not wanting help when I do, I just don’t know what I need and need help to work it out” *(Disabled Female aged 18-25, Carer, Reigate and Banstead) 93*

“Age does not help as you are seen as a young person who should be able to do more!!” *(Disabled Female aged 35-54, Waverley) 101*

“More support groups within my age range 18 to 24” *(Female aged 18-25, Guildford) 114*

“I mentor young people in secondary schools in Surrey and many are not considered 'bad' enough to get mental health support and counselling - charities are doing their best to help but often not always qualified to provide the support the children really need; we are letting our young people down. School counselling is often not very good quality and can do more harm than good. Some schools do not allow external charities in to help their students. Not enough free counselling for young people in enough areas i.e. close to them - travel too far is often not possible if parents don't drive, difficult public transport and timing of sessions for school children.” *(Female aged 35-54, Surrey Heath) 143*

“Greater support, more choices available, small residential spaces for young people to 'recover' with appropriate support. Greater understanding/empathy from professionals of MH struggles exploring what the client needs from them. Listening to the patient.” *(White/Asian Female aged 18-25, Reigate and Banstead) 182*

“I was kicked off CAMHS during covid and I am too old for them now.” *(LGBTQ+ Disabled and Neurodivergent Transgender Male aged 18-25, Reigate and Banstead)* 253

**Case Study - Erin** (pseudonym)

Demographic: LGBTQ+, Neurodivergent, Non-binary person, Young Adult, University student.

Summary: Erin deals with difficult family dynamics regarding negative opinions and denial about neurodivergent conditions. They received their ADHD diagnosis about six months ago and their Autism diagnosis about a month and a half ago. They started to experience mental health issues during school from the age of 9, however because they would get good grades, their issues were overlooked.

Upon entering university, their lecturers suggested they seek help at the free Well-being Service. Erin began therapy sessions, describing meltdowns and panic attacks but not feeling completely understood. They felt that the initial therapist was not qualified enough, which led to a referral for more counselling. Erin's current university counsellor (who is also late diagnosed with ADHD) was supportive in the process of seeking a neurodivergent diagnosis and referral, even though they couldn't provide direct advice.

University lecturers and module leads were open to feedback and making reasonable adjustments to support Erin to access the course. After lecturers asked them if they could have ADHD, Erin contacted the GP, however the GP seemed reluctant to refer Erin for an ADHD diagnosis. Erin was concerned about long waiting times for both ADHD and Autism diagnoses and the impact on their studies. After persistently advocating for themselves, they eventually received a referral for ADHD.

They found a sense of belonging when they went to university and joined a society for neurodivergent individuals. Their counsellor has been instrumental in helping them accept that it's okay not to excel in everything. Their partner is also supportive, but their parents continue to question why they haven't achieved more, despite managing multiple responsibilities.

Erin had high praise for their GP, Sarah, describing her as kind, honest, and easy to trust.

Erin has attended the Managing Emotions Programme accessed through a GP referral. They found it difficult to engage due to their preferred style of observing before participating, as well as their frustration with aspects of the program that seemed focused on neurotypical emotions, which they do not relate to. **This highlights the need for more tailored and neurodiversity-inclusive support services.**

Erin discussed their difficulty with regulation, explaining that they can identify emotional states but have trouble calming down. They find many calming techniques too intense and that their nervous system dysregulation affects both negative and positive emotions. **This highlights the need for more nuanced approaches in managing emotions, especially for neurodivergent individuals who experience emotional intensity differently.**

Erin discussed their experiences with the lack of support and understanding for neurodiversity, both in educational and workplace settings. They highlight the need for appropriate training and consultation with neurodivergent individuals when creating programs or resources aimed at supporting neurodiversity. Erin also points out instances where the classification of Autism is inaccurately categorized, such as being listed as a mental health condition when it's a neurodevelopmental condition. **This highlights the importance of accurate and informed representation of neurodiversity.**

Erin expressed frustration with the continued need to correct inaccuracies and misconceptions about neurodiversity. They also discussed the challenge of dealing with individuals who resist acknowledging or learning about neurodiversity, which can hinder progress in creating more inclusive and supportive environments. **This highlights the ongoing need for awareness, education, and acceptance of neurodiversity in society.**

Erin emphasised the importance of service providers and support systems having specific priorities and qualities. These include:

* Confidentiality, as privacy and the risk of information getting back to parents or teachers is a significant concern.
* Understanding the dynamic of having “nice but emotionally unreliable” parents and the impact this can have on seeking help.
* Not providing parents' contact details to the university, as they may not be helpful or supportive.
* The fear of judgment and long waiting lists, which may lead individuals to struggle in silence.
* The fatigue from advocating for oneself when encountering professionals who may not understand or prioritise their needs.

**Key takeaways**

* Empathy and knowledge about neurodiversity can improve support and communication within families and among peers.
* Neurodivergent individuals may perform well academically but this shouldn’t deter educators and support systems from addressing potential neurodivergent diagnoses and making reasonable adjustments.
* Neurodivergent practitioners and clinical staff are vital for neurodivergent people to feel understood and effectively access therapeutic programmes.
* It is important to have access to mental health and neurodiversity support, both during and after the university experience.
* There is value in having a supportive counsellor who understands the individual's unique needs.
* It can be challenging to find community support outside of a university environment.
* There are financial challenges that students may face, such as living on a minimum Maintenance Loan, and the importance of community and peer support, that can impact on mental health.
* There is a need for accessible resources and support systems outside the university setting.

**Focus group discussion:** Our focus and working groups consisted of 1 Young Adult. This was in part due to low engagement with the survey with this demographic and/or young adults having prior commitments in the daytime when focus groups and working groups were held to accommodate system professionals.

**Responses to the banner at Royal Holloway’s Festival of Volunteering 2023 asking “What is the biggest issue affecting students’ mental health in 2023?”**

1. TikTok – negative content loop.
2. GP problems.
3. Workload.
4. Feeling alone.
5. Online – social media.
6. Not being able to access 2 GPs at the same time.
7. Lack of resources.
8. Delayed appointments.
9. Isolation.
10. Expected to learn all new things and manage them at once (still not signed up to pharmacy).
11. Unresolved problems.
12. GRADES – and family pressure.
13. Having more information about different events and what’s on in ONE place.
14. Lack of structure.
15. Social media.
16. Peer pressure / to fit in with the ordinary.
17. Autism – whilst it can be a good thing, it can sometimes get overwhelming if trying to socialise with others.
18. Social media, especially TikTok.
19. No emotional support, especially from family for international students.
20. Education and the schedules being very different (from what they are used to).
21. Changing GPs.
22. Lack of wellbeing support / someone to talk to.
23. Education stress.
24. Indifference.
25. Pressures put on by teachers.
26. Undiagnosed ADHD/Autism – being told to access Autism support when you go for your mental health.
27. Unbelievable schedules and lack of emotional support provided by the educational institutions.
28. Caring too much about the image they want to build on social media.
29. Family pressure.
30. Issues with social media (group chats, culture, bystander and not feeling able to speak up).
31. Pressure regarding career and competition or need to be better.
32. Lack of organisation.
33. Variety of life skills you need to know.
34. Balancing everything.
35. Social media.
36. Home sick.
37. Shame – so many students feel embarrassed about not feeling great, but there’s nothing to be ashamed about! We all have mental health and some days we struggle and need help.
38. Changing GPs.
39. Social media.
40. Social and cultural expectations.
41. Overthinking every situation when you don’t need to.
42. Homesickness, culture shock and academic overwhelm/stress (from an international student).
43. Group activities on the weekend – we can get some lonely within two days.
44. Workload.
45. Adjusting.
46. Home sickness.
47. Home/life balance.
48. Not easy to find out about mental health support.

**Notes:** We spoke with a lower number of people from this demographic as it was a challenge to find established groups that could cater for the team to drop-in at short notice (agendas are often booked months in advance or meetings are held quarterly and didn’t align with the project’s timeline).

# Theme 2: Communicating the issue (174 coded responses)

The survey found communication to be one of the most significant barriers to accessing the right support. Some residents, especially those with dyslexia and other neurodivergences said they struggled to put into words their experiences with mental health.

Time constraints and a lack of understanding prevent clear communication and conversation within initial appointments, especially GP appointments.

Speaking with someone who is unfamiliar with your issue was also a significant barrier to communication and feeling understood.

Residents often felt dismissed and not taken seriously when discussing their mental health symptoms, especially at the GP or other non-mental health practitioners. For this reason, many residents had lost faith that the system can help them.

Communicating the issue/Communication (44 coded responses)

**Survey:** Communicating the issue was a large barrier to getting the right support, or any support at all. Residents felt that it was hard to put what they were struggling with into words, and that emotions or care settings can overwhelm them and make this even harder.

Both neurodivergent people and disabled people reported issues with struggling to communicate the issue. For this reason, neurodivergent people and those with learning disabilities said that talking therapies aren’t always appropriate for them.

Having more time, communicating in the way that the client prefers (in person, online or over the phone), and having a record of what was said, are all things that can help people’s ability to communicate the issue.

There are difficulties recognising how bad you are getting and when to start the process of reaching out for support.

**Quotes**

“Mental state affects the ability to discuss with others the problems being dealt with.” *(Female aged 65+, Surrey Heath) 4*

“It's difficult to get support and often it's delayed and takes too much time to explain one's situation” *(Disabled Asian British Female aged 26-34, Carer, Runnymede) 86*

“My main barriers to seeking support I find it tricky to explain how or know what I’m feeling, and I don’t like speaking about my feelings or anything personal. The only person I speak to about anything like that is my mum however there is somethings I’m just feeling like I can’t even tell my mum about. When I have sought support from community mental health teams it heightens my anxiety which made it difficult, and CBT does not work for my due to the nature of my autism and on the NHS that’s all they can offer me.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Waverley) 126*

“Less questions beforehand, make it easier to sign up for. And not forcing me to get on a phone call, because I don't do well over the phone. And a wider variety of types of therapy or treatment instead of several services offering the same ineffective therapy (CBT).” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Surrey Heath) 192*

“I don't think people with cognitive communication needs (e.g. learning disabilities /autism) find it easy to access mental health service as the emphasis is often on talking therapies without much reasonable adjustment for people's understanding / speaking difficulties” *(Female aged 35-54, Reigate and Banstead) 217*

“Sometimes I struggle to get my point across, often I find that I cannot process conversations while they are happening- I need time to reflect to fully understand any social interaction.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Mole Valley) 239*

“Learning difficulties, I do not understand things I cannot grasp or remember something, I have insomnia also and these amongst other things affect me daily as well as depression and anxiety” *(Disabled and Neurodivergent Female aged 55-64, Guildford)* 115

**Focus group discussion:** Participants raised suggestions about how this issue could be improved:

* Professionals need to be patient, ask one question at a time, and allow extra time for people to process the question and think about their answer before responding.
* Within appointments, allow the person to explain their experience, rather than assuming it will be the same as everyone else’s.
* Within appointments, provide all relevant information without expecting the person to ask the right questions to get to the information, which might not occur to them at the time.
* Explain things clearly and check the person’s understanding of what questions are asking, especially when discussing feelings and emotions.
* Explain jargon, acronyms, or medical terms.
* Provide a written copy of important information talked about in appointments including the name of diagnosis, options for therapeutic interventions, what medication to ask a pharmacist for and how to take it, what to do and who to contact if there are any problems.
* Recognise that when someone is unwell, they may not communicate in accordance with societal expectations. Avoid reprimanding them for swearing profusely as a form of expression.
* To help alleviate anxiety, respond to emails in a timely fashion, including sending an initial holding response so the person knows their message has been received.

**Notes**

Residents raised the following as ways to improve current support:

* More information online to help decide what you need to access and identify the issue.
* Not having GPs gatekeep GPimhs as you may not be able to communicate your issues accurately and be sent to the right place (or any place).
* Reasonable adjustments that reduce executive functioning requirements in appointments so that people can focus on communication. These ideas came from specific demographic groups, but they are things that can help all residents, e.g., questions before meetings for autistic people, visual aids for identifying emotions and needs for dyslexia, note taking for carers.

Lack of understanding (41 coded responses)

**Survey:** Residents commented about a lack of understanding and empathy from services and that their experiences were often dismissed or disregarded by the GP. There is a lack of understanding of mental health and how physical health/neurodivergence affects their lives and wellbeing (and if this is understood it is rarely accommodated).

**Quotes**

“I have a fantastic relationship with my CPN at Elmbridge CMHRS. I always feel heard, validated, and supported.” *(Disabled and Neurodivergent Female aged 26-34, Elmbridge) 34*

“I feel muted and helpless when discussing needs with health professionals” *(Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 52*

“It depends on the individual listening not all people offer the same support even within the same organisation” *(Disabled Female aged 55-64, Mole Valley) 58*

“Staff at clinical or contracted mental health services are not always very sympathetic. The safe havens / crisis drop-ins are depressing places and hard to get to. Some mental health services treat people like they are children and do [not] treat them with the dignity and respect due to any intelligent adult. The local services are also not very good at knowing about everything that is available locally or working in partnership with other services.” *(Male aged 35-54, Carer, Rushmoor) 71*

“People not understanding me or not being very [aware] of how my conditions affect my everyday life. Not being able to put how I am feeling into the right words.” *(Disabled and Neurodivergent Black Caribbean Female aged 18-25, Runnymede) 102*

“Lack of understanding of Mental Health by GPs” *(Male aged 65+, Woking) 151*

“They may have done the training and come out with standards phrases - but they haven’t really understood” *(Female aged 65+, Carer, Tandridge) 179*

“Some organisations provide support that is very much responding to the individual. others tend to follow a fixed process that is not culturally competent. I do not want to have to explain when I am ill what the impact has been of prejudice, discrimination and stigma on me or my family or the relevance of my history and traumas to my present illness” *(LGBTQ+ Disabled and Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

**Focus group discussion:** People have low levels of trust in psychiatrists and counsellors. Sometimes this is from issues regarding respect, and sometimes it’s from staff not understanding people’s conditions and experiences.

The experience of being diagnosed with Autism or ADHD later in life, often leads to anxiety and low self-esteem which often gets dismissed.

Listening (65 coded responses)

**Survey:** There is a strong desire to be heard and taken seriously by practitioners. Residents shared the feeling that professionals often don’t consider their lived experience, which puts some residents off from seeking help due to fears of lack of empathy or understanding.

Some individuals’ concerns have been dismissed due to not having a diagnosis whilst others feel that their conditions are dismissed, not understood or assumptions are made about them due to the diagnosis rather than listening to their current lived experience.

There was varied reports of how well people felt listened to and by whom, and that it ranged from person to person, day to day. It was highlighted that lived experience and local practitioners tend to listen better.

Residents want more open and empathetic environments, with less reliance on ‘book learning’ and more volunteers/people with lived experience who have the time for individualised support and better understanding. There were comments about when practitioners follow protocol too strictly it can hinder personalised responses.

People were aware that some organisations may struggle to effectively listen due to limited resources.

**Quotes**

“Open listening. GP all transactional now and only interested in individual physical symptom.” *(Female aged 55-64, Carer, Waverley) 133*

“I think these organizations rely too heavily on algorithms and guidelines, failing to hear the individual” *(LGBTQ+ Neurodivergent Female aged 26-34, Mole Valley) 195*

“Only some organisations providing support listen and respond personally. Others tend to follow an approach that I would call algorithmic. They are not responding personally but follow a fixed process that does not vary or adapt to each individual. They do not seem to appreciate my family situation or impact of issues on my family.” *(Disabled and Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

“I never know if I will be listened to and respected as I have had bad experiences.” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 26-34, Surrey Heath) 232*

“I constantly get turned away and not listened to. I now feel it's pointless reaching out.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 236*

Agreement with Statement 1: I feel listened to and respected when discussing my needs with organisations providing support.

“Recently this has become "agree" as I started therapy with a charity rather than NHS mental health. Constant turnover of staff made it difficult to form any kind of therapeutic relationship and feel listened to.” *(Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“Recent conversations with both my GP and a charitable organisation were positive, addressed my needs with regard to my mental health and my needs with regard to the person I care for who has a mental health condition and I felt listened to.” *(Female aged 55-64, Carer, Elmbridge) 120*

Disagreement with Statement 1: I feel listened to and respected when discussing my needs with organisations providing support.

“Speaking with other like-minded individuals from the local community with lived experience is more helpful than speaking with a doctor who lives very far out of the area.” *(Female aged 35-54, Carer, Spelthorne) 128*

“Third sector and charity organisations have always been better at listening and respecting.” *(LGBTQ+ Disabled and Neurodivergent Female aged 26-34, Guildford)* 178

**Focus group discussion:** People are more inclined to open up to a practitioner if they are listened to with empathy and respect, and more training in compassion focused therapy could be beneficial.

It’s important that practitioners respect that some people will research into their conditions and treatments and can bring valuable suggestions to their appointments. Parents and carers can often have valuable insights about their loved ones as they are with them 24/7.

Listening to carers and building a good working relationship based on trust and respect is essential. If a person has withheld consent for their information to be shared with their carer, the professional can still offer generalised advice on how to support someone with their challenges/diagnosis.

Seeing the same person (24 coded responses)

**Survey:** Residents said that being able to see the same person was either a facilitator to seeking support, an improvement they wanted, or a key factor in whether they felt listened to and understood.

They felt like this affected both their continuity of care, quality of services and, importantly, their ability to communicate their mental health concerns openly.

Residents wanted a named contact who could get to know you, your situation and that you could develop trust with.

**Quotes**

“The crisis line is brilliant but contacting new psychiatrists can cause me problems with continuity of care.” *(Disabled Female aged 65+, Tandridge) 17*

“Frequent changes of staff is the worst thing.” *(Disabled person aged 65+, Carer, Runnymede) 20*

“Best when the same person sees you each time & has time to get to know you \*and\* is well connected with local services (has visited/experienced most of them, not just attended endless meetings) i.e. some perspective & vision for persistent progress over an extended period (not just another time-limited referral).” *(Neurodivergent Male aged 55-64, Reigate and Banstead) 26*

“Not being passed around different people but having one person you can get to know and who can get to know you.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 166*

“Longer term input building a relationship and understanding me. People not leaving so frequently.” *(LGBTQ+ Disabled and Neurodivergent gender non-conforming person aged 18-25, Mole Valley) 249*

“Hit and miss on this one. No consistency. This may be part driven by government changes in regulation or poor communication within Surrey/Hants. Then it comes down to training re-training staff. Dealing with staff turnover.” 20 *(Disabled person aged 65+, Carer, Runnymede) 20*

**Focus group discussion:** Seeing a different person each time is anxiety provoking and distressing, while seeing the same person provides predictability, trust, a sense of safety and reduces the fear of being misunderstood.

Regular appointments with the same professional can mean changes in the person’s mood or symptoms over time are more likely to be noticed.

Autistic people need structure, routine, and familiarity, and take time to build enough trust with someone to open up.

When a professional moves on with no notice or transition, autistic people struggle with the change and the loss of someone they trust who knows their history. Being introduced to someone else on the team by the outgoing practitioner could help with the transition.

**Notes:** GPimhs currently supports some of this by having a consistent community connector. However, there are areas for improvement, for example, being able to access GPimhs support through referral by an organisation you trust (e.g. charity service).

# Theme 3: Access and Availability (149 coded responses)

Access and Availability was a large topic of discussion among survey respondents, a barrier to access and a popular thing residents wanted to see improved.

Primarily, residents wanted to access services in the ways they wanted and at the times that suited them whether it be online vs in person, out-of-hours, or close enough to get to without a car.

Issues were raised regarding physical accessibility, adaptions for neurodiversity and the cost of transport.

Wait times was one of the largest topics discussed and had consequences like putting people off accessing, people’s needs changing whilst waiting and being left to wait with little information or communication.

Accessibility (11 coded responses)

**Survey:** Issues raised by respondents included physical accessibility of venues (e.g., ramps and toilets), reasonable adjustments for sensory impairments (e.g., in counselling or making appointments) and reasonable adjustments for neurodiversity (e.g., text over calls, an advocate and appointment reminders).

Comments were also made about the lack of accessible transport or home visit options (for those who are unsheltered) and the need for safe places for people to talk with services that don’t take away independence.

**Quotes**

“Application process, length of time between applying and first appointment, length of time awaiting assessment, wait time for treatment, difficulty with attending venues at times set by service, accessibility issues at venues, lack of skills in delivering using online methods, lack of interim or supplementary support, lack of awareness of impact of multiple conditions” *(LGBTQ+ Disabled and Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

“Accessibility for Deaf and VI [Visually Impaired]” *(Disabled Female aged 35-54, Guildford) 223*

"A specific mental health representative/practitioner for local surgeries. Advice on activities and access that can help alleviate severe issues of mental health, depression and anxiety especially for people in difficult financial situations, and youth groups who should have better, cheaper access to exercise and sport facilities, including social activity facilities. There are few facilities for people in a state of homelessness that does not infringe on their independence, a safe place to reside and to discuss with someone about their difficulties and hopes for their future." *(Disabled and Neurodivergent Male aged 35-54, Waverley) 222*

Question 2: What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life?

“Accessible transport/Home visits” *(Disabled Female aged 65+, Reigate and Banstead) 50*

“Someone to support me with attending appointments and someone to remind me as I have poor time concept and memory.” *(Disabled Male aged 55-64, Waverley) 175*  
  
“Physical things like ramps/toilets etc. Understanding not patronising” *(Disabled and Neurodivergent Female aged 18-25, Carer, Waverley) 211*  
  
“Accessibility provisions for Deaf and VI [Visually Impaired] people” *(Disabled Female aged 35-54, Guildford) 223*

**Data:** Accessibility was in the top 10 things that Southwest Surrey residents said would improve their service uptake.

**Focus group discussion:** Neurodiverse participants raised that waiting rooms were overwhelming and there isn’t consideration for sensory environments. They felt the workforce lacks knowledge about sensory differences and how to accommodate reasonable adjustments. There was an overall feeling that it is not easy to ask for adjustments.

Availability (48 coded responses)

**Survey:** Topics relating to availability including lack of out-of-hours, local or face-to-face support. Two people commented that they don't reach out for help as they don’t want to take up space in limited mental health services.

**Quotes**

“More availability, especially of specialist and accessible assessment and intervention services” (*Disabled Female aged 35-54, Guildford) 5*

“I’m usually very busy with my family responsibilities and other things during the day. I go to a carers group one evening a month, but there is very little else available in the evenings when I’m free to think about myself and my well-being.” *(Female aged 65+, Carer, Guildford) 11*

“I often struggle most during the early hours of the morning or very late at night when people tend to be unavailable.” *(LGBTQ+ Disabled and Neurodivergent White/Black Caribbean Female aged 26-34, Mole Valley) 24*

“In person meetings at times outside of the working day” *(Female aged 35-54, Carer, Tandridge) 47*

“Availability out of work hours.” *(Black British Female aged 35-54, Guildford) 66*

“Longer ‘opening hours’” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 94*

“If family or friends are unavailable, where to go to for help at the weekends, bank holidays etc. I feel secure when I know I can pick up the phone and call my medical practice.” *(Female aged 65+, Carer, Waverley) 97*

“Availability of support around my area” *(Disabled Male aged 35-54, Tandridge) 100*

“There's nothing in Dorking out of hours, so having to drive to Epsom or Redhill is a bit daunting when in a crisis.” *(Neurodivergent Female aged 35-54, Mole Valley) 167*

“Appointment times outside of working hours” *(Female aged 35-54, Carer, Reigate and Banstead) 171*

“I work during the day, so appointments are usually when I am working” *(Latina Neurodivergent Female aged 26-34, Reigate and Banstead) 180*

“Online support or located nearer to my home.” *(Neurodivergent Female aged 35-54, Carer, Mole Valley) 256*

**Data:** Availability was a top 10 topic of discussion in the survey responses across all residents, regardless of age, gender, or other circumstances.

It was ranked in the top 5 barriers across all residents’ responses as something that prevented them from seeking support.

The only demographic that didn’t mention availability as much was those from North East Hampshire, but this is likely due to a lower number of survey responses in this geographical area, producing no consensus on key issues.

**Focus group discussion:** Carers noted that transport options and flexible meeting times are essential for carers, and that hybrid meetings (online and in-person) are effective.

Neurodivergent participants raised a need for those living in rural areas and understanding that people often rely on public transport for various reasons including medication side effects, and/or need out of hours appointments due to their own or their carers working hours to be acknowledged when improving service provision.

One participant mentioned they had been referred to a Surrey-wide group that was located on the other side of the county to them and inaccessible.

Cost (21 coded responses)

**Survey:** Some respondents said that they could not afford the cost of travel or the support that they were recommended. One person raised that older women do not have as much financial freedom to use services or experience to gain meaningful employment. Some also said that they viewed mental health services as underfunded, staff underpaid and under-qualified, which put them off seeking the use of these services. One person suggested that whilst waiting for mental health support, being offered subsidised memberships to physical health settings like leisure clubs would be useful to maintain mental health in the meantime.

**Quotes**

“There can also be a lack of understanding that older women lack the financial freedom to make choices which places invisible barriers to reach their full potential. This, combined with their understanding that they have no chance of increasing their pension or obtaining a paid job due to their age can trigger depression which is not addressed by simply attending a day centre.” *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*  
  
“Mental health has always been way behind physical health provision, from a monetary point of view. If you invest properly, the problem would not exist.” *(LGBTQ+ Disabled Male aged 55-64, Epsom and Ewell) 10*  
  
“In general, our support in the voluntary sector doesn’t really understand that people have many needs that are barriers. Such as economic difficulties that mean transport to support is expensive and venues need to be physically accessible.” *(Female aged 65+, Carer, Guildford) 11*  
  
“I’ve had CMHT before that advised counselling, but I couldn’t even afford the cost.” *(LGBTQ+ Disabled Male aged 35-54, Woking) 57*  
  
“The NHS needs a radical shake up and re-organisation. A transparent tax system needs to be introduced to show where the money is collected and spent.” *(Male aged 65+, Waverley) 65*  
  
“Having to consider the financial impact and having the time to do so.” *(Female aged 35-54, Runnymede) 118*  
  
“cost, stigma, understanding of employers, reduced cost, supportive employers” *(Disabled Male aged 35-54, Woking) 142*  
  
“Cost of talking therapies.” *(Female aged 55-64, Waverley) 156*

“The cost and how little people in general within the public health services know about Autism” *(Neurodivergent Male aged 35-54, Waverley) 191*

“More access to services like counselling through the NHS so that it is not unaffordable privately” *(LGBTQ+ Female aged 18-25, Mole Valley) 196*

“When I have to pay for help and assistance. in my home. I cannot afford the cost. I am deaf and I cannot get counselling other than on the phone. So, I don’t get what I am recommended to have” *(Disabled and Neurodivergent Female aged 65+, Guildford) 210*

“Cancelling the Aspire support groups is like telling neurodivergent people that they aren't worth it, especially when the group is well attended. If the National Autism Society/Aspire can’t fund it directly, financial support should be sought from the NHS or ask attendees to contribute.” *(Disabled and Neurodivergent Female aged 26-34, Guildford) 212*

**Data:** Residents living in South West Surrey, and gay and lesbian respondents commented on cost more than other groups.

**Focus group discussion:** Neurodivergent participants commented that good intentions and good training are no use if there is no funding to deliver the services that people need. One person was told they could not have an Autism assessment, as it was “too costly”.

Older adults explained that transport being organised to their lunch club allows some people to come that otherwise wouldn’t. Some can be picked up by others that live close. Others are charged £5 for a round trip which always isn’t affordable.

Privilege (2 coded responses)

**Survey:** Several white respondents responded that they had never experienced discrimination themselves, with only one respondent acknowledging that this was likely due to privilege, rather than the absence of discrimination. One straight white male respondent said that they felt like they were not a priority and that they ‘Strongly Agree’ that they were concerned that they would be discriminated against for this reason.

**Quotes:**

“I am mostly a straight white man so feel I probably have quite a high privilege in life”. *(LGBTQ+ Male aged 18-25, Rushmoor) 6*

“As a straight white male, I feel like I am less of a priority than others and was told that I was less of a priority than others for this reason when I accessed the old well-being centre and the CMHRS in the past.” *(Male aged 35-54, Rushmoor) 73*

Transport issues (12 coded responses)

**Survey:** Residents want to be able to access local community groups and community drop in hubs without the need for out of area public transport. Comments were made about the cost of transport to out of area services and unreliable/inaccessible public transport.

**Quotes**

Question 1 (Q1): Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

“Inability to get to places due to not being able to drive and public transport being rubbish”. *(Disabled Female aged 35-54, Reigate and Banstead) 87*

“I can’t use public transport and all the mental health service have been moved out of Epsom so getting to any face to face is impossible for me.” *(Neurodivergent Male aged 35-54, Epsom and Ewell) 103*

“Access to travel to community groups” *(LGBTQ+ Disabled and Neurodivergent Male aged 26-34, Runnymede) 122*

“Travel barriers,” *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

“I am also unable to travel so cannot get to safe haven.” *(LGBTQ+ Disabled and Neurodivergent Female aged 26-34, Guildford) 178*

“Single mums to get to communities’ groups in person. Zoom is available though.” *(Disabled Female aged 35-54, Epsom and Ewell) 201*

Question 2: What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life?

“Ease of travel (i.e.: bus pass) and the ability to access support remotely, such as on Zoom type meetings, texts and by email.” *(Disabled and Neurodivergent Female aged 35-54, Rushmoor) 112*

“Mitigating travel issues and costs when outside of my immediate vicinity.” *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

“Reasonably local as I only ride a bicycle.” *(Disabled Male aged 65+, Waverley) 252*

**Data:** Men, gay and lesbians, and those in Mid Surrey mentioned this topic more than other groups

**Focus group discussion:** Attending appointments in person is difficult for those who do not drive and live in areas with poor public transport links, or who struggle to use public transport.

Carers find it difficult to access support in different areas without a car.

Neurodivergent people have difficulty attending appointments due to issues with public transport. Service location can be physically inaccessible, especially for people who cannot use public transport and do not drive. Comments about lack of consideration for how illness complicates someone’s ability to use transport. One participant uses a wheelchair and thinks his needs have not been considered, he is unable to attend Recovery College locations due to transport and access difficulties.

Older adults raised that being alone, without transport, stuck at home is difficult, and that managing transport can be challenging. Being scammed by taxis is an issue for vulnerable and confused older adults. There was the suggestion to have somewhere in every town where older people can drop into that is near the bus station or train station. As discussed above, affordable transport provided by charitable organisations who run activities like lunch clubs, allows some older adults to attend that otherwise wouldn’t.

Wait times (51 coded responses)

**Survey:** A large proportion of respondents cited problems with obtaining appointments and long wait times for services. Many also said that due to disability/carer/parent/employment status, daytime only appointments and support resources created a large barrier to obtaining the support they need.

**Quotes**

“Anticipation of long waiting lists followed by poor / inexperienced service delivery reduces motivation even to start referral process” *(Disabled Female aged 35-54, Guildford) 5*

“I know that if I was to seek support from an NHS service, I would probably be waiting months to get it. By which time I might be feeling better anyway.” *(Female aged 18-25, Epsom and Ewell) 13*

“It's difficult to get support and often it's delayed and takes too much time to explain one's situation” *(Disabled Asian British Female aged 26-34, Carer, Runnymede) 86*

“Operational barriers - not being seen quickly enough by support services.” *(Disabled Female aged 35-54, Epsom and Ewell) 89*

“Being transparent about waiting times for help.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 94*

“NHS staff taking responsibility for delivering a service in a timely manager to people in a critical position before needing to go to hospital again.” *(Neurodivergent person aged 55-64, Carer, Spelthorne) 98*

“Unable to access support in many circumstances without a diagnosis (the wait for a diagnosis can be extremely long, delaying support and a further decline in mental/physical health). E.g. 7 years wait for an ASD diagnosis assessment (many wrong diagnoses in this time - causing damage). After the assessment, it's taken and discussed in the neurodevelopmental team if you have ASD. Then a minimum of 8 weeks, for a letter to confirm the diagnosis (still waiting 13 weeks later). In all this time I cannot access the neurodevelopmental team, any therapy or support going until I get this letter.” *(Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“One thing I find disheartening and makes me more reluctant to seek support is the sheer length of wait lists. My GP referred me to GPimhs a few months ago because he had concerns, and I still haven't heard from them. Waiting and hoping for that length of time is such a difficult thing to do. I put off seeking an autism diagnosis for a very long time because of the massive NHS wait lists. Even if I hadn't put it off, I would have still had a 3 year wait just to get the assessment that would entitle me to ASD-specific support. (thankfully, I got on the psychiatry UK waitlist through right to choose, which meant I only waited 4 months in comparison to 3 years). Reduced wait lists would make it feel like progress is being made to make me feel better, however, I understand that this isn't something that necessarily has a fix!” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford) 130*

“Waiting times and problems being disregarded at the GP” *(Female aged 18-25, Carer, Waverley)* *160*

“In person appointments in a timely manner. When I present for help I am already reaching crisis and need help then, not 4 weeks down the line” *(LGBTQ+ Disabled and Neurodivergent Female aged 35-54, Guildford) 170*

“Availability when you need it, not 6+ weeks later. It takes a lot to ask for help, and if it's not there when you need it, you're less likely to ask again, until you stop completely” *(LGBTQ+ Neurodivergent Female aged 26-34, Mole Valley) 195*

“I have personally not reached out to any singular organisation when needing support. I have used the self-referral process to admit myself to needing mental health support. The process takes a long time and there is little to no support in the intermediate time with something as simple as a check-in from a mental health practitioner while waiting for an appointment of support such as Counselling, CBT or Therapy.” *(Disabled and Neurodivergent Male aged 35-54, Waverley) 222*

**Data:** Wait times was in the top 5 topics discussed by all survey respondents and was the most popular thing that residents overall said prevented them from seeking support.

It was a popular topic of discussion across demographics, ranked 4th behind more information, availability, and preferred contact method in the improvements that people wanted (Q2).

**Focus group discussion:** Neurodivergent participants raised the long wait time for Autism and ADHD diagnoses can impact people’s mental health and that neurodevelopment conditions don’t start and stop at diagnosis – there needs to be consideration for people’s needs throughout the time they are on the waiting list.

# Theme 4: Bounce (127 coded responses)

Several survey respondents told stories of experiencing bounce, or how they felt they would experience it if they sought support. Residents describe being referred around in circles and not finding a service that they met the requirements for, or one that offered them meaningful outcomes, which resulted in the feeling that there was no support available to them.

Bounce (66 coded responses)

**Survey:** Residents described services being 'hit or miss', not being joined up, a lack of response, a lack of follow up, having tried all that is available, and having no support that fits their needs.

Prominent topics included signposting and it not being adequate, inappropriate signposting (doesn’t fit needs or told to go private) or causing people to repeat their stories.

These experiences cause residents to feel they are being passed around or forgotten.

**Quotes**

“I have previously contacted a domestic abuse agency who said that there was no specific support for older women and their only advice was to contact my local housing dept as I would qualify for supported housing. How to write older women off in the blink of any eye!” *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*

“Have fully trained receptionists, and triage teams that can support the person to be able to access the relevant organisations and get an appointment easily not being told to book to the web or do your own referral, often individuals have experienced anxiety getting to a place to book an appointment then to be told 'Not my job' do it yourself exacerbates the problems.” *(Female aged 65+, Surrey Heath) 4*

“More mental health support when you discharged all they tell you if you have a problem see the GP” *(LGBTQ+ Disabled Male aged 55-64, Waverley) 9*

“I/we do not neatly fit into criteria boxes for help. There never appears to be a defined answer to my/our questions. There is no can do" attitude. Always we can’t do something because, etc" (*Disabled person aged 65+, Runnymede) 20*

“There are so many services, and some with such specific requirements, people are sometimes sent by MH professionals to apply for support only to find that they don't meet all the criteria. A long wait for help, inducing huge amounts of stress, ending with huge disappointment and despair. Then another long wait for another service to reply as to whether they can offer support. The waiting for help is the worst time for some people who feel they have little or no hope of relief from their terrible circumstances.” *(Female aged 65+, Carer, Guildford) 22*

I think organisations see themselves as offering a particular service for a particular group of people and if that isn't you, you'll be bounced back to the referrer *(Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 52*

**Data:** Commentary relating to **bounce was the number 1 ranking most popular topic** for all survey respondents.

People aged 26-64 of all genders from across Surrey and North East Hampshire, and neurodivergent people consistently commented on this topic.

**Focus group discussion:** Carers want a named organisation responsible for holding carers throughout the process of accessing support and doing follow-ups.

There was mention of bounce due to either not meeting thresholds or being complex and having to repeat your story as big barriers.

Neurodivergent participants raised concerns of gaps in the system for autistic people without a learning disability and those who are autistic with mental health needs. Autistic people are referred to inappropriate services they can’t access. There’s an ‘either or’ culture between mental health services and neurodivergent diagnoses.

GPimhs/MHICS (2 coded responses)

**Survey:** Two people gave positive feedback about GPimhs/MHICS about liking having one point of contact and quick referral. Whilst this was not a popular topic of discussion in survey but was reviewed in focus groups and working groups.

**Quotes**

Question 2: What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life?

“More services like GPimhs (connecting services: mental, physical and community support) rather than being thrown into the abyss for months after a referral is made.” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“We have MHICS at my GP surgery now and I am lucky to have a GP who knows my mental health. I haven’t used this service yet, but my GP says it will better suit me rather than a referral to CMHT unless I’m in crisis.” *(Disabled and Neurodivergent Female aged 35-54, Hart) 110*

**Focus group discussion:** A carer found the GPimhs set-up to access services via one place useful as they previously found it frustrating retelling stories to multiple teams.

Alternatively, another carer described their son’s experience where appointments were conducted over the phone with a lack of follow-up or positive change. Instead, the practitioner increased medication which worsened their son’s condition and was referred to CMHRS. They felt the communication methods were not neurodivergent friendly and no reasonable adjustments were offered or made.

**Notes:** Almost everyone who was involved in this project’s engagement stages didn’t know about the GPimhs/MHICS service and/or when asked for what would make an improvement, described what the GPimhs/MHICS service is trying to achieve (see topic Bounce quotes).

No support available (52 coded responses)

**Survey:** There was mention of no support being available for neurodivergent adults, parents of children who have been sexually assaulted, or unpaid carers.

A large response was about:

* Lack of local mental health support, as well as support that was accessible through straightforward referral processes.
* CBT being ineffective for neurodivergent people and the lack of trauma focused care.
* No ongoing support for those with lifelong diagnosis.
* Lack of post crisis support or post suicide attempt support.
* Lack of ongoing support after discharge.
* Frustration of lack of support especially when lots of people have others in their life relying on them, then additional challenges arise and there is no support easily accessible.

**Quotes**

“There is no help I tried all the another just past to the next; There no support available in surrey for me I tried” *(Disabled and Neurodivergent Non-binary person aged 35-54, Waverley) 33*

“There is no support” *(Disabled and Neurodivergent Female aged 26-34, Mole Valley) 79*

“I’m very disappointed at the total lack of support for unpaid carers. I care for 2 people with differing disabilities and receive no support.” *(Female aged 65+, Carer, Elmbridge) 92*

“Not feeling like I would be helped as I’ve been let down on multiple occasions. Also, with adult services there isn’t the support that is needed for me in particular” (Disabled Female aged 18-25, Carer, Reigate and Banstead) *93*

“No resources available so everyone is between a rock and a hard place” *(Female aged 55-64, Carer, Surrey Heath) 96*

“I cannot access the neurodevelopmental team, any therapy or support going until I get (Autism diagnosis) letter. Additionally, there's no support for women with ASD who were diagnosed late in life (all material, information and support are directed towards children).” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“Services are often lacking because of financial and budgetary constraints, which are of course spread thin across the UK. This shouldn't mean that the correct support shouldn't be available when necessary and people are directed to an inappropriate resource just because it is free/cheap. (E.g., offering short-term basic counselling to people with long-term mental health conditions)” *(Disabled and Neurodivergent Female aged 35-54, Rushmoor) 112*

“Not enough support in Runnymede” *(LGBTQ+ Disabled and Neurodivergent Male aged 26-34, Runnymede) 122*

“No matter how much you scream for support I’ve learnt that in my case it isn’t coming and that’s difficult to come to terms with when you’re carrying so much on your shoulders and people are relying on you on a daily basis.” *(Disabled Female aged 35-54, Carer, Guildford) 140*

“Support for parents of children who have been the victim of sexual abuse being available which, it appears, it is not.” *(Disabled Female aged 55-64, Carer, Waverley) 148*

“There simply aren't services to meet diverse needs.” *(Disabled and Neurodivergent Female aged 35-54, Waverley) 186*

“All of the services I am given do the same cognitive behavioural therapy stuff, which I do not feel works for me as a neurodivergent person.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Surrey Heath) 192*

“It has been very hard to find organisations to signpost people towards if they have a learning disability or are neurodiverse” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Surrey Heath) 192*

**Data:** The feeling of no support being available was in the top 5 most frequently mentioned topics from all residents across the survey and was the number 1 top ranking additional comment left by residents at the end of the survey.

Those aged 65+ were the only age group to not have it in their top 10 topics.

Men were the only gender to not have this topic in their top 10 topics.

Neurodivergence and carers both had it in their top 5 topics.

**Focus group discussion:** Neurodiverse participants raised there is no help available for autistic adults without a learning disability, that there are constant hurdles and barriers to seeking help, and that services must be provided for neurodivergent support instead of referring to general charities. Older adults mentioned the lack of local third spaces.

Unknown outcomes (7 coded responses)

**Survey:** Residents frequently experience a lack of response from services, or a lack of action taken after referrals have been made. Residents didn’t want to wait so long for updates on action being taken, especially when in crisis.

**Quotes**

“I have sought help in the past, have completed questionnaires, but told there's nothing wrong, yet I know there is, but tick box forms don't help even when I've ticked the worst scenarios.” (*Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

“Lack of access, lack of response, lack of understanding, shortage of specialist staff, generally poor experience of getting timely support from professionals when it's needed.” *(Disabled Male aged 35-54, Woking) 35*

“Previously mentioned lack of follow up and long waiting times and need to be the pursuer all the time. When someone does appear, they are very nice but without any outcomes to the 'nice' meetings, what is the point?” *(Disabled and Neurodivergent Female aged 55-64, Carer, Elmbridge) 48*

“I am listened to but often don’t know the outcome e.g. after speaking to SPA recently. I got told I would be informed but I wasn’t for over a week which is such a long time when I felt in crisis.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Rushmoor) 69*

“It’s really ‘hit or miss’, support should be there theoretically but is not. Also, will I be listened too. To be frank in extreme distress I am more likely to contact The Samaritans, by phone. They Listen.” *(LGBTQ+ Disabled Male aged 55-64, Epsom and Ewell) 10*

“Accessing help is still hit and miss in 2023. Someone may inform you about a service, for you to find it has been abandoned or stopped. I wish services would stop trying to re-invent the wheel. When something works well, acknowledge it keep it, and broadcast it. Don't stop it because of funding, fight for it.” *(Disabled person aged 65+, Runnymede) 20*

“As a carer asking for a carer assessment, I was at first refused, as I was told my cared for person has mental health problems & that only physical problems qualify for a carers assessment. I disputed this through the help of Action for Carers & was then finally granted an assessment. However, although it came back that I had eligible needs nothing came of it. I raised this, again through help of Action for Carers, at one of their hubs with a CPA but never heard back.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

**Focus group discussion:** Carers mentioned the need for carer assessments to be followed through and refined, and that carers are provided with long repetitive documents that end with very vague unhelpful signposting.

# **Theme 5: Mental Health Stigma (109 coded responses)**

After the themes of communicating the issue, lack of information and access and availability, mental health stigma was a popular reason for residents not seeking support.

Mental health stigma affects residents access to support in every level of society:

(1) within themselves through internalised symptoms of feeling like a burden, feeling shame, and feeling that their mental health is their responsibility alone.

(2) in relation to others through fear of judgment from others, including experiences of being seen as an attention seeker or difficult by professionals.

(3) and in relation to society through fear of consequences such as being seen as unable to cope by those determining child custody or by employers/colleagues, as well as the multi-levelled of not feeling like you can prioritise seeking personal mental health treatment due to the expectations of others relying on you in your personal life or work.

Burden to others (11 coded responses)

**Survey:** Some respondents felt that they were a burden to others, especially their family. People may avoid seeking support as they don’t want to add to their adult family members’ mental load or cause them to worry. One person said that they wouldn’t seek help again as the services would try to involve their family (which they didn’t want).

**Quotes:**

“A sense of shame, not wanting to be a burden. Pride stopping me for asking for help.” *(Female aged 65+, Carer, Guildford) 22*

“Overloading my daughter with additional problems.” *(Female aged 65+, Carer, Waverley) 113*

“Not wanting to dump trauma on people and worry people with my own problems”. *(LGBTQ+ Male aged 18-25, Rushmoor) 6*

“Understanding the reasons but not wanting to share/burden family.” *(Female aged 55-64, Mole Valley) 135*

**Data:** Being a burden to others was in the top 10 responses to Q1 (what things stop you reaching out for support) behind topics related to communicating the issue, lack of information, access, and availability.

Feeling like a burden ranked in the top 5 barriers for those aged 18-25, gay and lesbians, and those who said that they wouldn’t reach out to anyone for support.

**Focus group discussion:** Neurodivergent people are prone to rejection sensitivity dysphoria, low self-esteem and feeling like a burden.

There were also discussions about people assigning GPs as their emergency contact/next of kin and that it shouldn’t be assumed that everyone will want family members involved.

**Notes:** This is common among older adults aged 65+ and those who are busy managing lots of responsibilities (e.g. carers). Therefore, it’s important that older adults can access information on support without having to rely on adult family members to guide them through the experience, and that carers are supported to reach out for help and prioritising their needs. Charities could help with both.

Can’t be helped (7 coded responses)

**Survey:** Some residents wouldn’t reach out for help due to being let down previously, feeling that they can never get better, and that their mental ill-health is just part of them, or that services couldn’t offer them meaningful help.

**Quotes:**

“A belief that no one could help me” *(Female aged 55-64, Carer, Elmbridge) 120*

“I feel I should be able to cope on my own after all the medication for anxiety and depression I have tried and all the therapy that I have taken part in. I feel I will never get better and don’t know what to lose to try.” *(Disabled Female aged 65+, Guildford) 107*

“I'm also very scared of doctors and I fear that they won’t be able to help me” *(LGBTQ+ Neurodivergent Female aged 18-25, Epsom and Ewell) 14*

“Not feeling like I would be helped as I’ve been let down on multiple occasions. Also, with adult services there isn’t the support that is needed for me in particular” *(Disabled Female aged 18-25, Carer, Reigate and Banstead) 93*

“I'm still at the stage where I don't feel my issues will ever go away so not sure what I would want changed” *(Disabled and Neurodivergent Female aged 65+, Carer, Runnymede) 104*

**Data:** Feeling like they can’t be helped was only a top 10 reason for young adults aged 18-25 not reaching out for support (Q1).

**Focus group discussion:** A participant had a negative experience of being told after discharge from CMHRS that they already have all the tools they need to manage their mental health.

**Notes:** This topic is a link between ‘personal responsibility’ and ‘no support available’, where people lack faith in the system and knowledge of its services, combined with the feeling that these are personal issues to be solved that others cannot assist with. Services that focus on holistic support/life support rather than wellbeing specifically may help these people to support and improve their mental health.

Fear of consequences (5 coded responses)

**Survey:** Some residents said that they wouldn’t reach out for support due fear that seeking support would be used against them in obtaining/keeping the custody of their children or would be used against them when job-seeking or would affect how they are viewed at work. One person didn't want to seek support for fear of being dropped by support and it further damaging their mental health.

**Quotes:**

“I feel that sometimes reaching out for support may be used against me for getting my son back. Worried they will see it as I can't cope.” *(Disabled and Neurodivergent Female aged 26-34, Waverley) 7*  
  
“Members of Surrey SEND team have been rude and said if I ask for help they will take my child away” *(Disabled and Neurodivergent Female aged 26-34, Carer, Spelthorne) 74*  
  
“There is always a worry for women with children to come forward and get help with their mental health.” *(Female aged 35-54, Carer, Spelthorne) 128*

“Fear of someone sending police or ambulance out when not needed. Fear of my family finding out how bad I am.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 168*  
  
“Feel it would be used against me while trying to get my son back” *(Disabled and Neurodivergent Female, Waverley) 173*  
  
“Services vary, although I will say that The Amber Foundation lied to me about what they could offer. And then they did things that made my mental health a lot worse (whilst treating me like I was lying whenever I asked for my needs to be met) and then decided to 'make a successful move on out of me' which put me in an unsafe and unsustainable situation which has had massive detriment to my wellbeing. And their entire service in Ockley is riddled with rape culture. I've had a very negative experience there, and since then I am hypervigilant when interacting with any other support services.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Mole Valley) 239*

Judgement from others/fear of judgement (14 coded responses)

**Survey:** Some residents didn’t seek support as they didn’t want to be judged be either those in their life or from staff members. Residents worried about what others thought of them and didn’t want to be seen as attention seekers.

**Quotes**

“I don't like to share my personal struggles with work. I fear they will judge me or sideline me.” *(Female aged 35-54, Runnymede) 150*

“I do feel that sometimes the people employed are judgemental.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Surrey Heath) 192*

“Worry about what people think and having to wait for support” (*Female aged 35-54, Spelthorne) 242*

“Judgement and disappointment from others, being told I’m not an emergency, being told I just have to deal with it” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Mole Valley) 248*

“Having it used against me, making me look like a bad person or that I can't cope” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 106*

“Lack of empathy/understanding (words and reactions feel fake/lack sincerity).” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“Not wanting to appear incapable, or weak” *(White/Asian Disabled Female aged 35-54, Elmbridge) 141*

“Other people reliant on me - family, work; negative feelings of self (self-blame, shame, self-criticism - other people cope, why can't I?); stigma (could it affect my job, future jobs, people's impressions of me)” *(Female aged 35-54, Surrey Heath) 143*

“Fear of my family finding out how bad I am.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 168*

**Focus group discussion:** Carers discussed the impact that judgement can have. It can be a massive blow, causing people to put up barriers and reject that organisation. Carers don’t want parenting advice but support on how they can make their caring responsibilities and mental health work together.

Lack of time (23 coded responses)

**Survey:** Residents raised that not having enough time to figure out where to start or what support is available whilst also looking after themselves/prioritise needs can be a barrier to seeking support. Their needs often go on the back burner as they have too many people relying on them.

**Quotes**

Question 1: Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

“Time and 'red tape' - referrals, waiting for appointments etc.” *(Female aged 35-54, Carer, Runnymede) 88*

“Too many people need me to help with their lives so put mine on the back burner.” *(Female aged 55-64, Mole Valley) 135*

“Finding time, waiting times, lack of face-to-face support” (Disabled Female aged 35-54, Carer, Guildford) *140*

“Time to seek help, not the right kind of help, long waits for adult assessments after finding out about child diagnosis this should be offered.” *(Disabled and Neurodivergent Female aged 35-54, Waverley) 197*

“Enough time to fit in time for own support” *(Female aged 35-54, Reigate and Banstead) 217*

“Recognising that I need the support. Having the time to get this support.” *(Female aged 35-54, Carer, Mole Valley) 244*

**Data:** Lack of time (to seek support) was in the top 10 most popular reasons across all survey respondents for not reaching out for support (Q1). It was primarily commented by 26-64s and women, rather than being commented by all demographics. This was also a popular comment among carers. Lack of time and resources from the system is also mentioned when asked about the barriers to seeking support (Q2).

**Focus group discussion:** Transport options and flexible meeting times are essential for carers. Hybrid meetings (online and in-person) are also effective.

Personal responsibility (9 coded responses)

**Survey:** Residents don’t reach out for help as they feel their mental health is their own responsibility and their problem to solve, and they should be able to deal with it themselves.

**Quotes**

“I honestly feel that I am best placed to help myself. … If I can’t help myself, I don’t think anyone else can do better than me.” *(Female aged 65+, Mole Valley) 84*

“None. I just need to man up and get on with it. Life can be difficult at times … I can take care of myself … They are my problems. I need to solve them" *(Male aged 65, Elmbridge) 119*

“Should be able to deal with it myself even though I know I should get support.” *(Female aged 55-64, Waverley) 158*

“Feel I do not deserve the help.” *(Disabled and Neurodivergent Female aged 26-34, Guildford) 212*

“Pride in usually having to be self-reliant. But mainly bad experience of 35 years running a support group for people able to live in the community, who don’t get the help they need from inexperienced social workers and very poor support from social housing associations.” *(Disabled and Neurodivergent Female aged 65+, Guildford) 210*

**Data:** This was in the top 10 reasons for not reaching out for support (Q1) for those who responded that they would reach out to no one for support.

**Focus group discussion:** Neurodivergent participants commented that men are conditioned to keep problems to themselves.

Shame (11 coded responses)

**Survey:** A barrier to seeking support or communicating honestly can be related to self-consciousness, shame, admitting to yourself you can’t cope, despair, self-loathing, denial, and guilt. Some more complex issues aren’t recognised and are dismissed as depression/anxiety.

**Quotes**

Question 1: Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

“Feeling self-conscious when opening up to others.” *(Female aged 18-25, Reigate and Banstead) 15*

“Shame and accessibility” *(Female aged 35-54, Carer, Runnymede) 83*

"Not wanting to admit to friends that I'm not coping. Inability to get to places due to not being able to drive and public transport being rubbish" (*Disabled Female aged 35-54, Reigate and Banstead) 87*

“Negative feelings of self (self-blame, shame, self-criticism - other people cope, why can't I?)” *(Female aged 35-54, Surrey Heath) 143*

"Embarrassment. guilt about taking support from someone else.” *(Female aged 35-54, Waverley) 144*

"Accessibility. Cost. Shame" *(Disabled Female aged 18-25, Waverley) 162*

“Waiting times, poorly organised charities whose scope is limited as to what they are able to do, despair and self-loathing” *(LGBTQ+ Neurodivergent Male aged 26-34, Rushmoor) 169*

“Guilt, shame, denial” *(Female aged 35-54, Mole Valley) 220*

**Data:** Shame was a top 10 reason for not reaching out for support (Q1) for those aged 18-25, women, and gay and lesbians.

Stigma (31 coded responses)

**Survey:** Respondents commented on stigma about seeking support from self, family, work and practitioners. Mental health behaviours can be stigmatised and seen as being made up for attention/a behavioural choice. Staff are seen as unempathetic and making assumptions based on appearance/employment/diagnosis/accommodation.

**Quotes**

Question 1: Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

“Judgements about myself and needing support”. *(Disabled Female aged 26-34, Elmbridge) 8*

“I'd say a lot of it is surrounding my anxiety with a lot of it with a fear of judgement and that people won't look at me the same. A lot of things I need support in would typically trigger a lot of the friends I’d go to for help, so I tend to bottle it in” *(LGBTQ+ Neurodivergent Female aged 18-25, Epsom and Ewell) 14*

“Feeling undeserving. Feeling like it is too complicated. Previous gaslighting by GP” *(Disabled and Neurodivergent Female aged 26-34, Carer, Epsom and Ewell) 67*

“I have had previous experience with people I trust (family) telling me that even though both my GP and regular counsellor determined I was likely depressed, that I was making it up for attention. I am not someone who does that and am worried of being interpreted in that way by other people I care about. I also worry that support takes too long due to wait lists, and often once the top of the wait list is reached, support for a particular issue sometimes isn't needed in the same capacity anymore.” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford) 130*

“Cost, stigma, understanding of employers”. *(Disabled Male aged 35-54, Woking) 142*

“Lots of stigma from society and some workplaces not wanting to adjustments or accept me for who I am”. *(Disabled and Neurodivergent Female aged 18-25, Carer, Woking) 199*

“People telling me that I'm faking or just overreacting because "everyone feels like that sometimes".” *(LGBTQ+ Neurodivergent Transgender Male aged 18-25, Guildford) 229*

“Not being a burden, attention seeking”. *(Neurodivergent Female aged 35-54, Waverley) 233*

Question 2: What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life?

“You are judged by your accommodation”. *(Disabled Female aged 65+, Carer, Surrey Heath) 29*

“In terms of wellbeing support, I accepted a long time ago that I deserve to seek support, regardless of other people's opinions, so the only thing that stops me is thinking about my parents' opinions. That would mean that for me, the biggest change needed to help me access would be societal, and reducing the stigma, but that's a bit bigger than I think you're asking about in this survey!” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford) 130*

“As someone with complex needs, I'm always judged”. *(Disabled and Neurodivergent Female aged 18-25, Carer, Waverley) 211*

Statement 5: I am concerned that I may experience discrimination, prejudice, or assumptions being made by organisations that provide support services.

“I am judged on my appearance”. *(Disabled Female aged 65+, Carer, Surrey Heath) 29*

“As someone with both PD (Personality Disorder) and ASD (Autism) I feel very judged with professionals making assumptions rather than believing what I say”. *(Disabled and Neurodivergent Female aged 35-54, Carer, Rushmoor) 69*

“I have experienced a lot of prejudice and discrimination in health settings about my mental health condition being behavioural (which it isn’t and has been proven it isn’t!). … My physical health is also open to discrimination because I have non epileptic seizures- which some people refer to as pseudo seizures which implies that you have control over them, and they are not real which isn’t the case! Therefore, yes this does worry me with other organisations”. *(Disabled Female aged 35-54, Waverley) 149*

**Data:** Stigma was a top 10 reason for not reaching out (Q1) across all survey respondents.

Stigma (primarily around mental health and other diagnosis) was a top 5 comment relating to reasons that people felt discriminated against or that they received judgment or assumptions (statement 5).

It was a top 10 reason for 26-64s not reaching out for support (Q1), and a top 5 reason for 18-25s.

Stigma (primarily from family and providers) was a top 10 topic commented on by 18-25s in the survey.

Stigma was a top 5 reason for both women and neurodivergent people not to reach out for support (Q1) and top 10 reason (Q1) for carers and those that said that they would reach out to no-one.

It was a joint number 1 reason (with wait times) for Trans/non-binary people not to reach out, and joint 3rd for gay and lesbians.

# Theme 6: Crisis and Prevention (118 coded responses)

Residents said that they wanted earlier accessible prevention-based services.

Overwhelmingly, residents reported difficulty in gaining GP appointments and poor experiences with the GP, leading many residents to delay reaching out for or receiving mental health support before escalating to crisis.

In addition, many residents held the belief that it was extremely difficult to avoid being bounced (i.e. being taken seriously, being able to access support you need or being able to get meaningful support) unless you were at a point of crisis.

A small number of residents also reported symptoms of mental ill-health (for example insomnia, fatigue etc) being responsible for not being able to access support before the point of crisis.

A small number of residents reported fear of escalation, like being sectioned or family being involved, as reasons they didn’t reach out for support.

Crisis (31 coded responses)

**Survey:** Several residents felt that mental health services were only accessible when you were in crisis. There was mixed feedback about crisis support with some saying that crisis lines were unhelpful, that they were rejected from A&E and that safe havens weren't nice places to be. Residents wanted more drop-in centres, for crisis settings to be accessible to neurodivergent people with sensory sensitivity, and for crisis services to be able to follow up.

**Quotes**

“Feel I have received a lot of support from medical and support services after taking drastic action and the help being initiated from team in Frimley Park hospital.” (*Female aged 65+, Waverley) 2*

“No meaningful response when calling crisis line” *(Disabled Male aged 35-54, Carer, Runnymede) 16*

“I would not be alive today had it not been for the crisis line team. The crisis line is brilliant but contacting new psychiatrists can cause me problems with continuity of care.” *(Disabled Female aged 65+, Tandridge) 17*

“[Need for] access to specialist clinical support out of office hours (without using A&E)” *(Disabled Male aged 35-54, Woking) 35*

“Crisis line poor. Worry about wait times in A&E but have bad experience of Safe Haven.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Tandridge)* *41*

“I have had good experiences with the safe haven and Farnham Road hospital ward staff, mixed with the CMHT and HTT, and bad with the crisis / SPA line and the psychiatric liaison team at Frimley Park.” *(Disabled and Neurodivergent Female aged 35-54, Hart) 110*

“We’ve a long way to go to make carers welcome and supported and where do we go in crisis. Services aren’t set up to support us” *(Disabled Female aged 55-64, Carer, Guildford) 147*

“Safe Havens should be given greater discretion in arranging follow up.” *(Male Carer aged 65+, Woking) 151*

“Making phone calls is very difficult so the crisis line is unhelpful. I am also unable to travel so cannot get to Safe Haven. I often become non-verbal when struggling to cope.” *(LGBTQ+ Disabled and Neurodivergent Female aged 26-34, Guildford) 178*

“Because I feel that the support will be inadequate, I am unlikely to seek it anymore. In the past I also did not think I needed help until I got to a crisis point, at which it is difficult to seek it out. Having to fill out questionnaires or describe the specificity of my struggles is really difficult and draining, dwelling on it makes it worse too.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Surrey Heath) 192*

“Safe havens only take people in what they identify as a crisis” *(Disabled and Neurodivergent Female aged 35-54, Epsom and Ewell) 208*

**Focus group discussion:** There is a lack of intermediate support for people struggling but not in full crisis, with a feeling that CMHRS only support people before or after crisis. There is a subjectiveness to what crisis means, and insensitivity to people reaching out for help when they are entering the system at a different point than what the system wants residents to do (e.g. a person was told to call 111 who were dismissive and said to call GP instead which had a negative impact on this person’s mental health).

Difficulty gaining appointments (11 coded responses)

**Survey:** Residents frequently commented on how it is difficult to gain appointments, especially with the GP. One person said that “it is so bad that you don’t even try unless your condition is urgent as then you know that you will be prioritised.”

**Quotes**

“Trying to get an appointment with any organisation can be a barrier. Waiting times are too long to get help.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 94*

“Getting a GP appt is near on impossible” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 95*

“Difficulty in getting appointments with GP.” *(Disabled and Neurodivergent Female aged 65+, Carer, Waverley) 113*

“Easier access to GP” *(Disabled Male aged 65+, Elmbridge) 129*

“If I could get a GP appointment, the situation is so bad that it’s not worth even trying so many people are putting up with physical and mental health issues and struggling on - unless really bad, in which case I would opt for urgent treatment unit in first instance and just get there early to be at the front of the queue” *(Female aged 35-54, Surrey Heath) 143*

“In person appointments in a timely manner. When I present for help, I am already reaching crisis and need help then, not 4 weeks down the line” *(LGBTQ+ Disabled and Neurodivergent Female aged 35-54, Guildford) 170*

“I am in a constant struggle with my GP's office to get an appointment in a way convenient to me – [describes sedative medicine and struggling to book same day appointment by 12pm] I struggle to get doctors to listen to my concerns about my physical health, despite valid grounds for concern. Consistently given phone appointments by my GP's office despite my dislike of them.” *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

“Inability to contact GP or get appointment quickly. Not knowing who to contact for help or what help is available” *(Neurodivergent Female aged 55-64, Surrey Heath) 183*

**Notes:** People waiting till crisis point to access support, can mean they end up at unsuitable services desperate for care e.g. Accident and Emergency departments or urgent care.

Fatigue (5 coded responses)

**Survey:** Fatigue and burnout were cited as barriers to seeking support under Question 1 about who residents would reach out for support if they were struggling to cope with day-to-day life. This is made worse by symptoms of ill-health (for example, insomnia).

**Quotes**

“Mental and physical exhaustion but also knowing that it will pass when I've had sufficient rest” (*Disabled and Neurodivergent Female aged 55-64, Waverley) 45*

“Tiredness” *(Disabled and Neurodivergent Female aged 26-34, Carer, Rushmoor) 46*

Burnout and fatigue” *(Disabled Asian British Female aged 26-34, Carer, Runnymede) 86*

“Learning difficulties, I do not understand things I cannot grasp or remember something, I have insomnia also and these amongst other things affect me daily as well as depression and anxiety” *(Disabled and Neurodivergent Female aged 55-64, Guildford) 115*

Fear of escalation (4 coded responses)

**Survey:** Some residents feared reaching out for support due to consequences of escalation. Residents didn’t want to be sectioned or have emergency services sent to them due to a misinterpretation. This prevents people from being honest with call takers and reflects the lack of trust in the system.

**Quotes**

Question 1: Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual? (multi-select option)

"Being misunderstood, being 'fobbed off', anxiety of making the call and introducing myself, thinking of myself as not worth it, thinking I'm taking up too much time. Also scared that if I tell someone on the phone, I've hurt myself/thinking of hurting myself/thinking of suicide, I'll be told to go to hospital and if I don't go an ambulance will be called for me (I did experience this once)." *(Neurodivergent Female aged 35-54, Mole Valley) 167*

“People never listening. Fear of someone sending police or ambulance out when not needed.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 168*

“Possibly being sectioned”. *(LGBTQ+ Disabled and Neurodivergent Female aged 55-64, Carer, Spelthorne) 214*

Statement 5: I am concerned that I may experience discrimination, prejudice, or assumptions being made by organisations that provide support services.

“I have had a visit from the police this weekend because they received a call from someone concerned that my disabled son was abusing me with physical violence, which is not true. This was shocking and deeply upsetting for me. The person who made the referral is a tutor employed to do daily living skills with my son and had a conversation with him about anger management. As a result of that discussion, he has falsely assumed that my son is physically violent towards me in the current moment which is not true. This tutor should have asked me first or asked a manager from his company to phone me to discuss. This did not warrant a visit in the night from the Police. Utterly ridiculous and a waste of police time. this is just ONE example of MANY”. *(Neurodivergent Female aged 55-64, Carer, Waverley) 250*

GPs (37 coded responses)

**Survey:** Residents largely felt that GP appointments were difficult to access and not long enough to discuss mental health. They felt that GPs weren’t caring or well informed. Some said that they were only offered antidepressants and weren’t aware of community services/groups on offer. Positive feedback was given when people were able to see the same GP who understood them and who they trusted.

**Quotes**

“We have MICS [MHICS] at my GP surgery now and I am lucky to have a GP who knows my MH. I haven’t used this service yet, but my GP says it will better suit me rather than a referral to CMHT unless I’m in crisis.” *(Disabled and Neurodivergent Female aged 35-54, Hart) 110*

“Lack of understanding from receptionists in GP practices” *(Female aged 65+, Surrey Heath) 4*

“My GP is not experienced in mental health.” *(LGBTQ+ Disabled aged 55-64, Carer, Epsom and Ewell) 10*

“Better accessibility at GP surgery.” *(Disabled Female aged 55-64, Mole Valley) 36*

“It can be hard to access the GP so don’t bother.” *(Disabled Female aged 35-54, Carer, Surrey Heath) 76*

“My experience with asking for support from doctors with anxiety and depression has not been positive, immediate solution was antidepressants.” *(LGBTQ+ Female aged 18-25, Mole Valley) 196*

“My GP is extremely kind and supportive.” *(Disabled and Neurodivergent Female aged 55-64, Surrey Heath) 207*

“Having double length appointments set aside for both neuro-divergent people and mental health issues on a daily basis at GP surgeries.” *(Disabled and Neurodivergent Female aged 26-34, Guildford) 212*

“Current GP system of not being able to see a designated GP who understands my personality and history means people are less likely to open up to mental health issues early enough to be sign posted to relevant services. Social prescribing has helped with this to a degree but continuity of care on an individual and long-term basis is lacking in the community.” *(Female aged 65+, Mole Valley) 221*

“When speaking with GPs about my situation, although they are sympathetic their time is very restricted and most medical practitioners do not have the support staff to allow for more in-depth and long-term care in consideration of mental health issues. ... [Need for] A specific mental health representative/practitioner for local surgeries.” *(Disabled and Neurodivergent Male aged 35-54, Waverley) 222*

“GP was good but has now left practice” *(LGBTQ+ Female aged 65+, Waverley) 228*

“GP is near impossible to access, unable to get appointments as have to ring at an exact time each day and Online enquiries are usually full within 5 minutes of opening each day. Appointments are phone appointments so no actual time slot which is too difficult to cope with. Livi [digital healthcare provider that lets you see a GP via video call] is also difficult as we have bad internet connection. Makes me feel isolated and unable to get the help I need.” *(Neurodivergent Female aged 35-54, Carer, Elmbridge) 247*

**Focus groups:** carers, older adults, and neurodivergent people had significant anxiety around medication changes and mismanagement and stated that they would completely avoid GP due to this.

Some older adults had a good relationship with their GP, but it took time to find the right one. GPs were felt to be gatekeepers to other services and that appointment times are too short.

Isolation (14 coded responses)

**Survey:** Several residents felt that they were left isolated and now trying to cope alone. Isolation acted as a barrier to accessing support as were factors such as social anxiety, being disconnected from community services and being disconnected from information, which made asking for help harder.

**Quotes**

“Isolation getting out to the places where support is.” *(Disabled Male aged 55-64, Carer, Guildford) 32*

“Feelings of isolation can make it difficult to reach out to anybody, but especially professionals when you're often required to leave the house and travel to attend meetings.” *(Disabled and Neurodivergent Female aged 26-34, Elmbridge) 34*

“Lethargy and reluctance to move out of my bed - unable to even speak to anyone - isolation.” *(Disabled Female aged 55-64, Woking) 38*

“Lack/fear of social connections.” *(Disabled and Neurodivergent Female aged 26-34, Mole Volley) 64*

“Distance to family” *(Disabled Asian: Indian Male aged 35-54, Reigate and Banstead) 68*

“Communicating my feelings and needs and being able to pick up the phone or go outside to an appointment.” *(Disabled and Neurodivergent Female aged 35-54, Hart) 110*

“My ability to shut down and try to continue to function alone, fear of being judged, awareness of how limited the mental health services are”. *(Disabled Female aged 35-54, Waverley) 111*

**Focus group discussion:**

* Isolation is a big problem in rural areas and people can feel trapped.
* Older people also have the issue of decreased mobility and ability to drive.
* Neurodivergent people experience anxiety in social situations, making them less likely to attend the social activities which are often encouraged to help address mental health concerns.
* Praise for Adult Social Services who have helped one isolated person get out once a week for a couple of hours.

**Notes:** Isolation and Loneliness (alongside Dementia) are core focuses for community-based services for the older adult demographic.

Prevention (16 coded responses)

**Survey:** Residents want support to be available for when they recognise their mental health is worsening before it reaches crisis. Residents want more community based drop-in locations that are available outside of working hours. Residents want more ongoing support after intensive support to help prevent relapses.

**Quotes**

“Earlier serious recognition of difficulty before situation worsens to threat to own life.” (*Female aged 65+, Waverley) 2*

“To be offered the opportunity for regular mental health check-ups as well as physical ones. I realise this is vague but sometimes I could do with checking in with a professional for one or two sessions when I am starting to feel mentally under par.” *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*

“More interest in my role by the social worker who is assigned to the person I care for, at least annually. Checking in with me, also gives valuable information around how my loved one is also doing and why.” *(Female aged 65+, Carer, Guildford) 22*

“Drop ins at community centres (for people such as carers especially & whom also have disabilities themselves) who have unpredictable time management & find keeping appointments difficult.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

“Services not joined up, no vision other than mitigating the current crisis, a life without direction/purpose” *(Neurodivergent Male aged 55-64, Reigate and Banstead) 26*

“There should be a place in town that I can drop in for help at any time, any day.” *(Male aged 65+, Guildford) 55*

“There needs to be more focus on "wellness" and on a holistic view of people's issues, and helping people build happy and healthy and sustainable lifestyles; and less focus on illness and crisis,” *(Neurodivergent Female aged 55-64, Hart) 70*

“Services need to be better at helping people build full and positive and active lives, not just focus on medication and promoting crisis services and dealing with relapses.” *(Male aged 35-54, Rushmoor) 73*

“A GP who I could see consistently and who was able to refer to services that will actually help (rather than only deal with absolute crisis situations)” *(Disabled Female aged 35-54, Carer, Elmbridge) 254*

“There is no SABP intervention you are either in hospital or not, there is no middle ground which should be looked at to help stop people being in a crisis” *(Neurodivergent Male aged 35-54, Epsom and Ewell) 103*

**Focus group discussion:** there is a need to consider developing care plans for all individuals not just for those with severe conditions. There is often a lack of care in the community aside from crisis support, and support often requires people to put themselves out there when they are at their most vulnerable.

# Theme 7: Holistic Needs (94 coded responses)

Many people praised specific charity services, saying that they felt listened to and that they were offered more flexible methods of access and more flexible/holistic approaches to support. These outcomes were especially valued by those with diverse needs like carers and neurodivergent people who struggle with complex referral methods and require both practical and mental health support. Peer support groups were seen as a valuable resource within focus groups, as well as charities being a key part of the communities’ network.

Charities (23 coded responses)

**Survey:** Overall, residents felt that charities listened to them, could offer more holistic support, and could offer specialised advice and guidance. People wanted more funding for charities, as they trusted charities to offer them effective help.

**Quotes**

“If more resources were given to local third sector / voluntary sector / charitable services and if clinical / secondary services would work better with them. It often seems like the clinical / secondary services don't respect or listen to the local third sector / voluntary sector / charitable services. However, it is on the rare occasions that they have that the support is most effective, and the system works best.” *(Male aged 35-54, Carer, Rushmoor) 71*

“Poorly organised charities whose scope is limited as to what they are able to do” *(LGBTQ+ Neurodivergent Male aged 26-34, Rushmoor) 169*

**“**Within some charities, individuals can supportive, but others are prone to bringing in their own experience rather than staying neutral.” *(Disabled and Neurodivergent Female aged 55-64, Runnymede) 3*

“I have reached out to a couple of charities for my mental health, but they've never had space for me, and I fear that I’m not mentally ill/autistic/ADHD/OCD enough" to go to a GP and have help and a true diagnosis. I'm really not sure what's wrong with me”. *(LGBTQ+ Neurodivergent Female aged 18-25, Epsom and Ewell) 14*

“Action for Carers has been invaluable.” *(Female aged 65+, Carer, Guildford) 22*

“As a carer asking for a carer assessment, I was at first refused, as I was told my cared for person has mental health problems & that only physical problems qualify for a carers assessment. I disputed this through the help of Action for Carers & was then finally granted an assessment. However, although it came back that I had eligible needs nothing came of it. I raised this, again through help of Action for Carers, at one of their hubs with a CPA but never heard back.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

“If I have sought help, it is usually because I know the organisation I am going to will help me.” *(Black British Female aged 35-54, Guildford) 66*

“Statutory services very bad. Most voluntary sector services very good.” *(Male aged 35-54, Rushmoor) 73*

"Catalyst - do not offer anything appropriate and nothing in my area.” *(Disabled Female aged 35-54, Waverley) 149*

“Despite the need for further therapy to deal with past and present issues, including an 8-year long period with psychotic symptoms, I have been outside of CMHRS services for about 3 years. I was for a period using Catalyst's services, but while partially helpful they are not equipped to deal with situations such as mine.” *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

“In extreme distress I am more likely to contact The Samaritans, by phone. They listen.” *(LGBTQ+ Disabled Male aged 55-64, Epsom and Ewell) 10*

“I have found great support from Action for Carers Surrey & feel 100% understood by them, at least. … Action for Carers are incredible with their help & knowledge” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 23*

“Art Matters and Mary Frances Trust care” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 152*

“I have often been told that my case is too complex then I'm too 'stable' to need support and then too 'unstable'. There is a lack of understanding that needs fluctuate. The NHS in particular continue to call me when I have stated on many occasions that I prefer written communication. Again, third sector and charity organisations are much better at this.” *(LGBTQ+ Disabled and Neurodivergent Female aged 26-34, Guildford) 178*

“In general, our support in the voluntary sector doesn’t really understand that people have many needs that are barriers. Such as economic difficulties that mean transport to support is expensive and venues need to be physically accessible. Not all understand that carers suffer with MH issues”. *(Female aged 65+, Carer, Guildford) 11*

“Accessing help is still hit and miss in 2023. Someone may inform you about a service for you to find it has been abandoned or stopped. I wish services would stop trying to re-invent the wheel. When something works well, acknowledge it keep it, and broadcast it. Don't stop it because of funding, fight for it.” *(Disabled person aged 65+, Runnymede) 20*

“If there wasn’t anything like Art Matters and Mary Frances Trust then I would have really struggled during the last 10 years (Art Matters) and since March 2020 (MFT), with lockdown I was isolated but with the online groups that MFT did I was able to get support and make friends. My daughter was shielding so there was extra stress.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead) 152*

“Recently ... I started therapy with a charity rather than NHS mental health. Constant turnover of staff [in the NHS] made it difficult to form any kind of therapeutic relationship and feel listened to.” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

**Focus group discussion:** Carers mentioned the highly useful Action for Carers program “Space to be You” that includes practical support and guidance, this charity is well used and feels like a good support system. Charities were praised for being accessible with clear admin and correct links. There was a positive mention of Mary Frances Trust in older adult focus group but also comments that online is not always accessible for everyone.

Hard to access (33 coded responses)

**Survey:** There were lots of comments about services being hard to access. People were turned away due to not meeting the criteria or for being autistic. It is hard to access and/or find appointments that are face-to-face, local, or flexible (drop-in or out of hours).

**Quotes**

“Trying to get the support is really hard, it's good when you get it” *(Female aged 35-54, Carer, Runnymede) 88*

“Difficulty in accessing first line NHS support (face to face GP).” *(Disabled Male aged 65+, Elmbridge) 129*

“Difficulty accessing GPs in general.” *(Disabled and Neurodivergent Male aged 55-64, Carer, Hart) 85*

“I think there should be a safe place where people can go just to talk and have support like a drop-in centre no appointments needed just for people to learn better social skills if they want to and some quiet calming rooms for people with autism etc. Just a place that feels safe to all with mental health problems it could be sponsored by someone to help the running of it, it would be a great help” *(Disabled and Neurodivergent Female aged 55-64, Carer, Surrey Heath) 209*

“The tight eligibility criteria to access service or even minor support service. The service is not built around the service user is built around what the Mental Health Trust think they can provide.” *(Disabled and Neurodivergent Male aged 65+, Carer, Woking) 215*

“Had perinatal support - good psychiatrist, reliable and regular appointments, good follow up care and offer of resources available if needed.” *(Female aged 35-54, Mole Valley) 220*

“Referrals to CMHRS. Being rejected due to having autism! *(Disabled and Neurodivergent Female aged 26-34, Waverley) 235*

“I constantly get turned away and not listened too. I now feel it's pointless reaching out.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Reigate and Banstead) 236*

**Focus group discussion:** Both carers and neurodivergent participants mentioned it was difficult to access support in different areas or attend appointments without a car. Older adults can find managing transport difficult and are often reliant on volunteers to get them to places or must pay which isn’t always affordable.

Holistic needs (38 coded responses)

**Survey:** Residents wanted staff and services to ‘see the whole person’ and not just the issue that they are being referred for. Those with overlapping diagnoses often felt that services couldn’t cater for their needs. People felt that services only address needs separately (even if needs are connected) which was not useful for building a long-term sustainable lifestyle which supported their mental health (for example, mental health concerns, financial concerns, relationship breakdown). Ultimately, residents highlighted it is important to assess that person for their specific needs not just performing protocol or addressing one thing at a time.

**Quotes**

“See the person, not just the 'problem'” *(Neurodivergent Male aged 55-64, Reigate and Banstead) 26*

“Allow other areas of my life to be explored, enable a long-term view, open the future.” *(Disabled and Neurodivergent Female aged 55-64, Carer, Elmbridge) 48*

“There needs to be more focus on "wellness" and on a holistic view of people's issues, and helping people build happy and healthy and sustainable lifestyles; and less focus on illness and crisis” *(Neurodivergent Female aged 55-64, Hart) 70*

“Services mostly seem to treat all clients (or potential clients) as if they have reduced capacity or are unintelligent. They don't seem to take the necessary holistic view needed for Recovery to work. They seem to have a fixed idea of what people's needs are and not really listen to people or work collaboratively with them.” *(Male aged 35-54, Carer, Rushmoor) 71*

“Services need to be better at helping people build full and positive and active lives, not just focus on medication and promoting crisis services and dealing with relapses.” *(Male aged 35-54, Rushmoor) 73*

“There are individual therapies for different diagnoses (i.e. trauma therapy for trauma) - but nothing to deal with the overlap of many diagnoses. Meaning you often have to do multiple therapies/groups for each individual diagnosis. Leaving you to piece it all together yourself which is very confusing.” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

A huge gap in the Mole Valley area for Mental Health Befriending. Some kind of structured scheme to support individuals to help them access clubs and local activities on an individual basis is needed. People need hand holding for a while to help them build confidence to get back into the community and access services. Richmond Fellowship used to deliver a very good mentoring scheme but like a back to work scheme. I am not sure if this still runs or not, but this needs to happen for encouraging those that have had CBT for six weeks to engage with local social activities. If a befriending scheme run that helped people access relevant community services i.e. attending the first few month’s sessions with them until they were settled this would help enormously. Just sign posting them doesn't work. *(Female aged 65+, Mole Valley) 221*

Nobody can understand the manner in which we live as a family within our home etc - the details of each and every person are so different and what is a big thing for one person is not material to another *(Disabled Female aged 35-54, Carer, Elmbridge) 254*

**Focus group discussion:** Peer support groups offer an invaluable combination of practical and social support that fits into people’s lives, that they cannot find elsewhere. Residents said that they helped feelings of isolation. Residents wanted more open access to groups, and more help in finding them. Some said that longstanding groups can be cliquey and exclusionary and that groups can be challenging environments to feel comfortable not being judged, but online can offer similar support with optional engagement.

Carers praised wellbeing prescription service due to the relaxed and nonjudgemental demeanour and ability to drop in and out of support whilst offering additional wellbeing services.

# Theme 8: Lack of information (78 coded responses)

Residents primarily searched for information about services online, rather than from their GP or in the community. Residents said that information about access and wait times are hard to find, and that information about services is often out of date. Some people felt overwhelmed by navigating the information and others said they didn’t know where to start to try and access support if they were in distress.

More information (55 coded responses)

**Survey:** Residents want an up-to-date centralised information point that includes accurate eligibility criteria and wait times, and more information on pathways of care. Many people had to do their own research into what is available. People want GPs to have more information about local initiatives and want to be able to easily access information about their own care. People want practical advice about how to get support not just general signposting.

A neurodivergent person suggested a care passport to give practitioners more information about their own needs and wishes. We have now developed this suggestion into a recommendation after further discussion in focus and working groups.

**Quotes**

“Knowing a bit more about the diagnosis process from websites like the NHS website. They just say to go to the GP if you experience this, but they don't lay out how it’s done. I get its hard as its circumstantial, but I fear that when i do eventually go to the GP for help, I’ll forget what i want to talk about as I’m not prepared for the process and I’ll miss so much out that it doesn't get diagnosed/taken seriously” *(LGBTQ+ Neurodivergent Female aged 18-25, Epsom and Ewell) 14*

“More advertised information in the community.” (*Female aged 65+, Waverley) 2*

“More information when you ask for help about what happens next. For e.g. “you will be discussed at MDT and then contacted”. *(Disabled and Neurodivergent Female aged 35-54, Carer, Rushmoor) 69*

“There does not seem to be any central repository of information about local services so it's hard to know where to find consistent, comprehensive, and up-to-date information.” *(Male aged 35-54, Carer, Rushmoor) 71*

“Websites are incorrect, Surrey has no idea of how far Guildford to Spelthorne is. Parents share better resources and advise” (*Disabled and Neurodivergent Female aged 26-34, Carer, Spelthorne) 74*

“I do not believe organisations are well informed about other services in place to meet diverse needs! Often, they do not know where to signpost you to or make any referrals. I have had to do all the research to help myself which has been arduous and unhelpful when trying to concentrate on my own recovery” *(Disabled Female aged 35-54, Waverley) 101*

“Well-informed organisations, accessible and easy to read support. I find it difficult to navigate where this support is unless I do a lot of research.” *(Disabled and Neurodivergent Black Caribbean Female aged 18-25, Runnymede) 102*

“One point of contact (where everything works behind the scenes to correct support) rather than having to do it myself (and jumping through numerous "hoops" beforehand). A centralised system (mental health, GP's, hospitals, community care etc) of basic information containing my wishes (doesn't have to be the reason, just what I can and can’t handle - and for it to be respected, not questioned). … Everything to be more streamlined (clear and concise) with easy access and understanding. Services, therapy options, community support, information etc (too many options/so much information make it confusing, especially when you're struggling already).” (*Disabled and Neurodivergent Female aged 26-34, Waverley) 109*

“Lots of charities offer support in many forms - but CMHRS does not seem to pass on this information to families. There should be central pool of information shared with patients and families - to avoid each new family having to discover what there is which takes time and effort when that is hard. Also, so inefficient.” *(Female aged 55-64, Carer, Waverley) 133*

“Having a centre hub of information and support services available (online)”*(Female aged 35-54, Carer, Reigate and Banstead) 153*

“A centralised website or organisation that I could contact, which could direct me to the most appropriate services.” *(Disabled and Neurodivergent Male aged 18-25, Tandridge) 116*

**Focus group discussion:**

* Leaflets in GP waiting rooms are often out of date and primarily about physical health.
* Leaflets promoting mental health services could be delivered to every household.
* Safe Haven information is hard to find with different websites stating different opening hours.
* There is a lack of information about how to make appointments with certain services.
* Professionals should provide information without needing to be asked and allow the person to ask questions to ensure they understand (one person was told to “just google it”).
* The lack of information about appointments (location, availability/cost of parking, and sensory environment) can cause anxiety.
* Signposting to other services is inconsistent, and information is often out of date.
* It can be hard to find what you are looking for when searching for information online or provide so much information that it becomes overwhelming.
* Carers want more information about their child or loved one’s care, the wider context around it, the “Triangle of Care” and services/activities that are available to them.
* People don’t research information on conditions and services until they need it, by which time they may be too busy caring for someone to do the research and need someone else to provide them with the information.
* Professionals would benefit from having more information about people’s triggers and coping strategies.

Not knowing what support is available (23 coded responses)

**Survey:** Residents often don’t know where to start looking for support and can become overwhelmed by navigating the information. Residents comment that conversations with staff can go round in circles when you don’t fit in the boxes of what is available. There is a want for central access point with an emphasis on needing local information as the number of options available can get confusing.

**Quotes**

Question 1: Who would you reach out to if you were struggling to cope with day-to-day life at any time, for example, you felt very worried or sad or had stopped going out as much as usual?

“Not always aware of services available in locality” *(Neurodivergent Female aged 35-54, Reigate and Banstead) 77*

“Not knowing what is available” *(Female aged 55-64, Mole Valley) 82*

“If one organisation could clearly explain every organisation providing help in the area it would be much easier to access the right assistance” *(Male aged 65+, Carer, Guildford) 91*

“Being confused by the number of organisations and helplines that are out there.” *(Disabled and Neurodivergent Male aged 18-25, Tandridge) 116*

“Not knowing what services might be available / appropriate for me” *(Female aged 35-54, Surrey Heath) 146*

“Not knowing who to ask” *(Neurodivergent Male aged 55-64, Epsom and Ewell) 193*

“Not knowing who to turn to” *(Disabled and Neurodivergent Male aged 35-54, Elmbridge) 251*

“Access and knowledge of support services / overwhelmed NHS” *(Female aged 35-54, Carer, Reigate and Banstead) 153*

Question 2: What do you feel are potential barriers to you seeking support when you are struggling to cope with day-to-day life?

“More obvious care pathways for people experiencing MH problems. People are often not motivated to seek help, are unsure of the best way of getting it, and faced with a complex network of different services. It would be useful to have an initial point of contact who could signpost to GP, IAPT, social prescribing, wellbeing service etc” *(Disabled and Neurodivergent Male aged 55-64, Carer, Hart) 85*

“Understanding what support is available for being partially sighted” *(Disabled Female aged 35-54, Reigate and Banstead) 87*

“Knowing where and how to access services. This could be through advertising i.e. posters or leaflets at GP surgeries, hospitals, libraries, CAB, even supermarkets.” *(Female aged 55-64, Carer, Elmbridge) 120*

**Focus group discussion:** Older adults may be less likely to search for information online and could benefit from seeing posters in community locations.

There’s no signposting to online groups (e.g. Facebook), carers groups aren’t widely signposted and rely on word of mouth, professionals need better knowledge of existing services, people need support on how to access services, diagnosticians need good signposting knowledge to understand wider system.

# Theme 9: Choice and Autonomy (76 coded responses)

Residents want to have a say in their treatment, have a choice of how they access services and contact organisations, and have access to all their information.

Transparency about care decisions, corrections of errors and notes, and understanding individual needs for reasonable adjustments are key to supporting individual needs.

However, across the demographics of survey respondents there wasn’t always a clear consensus of how each group wanted to access services, with different individuals, including those in similar situations, often wanting different things.

Suggestions included consistent workforce who could understand and accommodate them, with a focus on autonomy and confidentiality.

Autonomy (4 coded responses)

**Survey:** Residents want their care to promote autonomy and choice. This includes transparent decision making, clear plans, seeing and understanding patient notes, being able to contribute to and correct patient notes, open communication, having a say in your treatment, and being given all the options (not just put on a path of standard practice). One person said that they felt like they weren't a part of the GPimhs discussions about their treatment.

**Quotes**

“In my experience, too many folks are too ignorant of the fact that us AuDHDers often know what we need, and we get treated like infants far too often; even the standard practice of using ABA and/or PBS removes agency from us. I worked in Adult Social Care for over 6 years and despite their "specialising in Adults with LD, the senior staff clearly knew less than I know. There is such a reluctance to give any credence to our lived experiences.” *(Neurodivergent Male aged 35-54, Woking) 185*

“Sharing referral and assessment and care plan products with clients so that we understand what has been said about us, can contribute to make these more accurate and effective and can correct errors” *(Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

“The service is not accessible. It’s not transparent how decisions are made, and referrals and people (are) left to wonder what’s happened” *(Disabled and Neurodivergent Male aged 65+, Carer, Woking) 215*

“Being treated like a human being, not being given a diagnosis that I strongly disagree with and find harmful, being listened to (instead of judged) when I speak about a service failing me, effective diagnostic tools to find what IS going on, neurodivergent based support, support in boundary setting, text communication rather than phone calls. And open and honest communication/transparency about the options that are available.” *(LGBTQ+ Disabled and Neurodivergent Female aged 18-25, Mole Valley) 239*

**Focus group discussion:**

* Person centred care should consider the needs of the individual, rather than sticking to the standard treatment plan for that diagnosis.
* Being offered choices about therapeutic interventions is empowering and allows the person to select the option most suited to them.
* People want to feel involved in decisions being made about their care, such as submitting a statement to be considered at an MDT meeting rather than feeling decisions are being made behind their back by people who don’t understand the impact.
* People want to be able to see an accessible summary of what has been discussed and decided in appointments and correct any errors.
* If professionals explained how they have reached decisions about medication or therapeutic interventions, it would allow the person to challenge any incorrect assumptions and point out factors that have not been considered.
* People want to be able to speak to the person in the GPimhs or MHICS team who has prescribed their medication.
* People want to be asked what reasonable adjustments can be made to support them. Examples include a person with sensitivity to light feeling disempowered when a clinician assumed and turned off all the lights in a consultation room without asking them if that would be helpful, and someone being denied a request to turn off a radio in a waiting room.
* Understanding that reasonable adjustments are not just “someone trying to get their own way” by genuinely listening to someone’s needs and working with them in a constructive way.
* One person feels staff pay more attention to their needs if they show their National Autistic Society card, as “it looks official”.

Choice (16 coded responses)

**Survey:** Residents wanted more choice of service types they could access (for example, one-to-one or group settings). Others were frustrated by being offered support that wasn't local to them, was too short, or that they found that they didn’t meet the access requirements for.

**Quotes**

“Not enough information to make comparisons to my treatment which has been very good.” (*Female aged 65+, Waverley) 2*

“If there was more variety of therapy that was accessible!” *(Female aged 18-25, Reigate and Banstead) 15*

“Lack of appropriate support” *(Disabled and Neurodivergent Middle Eastern Male aged 35-54, Guildford) 44*

“Local and timely services.” *(Male aged 55-64, Carer, Reigate and Banstead) 60*

“I’ve asked for holiday clubs for SEND in Spelthorne and they reply with things in Guildford.” (*Disabled and Neurodivergent Female aged 26-34, Carer, Spelthorne) 74*

“Better advice on psychiatric medicine. My GP doesn’t know enough about changing my medication and my referral to CMHRS was refused. GPimhs discuss my medication, but I am not part of the discussion.” *(Disabled Female aged 65+, Guildford) 107*

“Self-referral to a wide range of options including voluntary sector. Greater awareness of help that is out there.” *(Female aged 55-64, Mole Valley) 135*

“Having a variety of options for activities available - mainly face to face to allow for a change of scenery! Allowing my carer along who is my advocate” *(Disabled Female aged 35-54, Waverley) 149*

“A variety of options available as not one thing suits everyone!” *(Disabled Female aged 35-54, Carer, Waverley) 161*

“Greater support, more choices available, small residential spaces for young people to 'recover' with appropriate support.” *(White/Asian Female aged 18-25, Reigate and Banstead) 182*

**Focus group discussion:** There is a lack of knowledge about the Right to Choose service for Autism assessments. CBT is not always appropriate for everyone and there is a feeling mental health services sometimes take on a ‘one size fits all’ approach.

Confidentiality (8 coded responses)

**Survey:** Three individuals were highly concerned about disclosure, information sharing and the protection of their data. Another said that because they work in the NHS and know too many people, it stops them from seeking support.

**Quotes**

“Making the complaints process easier. Talking to a complainant swiftly and not being so rigid in agreeing to erase data at the earliest opportunity to avoid epistemic violence.” *(Disabled Female aged 35-54, Carer, Surrey Heath) 39*

“Work disclosure constraints inhibit full and frank conversation.” *(Male aged 55-64, Carer, Reigate and Banstead) 60*

"Working for NHS [is a barrier] (know too many people in services)." *(Female aged 55-64, Mole Valley) 135*

Preferred contact method (32 coded responses)

**Survey:** Residents had diverse preferences for accessing appointments, services, and communicating with practitioners, including online, over the phone, face-to-face, text, local options, advocate accompaniment, and social media support groups.

**Quotes**

I don't like speaking on the telephone so would avoid any telephone support services *(Neurodivergent Resident aged 35-54, Mole Valley) 40*

Ease of travel (i.e. bus pass) and the ability to access support remotely, such as on Zoom type meetings, texts and by email. *(Disabled and Neurodivergent Female aged 35-54, Rushmoor) 112*

I am in a constant struggle with my GP's office to get an appointment in a way convenient to me - I live with hypersomnia on a sedative medicine, and struggle to book a same day appointment before 12pm, as expected by the surgery. I struggle to get doctors to listen to my concerns about my physical health, despite valid grounds for concern. Consistently given phone appointments by my GP's office despite my dislike of them. *(Disabled and Neurodivergent Male aged 35-54, Mole Valley) 174*

Being able to book appointments online with the GP. Having a well-being Centre in my town. *(Disabled Female aged 35-54, Surrey Heath) 206*

**Focus group discussion:** Neurodivergent people often find using the telephone very difficult and would prefer to contact services via email or text message and have appointments online or face to face.

Online appointments avoid the anxiety of travelling and attending in person and allow people to use closed captions if they find written communication easier to process.

Some older adults said they prefer to be contacted by telephone rather than email or text message, and do not have the technology to fill in forms or attend appointments online.

If a telephone appointment is arranged, it is important for the call to take place at the scheduled time as waiting can cause anxiety.

Greater understanding and empathy are needed if carers miss a phone call due to urgent caring responsibilities.

When appointments can only be booked online by filling in forms, it can be difficult for people with executive dysfunction to ensure they answer questions in the correct way to clearly explain the severity of their symptoms to get the right support.

Comments about workforce (16 coded responses)

**Survey:** Not very experienced or well trained, only listen from a professional perspective, bad relationships. One person suggested staff need support in how to make reasonable adjustments for mental ill-health. There are concerns about high staff turnover reducing continuity of and quality of care. Praise for charitable organisations including Action for Carers and Citizens Advice Bureau.

**Quotes**

“Experience of talking to counsellors who are never really able to listen from outside the perspective of their own professional knowledge, or dig deep enough to try to get to the real issues” *(Neurodivergent Male aged 55-64, Woking) 230*

“I have a care coordinator who I never hear from, and I don’t have a therapeutic relationship with” *(Disabled and Neurodivergent Female aged 35-54, Epsom and Ewell) 108*

“Contact with the individuals from community team had been good.” *(Disabled and Neurodivergent Female aged 65+, Carer, Runnymede) 104*

**Focus group discussion:** Some people criticised the attitudes of staff, in particular more senior clinicians, as lacking empathy, being judgemental, and overlooking a person’s background or context.

There was frustration when people attended appointments with professionals who had not read their files in advance, including from autistic people who had to explain their Autism and how that impacted them rather than discussing their mental health concerns.

Several autistic people reported professionals laughing at them when they said something unexpected.

It was noted that professionals should always introduce themselves, as people might not remember names and faces from previous appointments, especially neurodivergent people.

There is concern that some professionals see training as a tick-box exercise to reduce blame, rather than an opportunity to understand how to better support and treat people.

Mental health teams would benefit from specialists in each mental health condition and in neurodivergence.

Recovery College courses could be improved by being delivered by specialists with in-depth knowledge and experience, rather than a team that “know a little about a lot of subjects”.

# Theme 10: Connected Systems (56 coded responses)

The challenges faced by individuals utilising various service systems, including charities, public services, and long-term physical and mental health services, highlight the complexity of managing care paths across different systems for both patients and caregivers.

Connected systems (21 coded responses)

**Survey:** Many disabled residents and carers said that they needed mental health and physical health systems to work together and link up programmes of care. Signposting and awareness between different types of services needed to be improved for commonly co-occurring conditions (for example, eating disorders and Autism, learning disability and mental health, learning disability and neurodivergence, neurodivergence and sexual assault).

**Quotes**

“Clear pathways; online access and referral, effective onward referral and assessment; shared data across orgs so that assessment is dynamic and ongoing” *(Neurodivergent Transgender Female aged 65+, Carer, Epsom and Ewell) 213*

Disagreement with Statement 3 “I feel that organisations are well-informed about issues relating to diverse needs” and Statement 4 “I feel that organisations are well-informed about what other services are available to meet diverse needs”.

“Mental health and physical health do not talk to each other or even on the same computer systems to bring up medical notes!! Mental health do not understand physical health and physical health does not seem to understand how to help those with mental health issues and how these may manifest when you need medical treatment!” *(Disabled Female aged 35-54, Carer, Waverley) 161*

“There doesn't seem to be a joined-up approach across organisations” *(Female aged 35-54, Carer, Reigate and Banstead) 153*

“There are lots of organisations out there doing different things but often not joined up or aware of each other” *(Female aged 35-54, Surrey Heath) 143*

“There seems to be no 'joining up' of services for, say, people with both mental and physical disabilities/conditions, despite both having a joint impact and interacting with each other.” *(Disabled and Neurodivergent Female aged 35-54, Rushmoor) 112*

Agreement with Statement 4:

“Cross-referencing and awareness of other organisations is really good” *(Female aged 35-54, Runnymede) 118*

**Focus group discussion:** There is a need for joined up services to provide continuity of care, with an awareness that it is hard to manage both physical and mental conditions, and that people with mental health conditions may also have undiagnosed or diagnosed neurodivergent conditions.

Physical disability (17 coded responses)

**Survey:** Several disabled respondents said that there is a poor understanding of how sensory loss and physical disability impacts mental health. Conversely, one respondent expressed frustration about professionals assuming poor mental health issues due to physical disability. Residents feel left alone to cope, judged by others thinking they are over-exaggerating, and that people don't understand/aren’t well informed about disability, especially brain injury, in mental health services.

**Quotes**

“Some services can't deal with mental health and physical disability” *(Disabled and Neurodivergent Female aged 26-34, Guildford) 27*

“It can be tricky to access some forms of mental health support when you are limited by physical health issues.” *(Disabled Female aged 26-34, Guildford) 28*

“Disability - physical disability is not considered by mental health professionals or the buildings are often not accessible. Physical health services do not understand or have the correct skills to cope with someone who has a mental health condition. There is no link up between physical health and mental health!! Age does not help as you are seen as a young person who should be able to do more!!” *(Disabled Female aged 35-54, Waverley) 101*

“Because I have physical health needs that are complex, people made a lot of assumptions that these conditions must be making me depressed. This wasn’t the case.” *(Disabled Female aged 35-54, Carer, Surrey Heath) 39*

“My husband has MND [Motor Neurone Disease] and a lot of people do not understand the speed of this disease” *(Female aged 35-54, Carer, Spelthorne) 78*

“I have ME/CFS [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - a long-term condition with a wide range of symptoms, the most common of which is extreme tiredness] and it’s still seen as 'all in the mind' with no research or further investigation done” *(Disabled and Neurodivergent Female aged 55-64, Carer, Mole Valley) 90*

“My experience is that there are few people who are properly informed about disability” *(Female aged 65+, Carer, Elmbridge) 92*

# Key takeaways

## Carers

There is a lack of provision for localised carer respite with long waiting lists.

Services and commissioning need to distinguish between mental health carers, neurodivergent carers, and physical health carers as each group has different needs.

There are concerns around older adults who are carers, the support for them, and resources for when carers are unable to care for their person.

Out of the 91 carers who responded to the survey, 51 were also disabled.

## LGBTQ+

Organisations and residents assume that LGBTQ+ needs are already being met, however there is a lack of specific support for LGBTQ+ experiences and needs and established engagement between LGBTQ+ community and the system is non-existent.

Some survey responses included prejudice, homophobic, and transphobic views.

It was difficult to find forums and meetings where the team could engage with the community, with the majority of LGBTQ+ engagement coming from Pride in Surrey.

## Men

There aren’t as many casual spaces for men to socialise with other men in the community as there are for women. Existing sports/interest clubs tend to be formal with hierarchies and high cost.

Discussions leaned more towards – if men aren’t seeking support, how can we target service awareness at loved ones instead?

## Neurodivergent

Greater understanding of Autism is needed amongst mental health professionals, including awareness of the challenges autistic people face, how autistic people think and communicate including difficulty identifying emotions, how masking impacts a person’s sense of identity, and the prevalence of trauma caused by stigma, bullying and rejection by parts of society.

Autistic people have been denied mental health support, and existing support is being withdrawn from people once they have an Autism diagnosis, leaving them facing the same difficulties but with no support to help them cope, even when they present with mental health needs which are not rooted in their experiences as an autistic person.

Clearer communication is needed, including providing comprehensive written information about appointments, the exact location and what to expect, what to do between appointments and what will happen next, and methods of contacting services by email or text message.

A longer-term support offer with the same person each time would allow people more time to process information, to develop a routine and build trust in order to unmask and disclose personal information, and review and assess that person’s progress.

Neurodivergent residents consistently raised that CBT talking therapies are not effective in their current form. Autistic people often have alexithymia (difficulty recognising and identifying emotions) and may lack the cognitive flexibility to challenge their thinking patterns, making this therapy style ineffective and inaccessible as CBT is based on the interactions between thoughts, feelings, and emotions.

## Older Adults

Whilst mental health support is not specifically labelled, VCSE organisations are already utilising place-based holistic community support and essentially doing GPimhs/MHICS style signposting.

However, they need statutory support to continue this work to a high standard and it is better for each area to lead their own services as they can be tailored to the local population.

There is a lack of age-tailored mental health forums like ATLAS or Amplify Mindworks.

Services in the community focus on loneliness and Dementia

Social activities are attended mainly by women, even when marketed to all.

## Young Adults/University Students

The transition from under 18 to 18+ is a huge time of change for all young adults, they are also being asked to do everything on their own for the first time with little to no guidance. The assumption ‘you’re old enough now, you should know’ can negatively impact mental health.

Young adults commented on the lack of safe spaces, and awareness on how to access support. There is a want for local young adult community groups and spaces. Young LGBTQ+ people wanted to access mental health services which addressed gender identity related issues.

Issues affecting university students’ mental health include:

* social media.
* pressure from family, peers, culture, and society.
* isolation and loneliness.
* lack of structure (in comparison to non-higher education).
* multiple comments about not yet signing up with pharmacy/GP in university area.
* difficulties finding information.

The UCL conference the team attended second the issues raised by neurodivergent people about CBT talking therapies:

* At least 50% of adolescents referred to CYP mental health services have language difficulties.
* 71% of those are in the Youth Justice System.

## Co-production

## True co-production is a lengthy and continuous process. Whilst this project leaned more into co-design, all three project officers had current lived experience with the mental health system, LGBTQ+ experiences, neurodivergent experiences, young adult/university experiences, caring responsibilities, and supporting older adults.

Initiatives that include co-production, require continual support from system professionals and sponsors which can be a challenge when the system is struggling with workforce and resources issues.

However, there are benefits to involving lived experience experts in decision making and it’s important to recognise and reward their input and time accordingly.

**Quotes from working group participants**

How did you find being involved with this IMHN project?

“I felt welcomed, valued & heard. The groups were very well organised from start to finish. The reminders & instructions were clear, unambiguous & timely. The sessions were friendly, kind, compassionate, structured & well administered.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Hart)*

“I enjoyed the way the groups worked, and I also enjoyed the discussion it enabled with other people with similar experiences - I learned so much from other people’s experiences and viewpoints and I'm really grateful for that! It felt like an incredibly productive use of my time, being able to contribute to such meaningful discussions and feel listened to is something that some similar groups haven't managed to achieve!” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford)*

“It was incredibly empowering, and I am so grateful that I was able to be a part of this project.” *(Disabled and Neurodivergent Female aged 35-54, Hart)*

“It was a bit hit and miss as many people had a story to tell and I felt at times this was an offloading process and we were somewhat missing the point.” *(Disabled Female aged 55-64, Carer, Reigate and Banstead)*

Other comments about this project:

“I very much value the opportunity to share my lived experiences for the benefit of others. I also really enjoyed meeting other people from a wide range of backgrounds.” *(Disabled and Neurodivergent Female aged 35-54, Carer, Hart)*

“I find this project incredibly interesting, and I have enjoyed participating in the discussions about recommendations. I am really grateful to have been able to join in! Thank you!” *(LGBTQ+ Disabled and Neurodivergent Non-binary person aged 18-25, Guildford)*

“I didn’t know my lived experience insights could actually be helpful. The focus groups have made me feel my mental health struggles can have a positive impact.” *(Disabled and Neurodivergent Female aged 35-54, Hart)*

# 

# Recommendations

**Implementation of these recommendations:**

We recognise that the current financial landscape will limit the ability to implement many of these recommendations, however, we hope the mental health system will think innovatively as to how the suggested changes can be implemented within the current structures to create a more accessible offer for residents of Surrey and North East Hampshire. For recommendations for which no funding solution can currently be found, we hope commissioning teams from the ICBs (Surrey Heartlands and Frimley) and Surrey County Council (SCC) are maintaining a forward plan of need, knowing which gaps in the system exist which these recommendations can be added to, and will consistently review and add to the Joint Strategic Needs Assessment (JSNA) based off local research such as this report which highlights areas of future commissioning needs.

## Information

1. Review existing good practices of information sharing happening in the system and offer a standardised approach across the area for information sharing before the appointment. For example, who the clinician is, what to expect i.e., ‘this appointment is to introduce the service and assess your needs’, including a way to submit accessibility needs.
2. Review existing support directories, and if those are not adequately meeting people’s needs, then consider alternative options. For example, there is an assumption that Surrey Information Point fills this need, although people find it difficult to navigate, often out of date, and not relevant for MHICS teams in North East Hampshire.
3. Research existing community magazines in each district and borough. Use their lessons learnt to provide support to the residents who create these and support the expansion of more local community magazines that can include information about mental health and wellbeing support across more areas in Surrey and North East Hampshire.
4. Contact people on GPimhs/MHICS waiting lists and other community mental health services to update on waiting times. Community Connectors should keep information about waiting length for signposted organisations and maintain this list to increase transparency on speed of service upon referral.
5. Promote the availability of mental health services to support loved one’s mental health needs as well as the primary client, which could include providing information to help loved ones understand the primary client’s diagnosis.
6. Expand targeted marketing of mental health services to include those within the primary client’s support system as residents are less likely to independently source support for themselves when they need it and could be encouraged to do so by friends and family.
7. Provide information prior to the first appointment about the clinical and community staff the client will see. This could be either in the appointment communication or by directing to staff profiles hosted on service provider or SABP websites. We recommend staff profiles include a person’s name, role, photo, and suggest including pronouns, and if the professional is comfortable, other relevant information, such as if they are neurodivergent, to allow clients to understand if a professional has shared lived experience.

## Improving Current Service Offer

1. Include LBGTQ+ services as standard practice when signposting people to support.
2. Include services for parents, siblings, carers, loved ones as standard practice when signposting people to support.
3. Review commissioning of LGBTQ+ services within Surrey and North East Hampshire as there is currently a lack of tailored support with a need to create welcoming spaces for LGBTQ+ specific experiences.
4. Improve the relationship and communication between physical health care providers and mental health care providers at primary and secondary levels to increase holistic approaches to care across the Surrey and North East Hampshire system that look at individual need and the whole person.
5. Community Connections, peer support providers and commissioners to review geographical boundaries of peer support meetings and work together to ensure equality of offer across the area.
6. Signpost people to Community Connections peer support groups, or other commissioned providers, whilst clients are on clinical waiting lists to help bridge the gap and help prevent bounce or escalation of need.
7. Community Connectors and GPimhs/MHICS Lived Experience Practitioners should have a list of minority ethnic specific support including nationwide services, especially ones with access for non-English speakers.
8. Community Connections providers to work with minoritised ethnic communities to co-design mental health peer support groups with specific provision by age, gender, religion, language etc. For example, a group specifically for older adult Muslim males, new mothers, or Nepalese speakers. These should sit within spaces already used by those communities. Many residents felt they wanted groups of people who understood their experience of living in Surrey and North East Hampshire and were at similar stages of life. Residents who do not have English as their first language find it extremely difficult to use mental health services, however peer support provision could be established within the area in non-English languages which work with communities in collaboration with Community Connections providers who have knowledge and experience of offering mental health support.
9. Update the online information SABP has about LGBTQ+ specific issues (including gender related issues) to ensure that the signposted information includes both local and national support services.
10. Identify and promote community created spaces that act as safe spaces for people not in crisis but with wellbeing needs to help tackle isolation e.g. volunteering opportunities, Women’s Institute, Libraries, Men in Sheds, Andy’s Man Club, Scouting and Girl Guides, Sports Clubs.
11. Review how information about newly commissioned or changed mental health support services is shared with professionals across the system – especially the GPimhs/MHICS Community Connector professionals – and review how key information websites are accurately maintained.
12. Offer a variety of therapeutic options so the most effective approach can be identified, as every individual’s needs will be different. Recognise that some interventions can be inappropriate for certain people, for example many autistic people feel CBT does more harm than good, unless specially adapted for them. Educate people on the various options available, to empower them to choose what is most suitable, and promote a more holistic approach to mental health.
13. Mental health services should hire highly trained Autism specialists and practitioners with lived experience of neurodivergence, who can understand the person’s context without them needing to explain their neurodivergence. This will help improve trust and engagement, increase insight into how neurodivergence and mental health are interconnected, and the challenges people face. Lived experience insight will also help make sure that support or therapy options are appropriate for neurodivergence needs.

## Appointment and Access

1. Review the sensory environment of facilities (waiting rooms, meeting rooms etc.) with awareness of lighting, sound, etc. Identify places where people could be offered a quiet, low sensory waiting option, such as in SABP’s newer buildings.
2. Train reception staff to recognise when people are uncomfortable in the waiting room environment, how to support and offer appropriate reasonable adjustments, and increase awareness and sensitivity of people’s needs.
3. Explain the purpose of Multi-Disciplinary Team (MDT) meetings as standard (when people have capacity and/or explain to their carer), including when the outcome of the meeting would be discussed with the individual. Support anyone who wishes to provide more information about themselves to produce a written statement which could be read out on their behalf.
4. At the end of an appointment, summarise key discussion points and actions with the client with the opportunity to add or correct details. Allow the client to receive a copy of these action points and takeaways should they wish to.
5. Using the existing learning disability care passport by Surrey County Council (SCC) as a starting point, develop a general care passport for physical and mental health clients including reasonable adjustments, support system, history, medication etc. Signpost people to this before their appointment to support them to access the care they need.
6. Offer appointments in person, online or on the telephone so the individual can choose the option that best suits their needs. Online appointments may be less stressful and anxiety provoking for autistic people than travelling to attend in person or coping with a phone call and allow the use of closed captions for people who prefer visual communication or have hearing loss but may be inaccessible to people without the necessary skills, confidence or technology.
7. Assess the accessibility of Safe Havens/Harbours and other CMHTP supported services, including actively making sure spaces are neurodivergent friendly and considering public transport routes during commissioning and planning.
8. Review services to ensure each has a clear pathway for communication with the service, offering a variety of methods (text, email, phone) with clear expectations about time frames when services will respond. Include clear contact processes for amending inaccurate notes and appointment changes/cancellations.
9. Map the existing offer of mental health and wellbeing services outside of conventional working hours (Monday to Friday, 9am-5pm) and highlight absent provision in each geographical area or clinical type.
10. For neurodivergent individuals, the GPimhs/MHICS standard offer of 4-6 weekly appointments may be too brief. Longer-term support with sessions every fortnight or month and extended appointment lengths are recommended to allow for additional time to process information and ask questions to clarify understanding.
11. Offer neurodivergent individuals short follow up appointments or individual emails for addressing questions that come up after they have had time to process their appointment.
12. Ensure up-to-date information is available about post-suicide attempt support pathways so that relevant information can signposted to and shared with individuals at that time.
13. Where possible, endeavour to match clinicians with patients based on their shared experiences to provide more effective care as shared experiences can help people understand each other better and build trust quicker, i.e. clinicians from minority ethnic cultures or neurodivergent.

## Carers Support

1. Distinguish between mental health carers, neurodivergent carers, and physical health carers when commissioning services as each carer type has different support needs and experiences.
2. Carers assessments need to be undertaken consistently by professionals once a carer is identified. Assessments must be clear and concise with the outcomes followed through and monitored by a named professional, service, or organisation.
3. Carers assessments must be carried out by professionals with thorough training in showing empathy and understanding for the context of each individual’s situation to avoid making assumptions, as each carer’s approach will be different depending on their loved ones needs and challenges.
4. Assign a named organisation responsible for guiding carers through the support process to help reduce carers bouncing around the system unable to find the help they need. This organisation is to be mandatory signposted to when a carer is made known to the system.
5. Carers require more support and increased communication with professionals while respecting patient confidentiality. Carers should be included in pathways, and a consistent named contact professional should assess both the client and their carer/family members. Promotion of Home Treatment Teams and Recovery College is also important.
6. Commission psychoeducation for Older Adult carers and carers of Older Adults to build an understanding about ‘why we care’ and the ongoing capacity and resilience of carers, with focus on adaptability to help avoid people getting locked into co-dependency.
7. A review of opportunities for carer respite in each district and borough should be undertaken, as there is currently no consistent respite offer for carer breaks. Instead, carers are reliant upon charity organisations with long waiting lists.
8. Review long term carer support and the resources available when a carer cannot continue their caring responsibilities. Increase awareness of resources available for care planning for when carers are unable to care for their person.
9. Provide individualised and empathetic support for carers, recognising this may require flexibility, consistency and perseverance in encouraging them to accept it, as keeping carers healthy supports the work of health and mental health services.

## GPimhs and MHICS

1. Review which external roles could triage people for GPimhs/MHICS service other than GPs and allow Community Connector organisations and GPimhs/MHICS Lived Experience Practitioners to directly communicate with the GP when they identify someone in need of the GPimhs/MHICS service to improve integrated working and help reduce bounce when accessing GP appointments.
2. Residents lack clarity on what the GPimhs/MHICS services offer. Clearer communication is required about its purpose, the referral pathway, waiting time, type of mental health support provided, and its non-crisis nature.

**Minoritised ethnicities**

1. Professionals from minority backgrounds should be supported and encouraged into working in mental health services – especially in clinical roles such as therapists or counsellors so people can choose to speak with someone who understands their cultural environment without having to explain the ‘why’ each time.
2. Develop a strategy to reach out to specific communities through mental health ambassadors attending community venues and events to promote services and support, and signpost to organisations.
3. Residents would like more opportunities for Mental Health First Aiders to be trained within minority ethnic communities to spread awareness of mental health, support and signpost people and break down stigma.
4. Ensure professionals record service users’ ethnicity, as this data can be used to understand need and access within minority ethnic communities.

## Unmet Need

1. In the event of appropriate support not being available, professionals are to record ‘needs not met’ to flag the system and feed this information back into the wider system for learning and creating future commissioning plans.
2. Allow people to opt in to be contacted after discharge if their needs were not met and a suitable new service becomes available. Review any cases in which needs were not met after 6 months.
3. Link people to Community Connections newsletters, such as Mary Frances Trust, Action for Carers and Catalyst, as standard. Practitioners should explain what the newsletter is for and support clients to sign up within the appointment time to help streamline the process. These newsletters include information about existing support groups and keep people informed about new offers in their area.

## Training

1. Work with GPs to identify how to support their understanding of mental health and codesign additional bitesize training regarding psychiatric needs and medication, information around the local offer and partnership working across Primary Care and Secondary Care.
2. Partner with LGBTQ+ charities (e.g. Blossom LGBT CIC) to build knowledge and commission mandatory training for workforce to improve inclusivity and understanding.
3. Commission specialist training for mental health practitioners in primary and secondary care in the mental health needs of autistic and neurodivergent people, co-designed and co-delivered by neurodivergent people, to go beyond the basics covered by the Oliver McGowan training, covering:
   * The spectrum of neurodivergent conditions,
   * Considering neurodivergent presentation during mental health assessments, including understanding of masking, stimming, body language and communication differences,
   * The use of augmentative and alternative communication (AAC) for neurodivergent and mental health conditions and consequential communication challenges, including stress induced mutism,
   * Comorbid and cooccurring conditions and diagnostic overshadowing,
   * Recognising burnout, and how this can be exacerbated by conventional treatments for depression if it is misdiagnosed.

## Other

1. Identify a dedicated named lead within the mental health system to build and maintain working relationships with higher education institutions in Surrey and North East Hampshire, including University of Surrey; Royal Holloway, University of London; Merrist Wood College; Nescot College, Farnborough College of Technology and more. Direct working with universities and colleges will increase communication about support and services available to their students in the local community.
2. Establish peer-support groups or forums aimed at the Older Adult demographic (65+), which could also present opportunities to share lived experience to develop services and training. Current commissioned services for this demographic tend to focus solely on Dementia and loneliness, leaving other mental health needs of people in this age group unmet. Collaborating with knowledgeable local community support organisations like Age Concern Epsom & Ewell, Age UK, and faith centres is recommended.
3. Ensure CAMHS leavers are signposted to GPimhs/MHICS with clear instructions on how to access it, to support young adults to find the services they need in a holistic and timely way.

# Glossary

**AAC**

Augmentative and Alternative Communication. This is communicative systems such as objects, symbols, charts, photographs, signing and electronic aids which augment a message and may be alternative to speech.

**ABA**

Applied Behaviour Analysis is a term for interventions that are based on observing and understanding people’s behaviour, identifying why people act in certain ways and how the environment around them could affect their actions. Controversial as interventions range from using encouragement and rewards to intensive behavioural interventions and cruel methods that use punishment. For more information see <https://www.autism.org.uk/advice-and-guidance/topics/positive-behaviour-support-pbs>

**ADHD**

Attention Deficit Hyperactivity Disorder

**ASD**

Autism Spectrum Disorder

**ASPIRE**

Peer support group for autistic adults run by the National Autistic Society. Three of the six groups in Surrey and North East Hampshire closed in 2023.

**Bounce**  
Bounce occurs when a person (and their carers/family): has difficulty getting into services, is passed between services, or is ‘dropped’ by services, has their view as an expert in their own lives disregarded in a way which results in that person’s needs not being met and an accompanying feeling of rejection and/or invalidation or trauma. (Definition from Surrey MHIP)

**BPD**

Borderline Personality Disorder

**CAB**

Citizens Advice Bureau

**CAMHS**

Child and Adolescent Mental Health Service

**Carers**

When this project refers to carers, this is someone who cares for a friend or family member who cannot cope without their support.

**CMHT**  
Community Mental Health Team

**CMHTP**

Community Mental Health Transformation Programme

**CMHRS**

Community Mental Health Recovery Service

**Cognitive behavioural therapy (CBT)**

A talking therapy that can help you manage your problems by changing the way you think and behave. It's most commonly used to treat anxiety and depression but can be useful for other mental and physical health problems. (definition from NHS)

**CPA**  
Care Programme Approach “a package of care for people with mental health problems, including a care-coordinator and a care plan.” *(*Definition from NHS website)

**CPN**

Community Psychiatric Nurse

**Deductive coding**

Creating codes before doing data analysis and applying them to the data.

**Demographics**Refers to the specific characteristics within a population and includes factors such as age, income level and geographic location.

**Frimley Health and Care ICS**The Integrated Care System that covers East Berkshire, Surrey Heath, Farnham, and North East Hampshire.

**GPimhs**  
GP integrated mental health service in Surrey Heartlands ICS.

**Holistic**In the NHS the term “holistic care” refers to a method of providing healthcare that considers the entire individual, including their emotional, social, and psychological well-being in addition to their physical health.

**IAPT**

Improving Access to Psychological Therapies. The old name for NHS Talking Therapies for Anxiety and Depression.

**ICB**Integrated Care Board

**ICS**Integrated Care System

**IMHN (Independent Mental Health Network)**

Network of people (aged 18 years+) living in Surrey and North East Hampshire that have lived experience of mental ill health or care for somebody with mental ill health.

**Inductive approach to coding**

Generating themes from qualitative data/textual datasets.

**MDT**Multi-Disciplinary Team

**MHICS**Mental Health Integrated Community Service in Frimley Health and Care ICS

**PBS**

Positive Behaviour Support “**widely used and person-centred approach to identifying and meeting** a person’s support**needs …** if someone is distressed and at risk of harming themselves or others … based on working with the individual and their support network to understand why someone is distressed, the impact their environment has on them and the best ways to keep them safe and happy.” (Definition from National Autistic Society)

**Qualitative data**

Non-numerical data that is collected and analysed, such as words, images, or observations.

**Quantitative data**Numerical data that can be measured or counted. Often used in research and typically collected through methods such as surveys, experiments, and statistical analysis.

**Reflexive thematic analysis**

Continuous and reflective analysis, identifying, analysing, and interpreting patterns in qualitative data.

**SABP**  
Surrey and Borders Partnership NHS Foundation Trust

**SEND**  
Special Educational Needs and Disabilities

**SPA**  
Single Point of Access

**Surrey Coalition of Disabled People**

User-led charitable organisation that advocates for Disabled people in Surrey and North East Hampshire.

**Surrey Heartlands ICS**The Integrated Care System that is split in four place-based partnerships or Alliances:

Guildford and Waverley; East Surrey; North West Surrey; and Surrey Downs.

**Surrey Information Point**  
The predecessor of Connect to Support Surrey, an online directory of wellbeing, care and support services in Surrey.

**Surrey Minority Ethnic Forum (SMEF)**

“Supports and represents the needs and aspirations of a growing 24.4% ethnic minority population in Surrey. We provide support for over 60 grassroot community groups, build relationships between faith groups, and run projects to help ethnic minority groups across the county.”

**Serious Mental Illness (SMI)**

“The phrase severe mental illness (SMI) refers to people with psychological problems that are often so debilitating that their ability to engage in functional and occupational activities is severely impaired. Schizophrenia and bipolar disorder are often referred to as an SMI”. Definition from UK government.

**VCSE**

Voluntary, Community, Social Enterprise

**VI**Visually Impaired

# Additional Information

You can find the following information linked in the blog post about this project on the Surrey Coalition of Disabled People’s website.

* *Exploring the ways Community Connectors in SABP’s GPimhs and MHICS services map their clients’ needs* report.
* *Pathways to Change* report.
* Online Survey (pdf version)
* Online Survey (plain text version)
* Online Survey (easy read version)

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