Sussex Health&Care

Changing the language:

a guide to language for mental health

Contents:

Introduction

Language has power. It can help a person to feel understood, and validate their experiences, or could make them feel alienated and potentially cause harm.

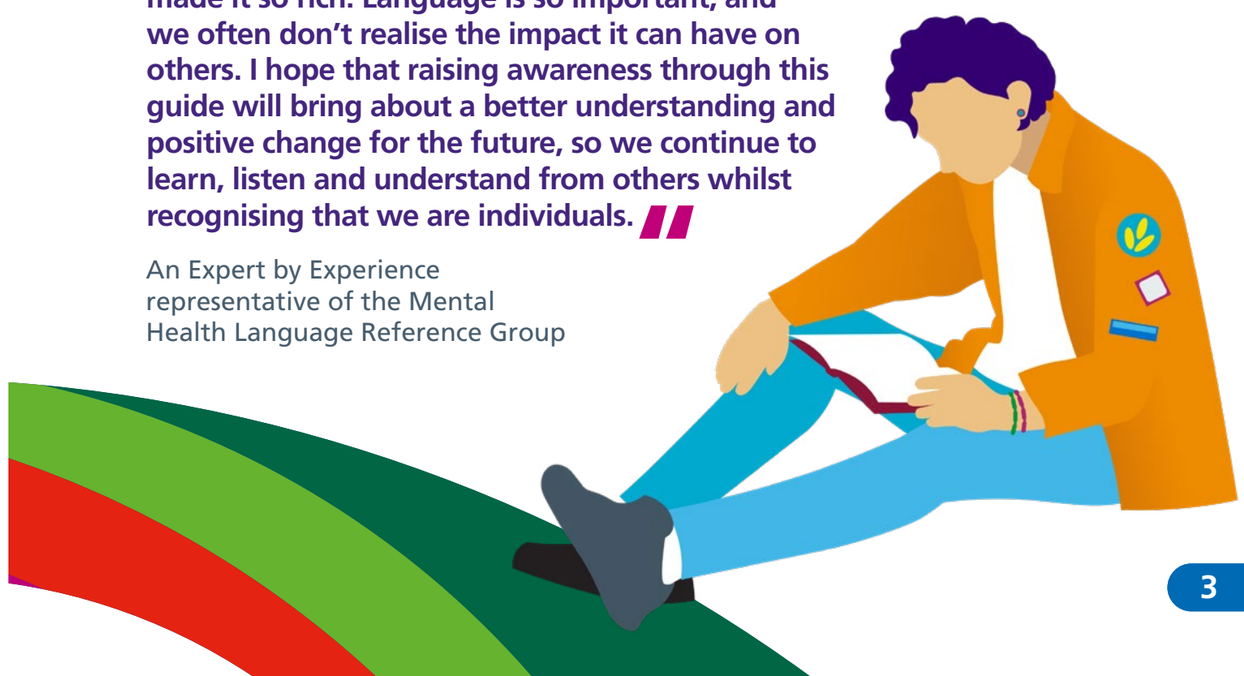
This guide has been developed as a resource to prompt discussion about the language we use in healthcare, to help us to all think about the impact that our words can have and support positive change. Whether it be used in conversations, meetings, training, or during our own times of reflection, the guide is about encouraging supportive conversations, recognising and valuing people's differences and preferences, and creating a culture that benefits everyone.

This guide does not replace other useful language guides that already exist. It brings together local learning from the Changing the Language project in Sussex, and the feedback that we have heard over the last two years.

The Changing the Language Guide has been coproduced by people with an interest in supporting a positive change of the language we use. The group includes people with lived and living experience of mental health difficulties and using services, experts by experience, families and carers, and people working in health and care services across Sussex.

The guide will be regularly reviewed and updated. If you have any questions, comments or feedback, please contact spft.communications@nhs.net.

> **"Whilst co-producing the guide I was able to freely share my own experiences and learnt so much from others in the group. Having such a diverse range of experiences and discussions was what made it so rich. Language is so important, and we often don't realise the impact it can have on others. I hope that raising awareness through this guide will bring about a better understanding and positive change for the future, so we continue to learn, listen and understand from others whilst recognising that we are individuals."**
>
> An Expert by Experience representative of the Mental Health Language Reference Group



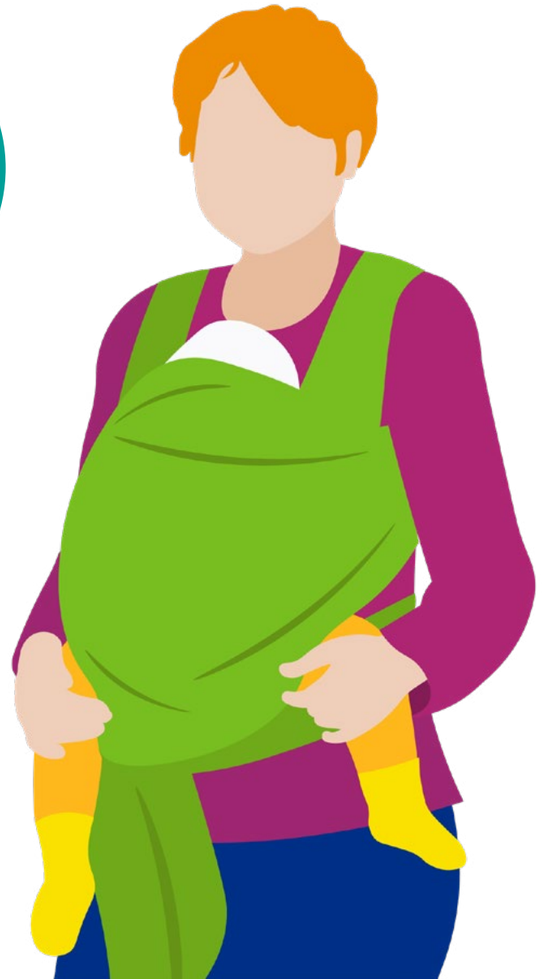
Why language matters and the role of language

In developing this guide, many people shared their experiences of examples when language has had a negative and lasting impact on them. It's vital that we all recognise how powerful language can be and choose to make positive choices and changes.

We have used this wealth of insight to create this guide, reflecting the varied approaches, opinions and experiences individuals and communities have.

It's also worth noting that language can be received differently based on a person's experiences and perspective, so we might not get it right all the time. By inviting people to have open conversations about their preferred language and supporting people to share their language preferences, it can help people to feel safe and recognised when seeking support for their health.

The language we use can also influence others, including friends, family and carers of people who are seeking support. Because of this it's important that we use language, which is positive and supportive, which is not about blame, but instead about what can be done to help the person who is seeking support.



"The language used by mental health services significantly impacts my comfort and trust in the care provided. Respectful and empathetic language makes me feel understood and valued, fostering a safer environment for my mental health journey."

A staff representative
of the Mental Health
Language Reference Group

Cultural differences

Through the Changing the Language project we have spoken with people from a range of backgrounds and cultures and been able to listen to their views and experiences.

We have learnt that in some cultures there are distinct differences in the way that mental health and wellbeing are spoken about. There can also be high levels of stigma, which can result in people not feeling able to seek support from fear of being judged or bringing shame to their family or wider community.

It is however really important to not make assumptions or blanket statements. Whether this be about the sort of language a person would or would not prefer, or of their understanding of the language you are using. For example, one person might prefer more medical terminology to be used when speaking with them, whereas another might prefer the information to be in more simple everyday language.

The best way to approach this is to ask the person what language or words they want to be used and explained, and what works for them. If a person does not speak English, then we should offer an interpreter in appointments and conversations, and have translated information readily available for them.

Healthwatch provide some guidance on this:
healthwatch.co.uk/advice-and-information/2022-05-19/does-nhs-have-provide-interpreter

"Inclusive language to me means using terms that respect all identities and experiences. It's about acknowledging diversity and ensuring no one feels alienated or misunderstood because of how they are described or addressed."

A staff representative
of the Mental Health
Language Reference Group

Content warning

The purpose of this guide is to help us all to be more aware of the language that we use, and the impact that it can have.

Throughout the guide you will find examples of what could be considered inappropriate language, which you may find uncomfortable, offensive, triggering, or discriminating. The examples are included to highlight people's experiences, and to prompt helpful conversations about language use with an aim of bringing about positive change.

Developing a guide

Language principles

Language is ever-changing. We need to ensure that the words and phrases we use are informed by current research, social behaviours, and feedback from our communities.

We have developed a set of principles for you to consider. These are not a list of rules, but instead an opportunity to prompt us all to think about the language that we currently use, and how we could do things differently to ensure an individual's respect and dignity but also quality of care:

- The language that works best is clear, supportive, person-centred, inclusive, and adaptable.
- Clear and simple language that is accessible, relevant and everyone can understand.
- Language tailored to the person in front of you, which recognises a person's preferences and background.

"In the past I have felt uncomfortable and stressed when someone has used acronyms with the assumption I would understand what they were talking about. This affected my ability to fully participate in conversations."

A staff representative
of the Mental Health
Language Reference Group

How to use and apply the guide

Here are some examples of how you might use the guide:

Use the guide in conversations and meetings with your colleagues

Bring the language guide into meetings with your colleagues and discuss it together. Think about how you as a team or service could start to incorporate some of the feedback and learnings in the guide.

Have conversations with people accessing services

Speak to people about the words and phrases they prefer in appointments and record the preferences that they share with you. And even more importantly, adopt the language that they have shared with you in your future conversations with them. This includes with service users, families and carers.

Read and reflect on the guide on your own

After reading the guide, spend some time thinking about the language you use, and whether there are any unconscious biases that you were not aware of that have previously impacted the language you use. Or are there other words you could use that would be more inclusive and supportive?

Use the guide as an ongoing learning tool

Remember, it's ok if you do not always know the right words or language to use in every situation. If you are unsure, ask the person with polite curiosity.

Share the guide

We want as many people as possible to read the guide. Please help us to share it far and wide with your colleagues, contacts, friends and family.

"The language that you use tells me whether or not you see me as an equal partner in a therapeutic relationship. That whilst you might not always agree with me, you will listen, respect and genuinely reflect on my thoughts and views."

An Expert by Experience representative
of the Mental Health Language Reference Group

Changing the language

Reflecting on the language we use

Language is always evolving, so it's important that we are adaptable too. Developing a list of do's and don'ts might seem like it would be helpful, but instead, what if we all made a commitment to reflect on the language that we are using day to day as an ongoing learning process?

Try asking yourself the following questions:

- Why am I using these words?
- Am I using any jargon or acronyms?
- Could these words be harmful or offensive?
- Who am I speaking to/who is the audience?
- Will these words/terms be understood?
- Do I appreciate the implications/impact of the language I am using?

If the above questions have highlighted that there are some words that might not be suitable, try instead to make a conscious effort to adapt and change this language, or reach out to colleagues and groups who could help you to do this.

If you hear language that you feel is inappropriate, challenge this in a way that feels appropriate to the situation, and that you feel comfortable to do so.

> **"Avoiding technical jargon and using clearer, more relatable language would make services feel more accessible and less intimidating."**
>
> A staff representative of the Mental Health Language Reference Group

Examples of how language can be adapted

During the Changing the Language project we have heard many examples of language that has been used which is inappropriate or unhelpful. We wanted to share some direct examples of words we have explored together as a group to show how words can be adapted, or how other options can be given.

These are just three examples, but there are many others:

Assessment	Discharge	What we call people who are accessing services and support
Feedback was that the word 'assessment' can feel like a test you can pass or fail, or that you are being judged.	Feedback was that the word 'discharge' can feel very final - like the door is being closed on you. 'If I need help again, how do I get back in?'	Feedback was that some people do not want to be called a patient or a service user.
Other alternatives could include: • Consultation • Conversation • Information-gathering • Health and wellbeing discussion • Initial appointment • Introduction	**Other alternatives could include:** • Warm handover • Transfer of care • 'Step down' • Transferred back into the care of your GP • End of episode of support	**Other alternatives could include:** • Client • Customer • Service leader • Consumer • Expert by experience • Survivor • Person with mental illness • Person receiving support

Q: Can you think of a word that you use regularly which could be adapted to be more inclusive?

The investigation period and diagnosis

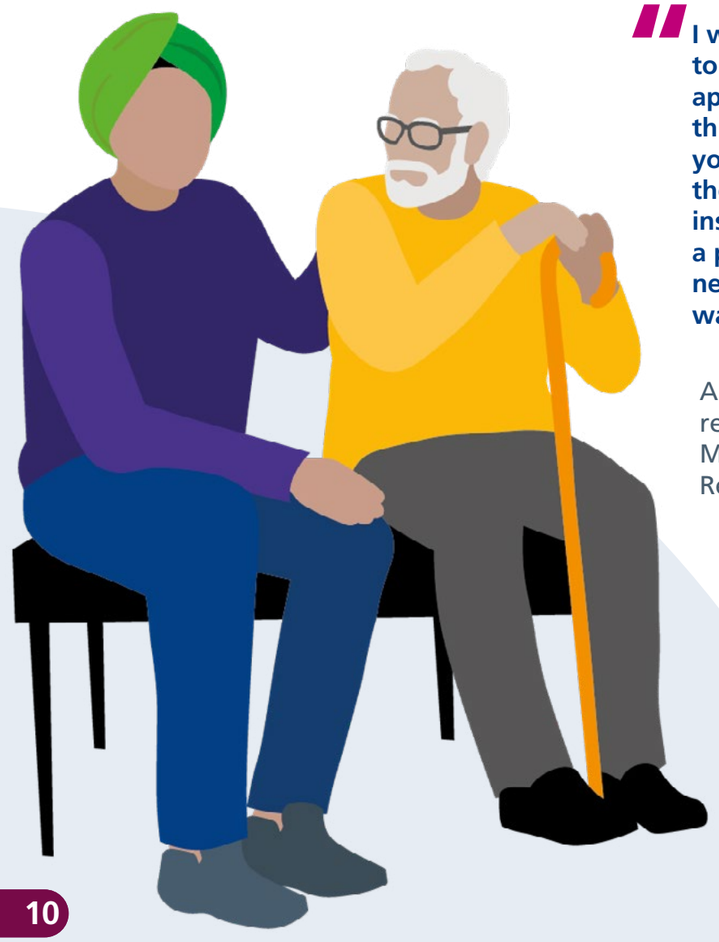
People told us how they felt about language and what had been helpful or unhelpful for them in the past.

When someone is experiencing difficulties with their mental health, and is seeking support, there will be appointments and meetings to find out what has been happening, and to look at options of what might be helpful for them.

In some cases, people might be given a diagnosis, or a name for what they are experiencing. We asked people how they felt about this.

Opinions varied on whether being given a diagnosis is helpful or not - some people described it as being validating, while others did not want the 'label', or the potential stigma that can be attached to it.

It is important if someone receives a diagnosis that we avoid using these terms as a label for a person, or a way to describe them - everyone is different, and a diagnosis only shows part of the individual and not a full picture of all that they are. This is also important to keep in mind when speaking to, or about people, for example in appointments or on the phone.



"I want your language to show me that you appreciate that I know things about myself that you do not, and that the way that you would instinctively deal with a problem might not necessarily be the best way for me to tackle mine."

An Expert by Experience representative of the Mental Health Language Reference Group

Areas for more consideration

In addition to mental health language, there are groups of people who need more thought and consideration in the language that we use, as historically they may have been overlooked.

There are some specific groups that we have chosen to explore and discuss together as a reference group, including people who:

- Speak English as an additional language, or do not speak English
- Have accessibility needs and/or a disability
- Are neurodivergent
- Have been identified as having complex emotional needs, such as a diagnosis of personality disorder
- Have a learning disability.

This is not to say that there are no other groups of people that need further consideration too.

Accessibility needs, and/or disability

It is considered acceptable to use the terms 'disabled people' or 'people with a disability', however it is worth noting that in the social model of disability, it is not someone's condition or impairment that disables them - it's the barriers created by society. Some people may also prefer 'people with a health condition or impairment'. Therefore, wherever possible, use person-first language, i.e. refer to the person first and the disability second.

- Sometimes, you might need to refer to people who are not disabled. In this case use non-disabled person/people, and avoid able-bodied, or normal.
- For some people, their disability can cause them significant discomfort and pain. Avoid phrases like 'suffers from' which assumes the person's experience of their disability and can suggest a sense of hopelessness. Instead, say someone has [name of condition or impairment].
- It can be more positive to refer to 'people with care and support needs' than using the term vulnerable. Labelling people as inherently vulnerable can be disempowering, shifting the focus away from people's abilities to make decisions with support.
- Wheelchair users may not view themselves as 'confined to' a wheelchair - try thinking of it as a mobility aid instead.

Key points to consider when thinking about communicating with disabled people and those with a health condition or impairment are:

- Everyone is different and the language used should be agreed through conversation with the individual.
- Use neutral language, i.e. person who has had a stroke rather than a stroke victim.
- Emphasise abilities, not limitations.
- Ask to find out if an individual is willing to disclose their disability.
- Use language that highlights the need for accessibility rather than the presence of a disability, i.e. accessible toilet, accessible parking, assistance dog, assistive technology.

Deaf and hearing loss

People who are deaf, have hearing loss or are hard of hearing will not usually describe themselves as having an impairment. Many deaf people whose first language is BSL consider themselves part of 'the deaf community' – they may describe themselves as 'Deaf', with a capital D, to emphasise their deaf identity.

Visual impairments, sight loss and blindness

Those with visual impairments may refer to being blind, sight impaired, partially sighted, or visually diverse. The term "visual impairment" is used to describe sight loss that cannot be corrected using glasses or contact lenses. The word "blindness" is commonly used to describe total, or near-total sight loss.

Useful resources:

- **Government guide to inclusive language about disability**
- **Royal National Institute of Blind People (RNIB): Creating accessible information for those with sight loss**
- **Royal National Institute of Blind People (RNIB): Communicating with someone who is deaf or has hearing loss**

Complex emotional needs, such as personality disorder

We recognise that the term 'complex emotional needs' can be controversial and there is much conversation and debate happening locally, nationally and internationally, as to whether the term 'personality disorder' is a valid diagnosis. We are including a section on this in the guide as it is a term which is currently used in Sussex Partnership NHS Foundation Trust. We will continue to review the contents of this guide and update it as language around this develops.

When researching and writing this section we heard from people about the significant levels of stigma that are attached to the term and diagnosis of personality disorder (PD). This can be very upsetting and harmful as the individual may feel labelled by professionals and by society.

The language used in personality disorder services can influence how individuals view themselves and their potential for recovery, can impact their therapeutic relationships due to mistrust or disengagement, and also shape broader societal attitudes and discrimination.

All people have the right to be treated with respect and to be offered the appropriate support and interventions based on what they need rather than their diagnosis alone. It is important that we do not use language which suggests that a person is just a set of symptoms or a diagnosis - this is dehumanising and can also make the person feel punished or judged for the difficulties they have.

If you are making a diagnosis of a personality disorder:

- Provide the opportunity for the person receiving the diagnosis to be able to ask questions.
- If the person expresses that they do not want to be given a "label", the person's choice should be taken into consideration. Appropriate intervention should be offered based on need rather than a diagnostic label.
- Explain why you are making the diagnosis, what it means, and the support that is available to them.
- A personality disorder diagnosis should in no way detract from a person's physical health needs and treatment. Physical health and mental health difficulties often exist alongside each other, so it is important that we consider all these regardless of a person's diagnosis.

Complex Emotional Needs Services

Complex Emotional Needs (CEN) services in Sussex are available to help people increase knowledge, understanding and support for people living in the community with complex emotional needs and/or with a diagnosis of personality disorder. This includes aspects such as managing emotions, trauma, and struggling to cope with emotions and difficulties with relationships.

sussexpartnership.nhs.uk/your-mental-health/getting-help/complex-emotional-needs-services

Useful resources:

- **“Shining lights in dark corners of people’s lives” - The Consensus Statement for People with Complex Mental Health Difficulties who are diagnosed with a Personality Disorders**
- **Personality disorder: no longer a diagnosis of exclusion: Snowden and Kane (2003)**
- **Royal College of Psychiatrists - Services for people diagnosable with personality disorder, position statement (2020)**
- **Escaping iatrogenic harm: A journey into mental health service avoidance: Aves (2024)**

English as an additional language, or do not speak English

We held a bespoke workshop with linguists from Sussex Interpreting Services, and they shared some very helpful insights with us on how best to support a person who does not speak English, or speaks English as an additional language:

- When developing written information, use short and simple language which can be easily translated into other languages. Please note, some medical words and terminology do not directly translate for example, Cognitive Behavioural Therapy.
- Be aware and respectful of cultural differences.
- Words about race and ethnicity should be avoided if not relevant as it can make people feel uncomfortable.
- Be mindful and consider how sentence structures can differ in other languages.
- Wellbeing and mental wellbeing are terms that are not recognised in some languages and cultures.
- Do not rely solely on online information as some communities do not use digital technology, or the information would not be readily available in their language.

Useful resources:

Sussex Interpreting Services (SIS) have developed a number of useful resources:

- **Translatable resource library for service users**
- **Guidelines for service providers working with Sussex Interpreting Services and interpreters**
- **Free bilingual resources for people to use when trying to make an appointment with someone they know has a language need**

Learning disabilities

All communication is meaningful. When communicating with people with a learning disability consider the other communication tools you can use, including body language and how we listen to each other.

- Check in with the person that they understand what you are saying at intervals throughout the conversation.
- Consider the place you are communicating in. Are there lots of distractions? Perhaps try to find somewhere quieter.
- Be patient and try not to rush.

Mencap Charity have developed some helpful guidance to support with when you are communicating with people with a learning disability: **mencap.org.uk/learning-disability-explained/communicating-people-learning-disability**

Useful resources:

- **Mencap: Your guide to communicating with people with a learning disability**
- **Mencap: Easy-read version of communicating with people with a learning disability**
- **Mencap: Short video on communicating with people with a learning disability**
- **Oliver McGowan mandatory training on Learning Disability and Autism**
- **NHS England guidance on how to create easy read documents**
- **Brighton and Hove Speak Out Advocacy: Guidance on good support for people with learning disabilities in health services**
- **Brighton and Hove Speak Out Advocacy: Thumbs up to good health services for people with learning disabilities**

> **Negative or stigmatising language in the past made me feel marginalised and hesitant to seek help. Positive, affirming language has encouraged me to be more open and proactive about my mental health.**
>
> An Expert by Experience representative of the Mental Health Language Reference Group

Neurodivergence

We all think, learn and process information and feelings differently. It is important that we keep this in mind when considering our language, as well as our behaviours.

Neurodevelopmental differences, including ADHD, autism, dyspraxia, Tourette's Syndrome and tic disorder, mean that a person's brain works differently from those who do not have a neurodevelopmental condition (neuro-majority).

Whilst neurodivergent people can experience difficulties including reading social cues, having challenges with coordination and motor skills, and feeling socially isolated, neurodivergent people can also have a range of strengths and abilities, which can help them to excel in education, work and hobbies. These strengths include attention to detail, ability to hyperfocus and concentrate, and creativity.

It is important to note that we can all experience sensory overload, which is when the brain feels overwhelmed by the amount of information it is receiving, including loud noises, strong smells, sudden changes in light, emotional situations. This can cause us to have a physiological response in our bodies, for example difficulty concentrating, stress, or panic.

The Sussex Neurodevelopmental Pathway Programme Lived Experience Advisory Panel (LEAP) developed some guidance with recommendations of some preferred words to use and avoid. We have included an extract from the guide below, but you can view the guide in full at the following link:

int.sussex.ics.nhs.uk/new-language-guide-to-support-converations-and-work-regarding-neurodevelopment-conditions/

Use	Do not use	Why?
Autistic people or people on the autism spectrum	People with autism	Not everyone agrees but increasingly and in general autistic people do not like 'person-first' language. This is because they see autism as part of who they are and not separate from their personhood.
A person with ADHD	An ADHD person	Identity-first language is preferred by many people with ADHD because the way you experience the world is directly affected by your condition and/or disability.
Autistic people with a learning disability or autistic people without a learning disability - Autistic people with high support needs or autistic people with low support needs	High or low functioning Asperger's syndrome	Some individuals may find terms such as 'high functioning' or 'Asperger's syndrome' as meaningful ways to refer to themselves and this choice should be respected. However, 'low functioning' is a disrespectful (and often inaccurate) way to talk about people and 'high functioning' can dismiss the support needs of autistic people without a learning disability. Individuals are no longer diagnosed with Asperger's in favour of a general autism diagnosis.
A neurodivergent individual	A neurodiverse individual	The neurodiversity movement promotes equally valuing all human minds and neurotypes. You cannot be a neurodiverse individual because it's not possible to be 'a diverse individual'. Neurodivergent means having a mind that functions in ways which diverges significantly from dominant societal standards of 'normal'. Forms of neurodivergence include lifelong neurotypes such as autism and ADHD.

Useful resources:

- **SEDS Connective: more information about Neurodivergence**
- **Brighton & Hove adult autism strategy and action plan**

Guidance

Initial contact and consultations

It is really important that we ask people about their preference of language at the earliest opportunity when they first enter mental health services or support. For example, in their first appointment. Not only would doing this help staff to feel confident that they are using words that the person prefers and can relate to, but also shows the person accessing support that their opinions and preferences are valued and will be respected.

Some examples of the sorts of questions you could ask are:

- What would you like me to call you?
- I understand that you have a diagnosis of [insert]. How do you feel about that diagnosis, and would like me to speak with you about it?
- Are there any words that have been used so far which are unclear or unhelpful for you? What words would work better?

And then lastly, make sure that you record what the person shares with you so that this language can be adopted in all future conversations with them without them needing to repeat themselves.

If there is not an obvious place where you can capture this information, it might be a good opportunity to look at the system you use and see if a new field or box could be added.

The NHS England Reasonable Adjustment Flag is a national record where health and social care workers can record any reasonable adjustments for patients, such as language preferences: **digital.nhs.uk/services/reasonable-adjustment-flag**

> **"I'd like mental health services to use more person-first language, focusing on the individual rather than their diagnosis."**
>
> A staff representative of the Mental Health Language Reference Group

Letters, documents and service materials

Through this work we have learnt a lot about the importance of the information we share and how we communicate with people, such as in letters. We have explored together current examples of letters and service information to discuss what works well, and what could be improved.

When developing new written communications, we recommend you consider the following:

- Where possible, coproduce the information with people who will be accessing the service or support.
- Consider the language you are using when making a diagnosis - this can be a significant moment which people will remember, so be mindful and considerate of the language you are using and how you are sharing that information.
- Tailor letters based on a person's preferences and the feedback you have received from them. For example, if they have told you that they prefer to be referred to as 'an autistic person' rather than 'a person with autism', be respectful of this wherever possible.
- Use language that is kind and supportive, and not in a way that is talking about the person behind their back, even if the letter is not being sent directly to them. Be aware that letters could be requested to be seen by the person as a Subject Access Request (SAR).
- First impressions matter - a letter might be the only contact a person has from a service, and it can have a lasting impact.
- Avoid using jargon and abbreviations and use an open and friendly tone of voice.
- Text should be broken down into short sentences, and any complicated words or terms should be explained.
- Try to manage expectations by giving clear and accurate information, such as when someone is likely to hear from the service or be offered an appointment.
- Make letters and documents accessible for people with visual impairment and clearly state how the person can access it in a different format or language.

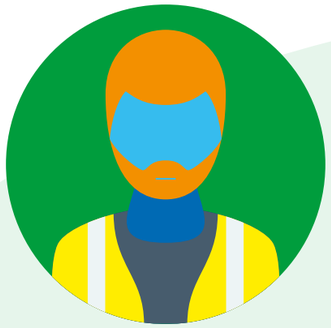
Q: Are there documents that you use regularly in your service which could be updated to be more inclusive?

Crisis and suicide

Grassroots Suicide Prevention have written a guide on how to talk about suicide safely. It includes words and details to avoid when you are speaking about suicide to help protect vulnerable people from reading things which may be triggering, as well as contributing to a wider change in the language we use around suicide.

We have included an extract from the guide below, but you can view the guide in full at the following link: **prevent-suicide.org.uk/get-involved/fundraise/fundraising-hub/how-to-talk-about-gsp/**

No thank you	Yes please	Why?
Commit suicide Successful suicide	Died by suicide Ended their life	Associates suicide with crime/sin Implies you can ‘succeed’ which is a positive word
They were suicidal	They experienced suicidal thoughts / suicidal ideation	Avoids reducing a person to a negative characteristic Experiencing something is different from it being your identity
Unsuccessful / successful suicide	Made an attempt on their life Made a non-fatal attempt to take their life	Presents suicide as a desired outcome
A cry for help	A suicide attempt	Unhelpful phrasing - all suicide attempts should be taken seriously
Suicidal ideation is ‘attention-seeking’	Do not use these words	Telling someone they are ‘attention-seeking’ comes with negative connotations and could reinforce that their problems don’t matter or that nobody cares, which is not true
Suicide can be ‘cured’ or ‘solved’	Suicide has many causes and factors unique to each person	Suicide should not be framed as a ‘problem’ or ‘illness’ with one ‘cure’ - this is not the reality for many people
Suicide is ‘selfish’	Do not use these words	There is nothing ‘selfish’ about struggling with thoughts, feelings or situations that are causing pain or distress
A completed suicide	Died by suicide	This implies that suicide is an achievement or a situation that only has one end



“It’s not complicated: speak to me the way that you would want to be spoken to, should one day you wake up with my illness and problems to deal with”

An Expert by Experience representative of the Mental Health Language Reference Group

GRASSROOTS SUICIDE PREVENTION

Taking a trauma-informed approach

Trauma-informed practice is an approach taken in health and care services which recognises the impact that trauma can have on a person, their development, and their health. It asks the question “what happened to you” instead of “what is wrong with you”.

Trauma-informed language uses five (5) key principles to acknowledge the impact of trauma on individuals by creating an environment of safety, trust, empowerment, choice and collaboration and respect.

The approach acknowledges that for us to provide effective healthcare and support, we need to have a full picture of a person and their situation, and all the contributing factors that can impact a person’s wellbeing.

Any communications that you are developing can be filtered through the key principles below.

Safe:
use words that promote emotional and psychological security. Are we validating experiences without judgment?

Trust:
is this honest, will this happen, is it consistent, open and transparent? Are we avoiding triggering or re-traumatising language?

Empowerment:
are we encouraging autonomy and affirming strengths?

Choice:
are we offering choice where we can?

Collaborative:
are we doing things together and sharing decision making?

It is also important to remember that it is not just about what we say - the environment we create is also part of our language. Signage, posters and leaflets all communicate who we are as an organisation or service, our expectations of people accessing our services, and our commitment to the way we provide support. Make sure there are positive and reassuring messaging on display, including signage which explains to people the positive things we are trying to do rather than telling people to stop doing things. For example, “We want this to be a safe area. If you have any concerns or are feeling anxious, please talk to us”.

By embedding trust, empowerment, and sensitivity in your communication, you foster a safe, supportive environment where individuals feel valued and heard.

Here are some suggestions of ways to take a trauma-informed approach to the language you use:

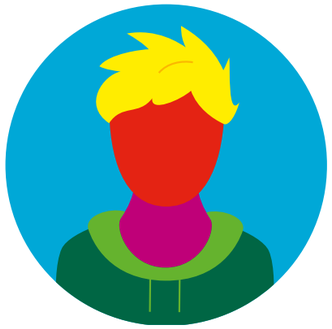
- When speaking about a person, don’t depersonalise them - use their name, write as if you were talking about a friend or relative, and reduce stigmatising and shaming language.
- Be mindful of tone and body language.
- When referring to a person or group of people, instead of using words such as ‘hard to reach’ or ‘difficult to engage’, consider words such as ‘underrepresented’ or ‘under-served’.
- Use open ended questions to empower the person and support choice. For example, “can you help me understand what’s going on?”
- Respect boundaries - if someone isn’t ready to talk, respect their choice and reassure them of your support.
- Reinforce trust and empowerment - follow through on promises, be consistent, and remind individuals of their strengths and agency.

Useful resources:

Sussex Integrated Care System (ICS) recommend following **the Scottish National Trauma Transformation Programme.**

- **UK Government Guidance: working definition of trauma-informed practice**
- **The Innovate Project: trauma-informed practice**
- **Creating safe spaces - The power of trauma-informed language: Reggie D Ford (2023)**

Closing summary



"Language changes all the time, so it is important that we keep up; keeping our eyes and ears open and listening sensitively to our communities is critical if we are to effectively work with them.

This guide is a culmination of two-years' worth of honest conversations, not avoiding the tricky topics, and working in collaboration with stakeholders. It is an excellent example of how working with people who have a lived experience of accessing mental health support we can develop solutions together."

Dr Oliver Dale, Chief Medical Officer, Sussex Partnership NHS Foundation Trust

"For me, using respectful, accurate language in mental health is essential because words shape understanding and empathy. Thoughtful language reduces stigma, promotes inclusivity, and encourages people to seek help. By validating diverse experiences and avoiding harmful stereotypes, we foster an environment where individuals feel supported rather than judged.

Empowering terms help individuals view their mental health challenges as aspects of their experience, not definitions of their identity, and create a society more compassionate, informed, and willing to embrace mental health issues openly.

This is why I fully endorse and commend this new language guide."

Neil Blanchard, Chief Executive, Southdown

"Language is important – it can be supportive or divisive. The same term may have completely different meanings by varying the context or cultural/ geographical background. Equally, we may be trying to share the same feelings but using differing terms.

It is recognised that 90% of communication is nonverbal. Yet, in the modern world, where so much communication is remote or via the written word, it is especially important to remember the power and impact that our language can have."

Dr Bikram Raychaudhuri, GP and Clinical Director for Mental Health, Population Health Management (Prevention), NHS Sussex

"The Changing the Language Guide is a comprehensive tool to support more inclusive and patient focussed terminology and care.

Its content links completely to the ICB values of respect and dignity, compassion, everyone counts and improving lives together. It demonstrates our joint commitment to quality of care and how we work together for patients to improve their experience of our Sussex mental health services"

Bianca Kokkolas, Deputy Director of Commissioning and Transformation, Adult Mental Health Programme, NHS Sussex

Further reading and references

Developing a guide

Starting in 2022 as part of the Community Mental Health Transformation programme for adults and older adults in Sussex, people had told us that sometimes the words and phrases they had heard when seeking mental health support or services in the past had been unhelpful, inappropriate or at times, harmful.

Using this feedback, the 'changing the language' project was established in 2023 to listen to people's experiences, reflect on what could be done differently, and develop some solutions to improve. In focus groups and workshops, we gathered feedback from more than 90 people across Sussex with lived/living experience of mental health difficulties, families and carers, and people working in various roles across the health and care sector.

There was a lot of interest in this work and a willingness from those involved in the sessions to be part of making a difference, so the Mental Health Language Reference Group was formed. A collaboration of people from a range of backgrounds, roles, and experiences, the group meets monthly and provides a reference point for teams, services and organisations to approach when they are looking to develop or update written resources, for example letter templates.

A small task and finish group was established to develop the inclusive language guide, which included members of the reference group and other people with an interest in contributing to this resource.

We would like to thank the following organisations for their involvement and support in developing the guide:

- BHT Sussex
- Capital
- Changing Futures Sussex
- NHS Sussex
- People Participation Team
- Possability People
- Southdown
- Sussex Coproduction and Lived Experience (SCALE) Network
- Sussex Health and Care
- Sussex Interpreting Services
- Sussex Partnership NHS Foundation Trust
- West Sussex County Council
- West Sussex Mind

References

- Bradford District and Craven Health and Care Partnership: Inclusive language guide
- Brighton & Hove City Council: 'My pronouns are' campaign
- Council for Disability Income Awareness: Identity first or person first language - where do you stand?
- Collaborative Ethnographic Working in Mental Health: Knowledge, Power and Hope in an Age of Bureaucratic Accountability: Neil Armstong (2023)
- Dementia Support: Communication and language for people living with dementia
- Escaping iatrogenic harm: A journey into mental health service avoidance: Aves (2024)
- Furthering the person-first versus identity-first language debate: Lisa B. Grech, Donna Koller & Amanda Olley (2023)
- Healthcare Improvement Scotland: Inclusive language guide
- Healthwatch: your rights to language support in NHS settings
- Mencap: Your guide to communicating with people with a learning disability
- Mencap: Easy-read version of communicating with people with a learning disability
- Mencap: Short video on communicating with people with a learning disability
- Mind: A mental health language guide
- National Survivor User Network: The language of the mental health lived experience landscape
- National Trauma Transformation Programme (Scotland)
- NHS England: Good communication with patients waiting for care
- NHS England: Reasonable Adjustment Flag
- Norfolk Community Health and Care NHS Trust: We Care glossary of inclusive terminology
- Oliver McGowan mandatory training on Learning Disability and Autism
- Oxfam: Inclusive language guide
- Patent Information Forum: A quick guide to using plain language
- Personality disorder: no longer a diagnosis of exclusion: Snowden and Kane (2003)
- Royal College of Psychiatrists - Services for people diagnosable with personality disorder, position statement (2020)
- Scottish Drugs Forum: Moving beyond 'people-first' language
- West Sussex Safeguarding Adults Board: Audio version of Language and terminology learning briefing
- West Sussex Safeguarding Adults Board: Language and terminology learning briefing