COMMUNICATION GUIDE

HOW TO TALK ABOUT MULTI-SENSORY EXPERIENCES IN CAMHS SETTINGS

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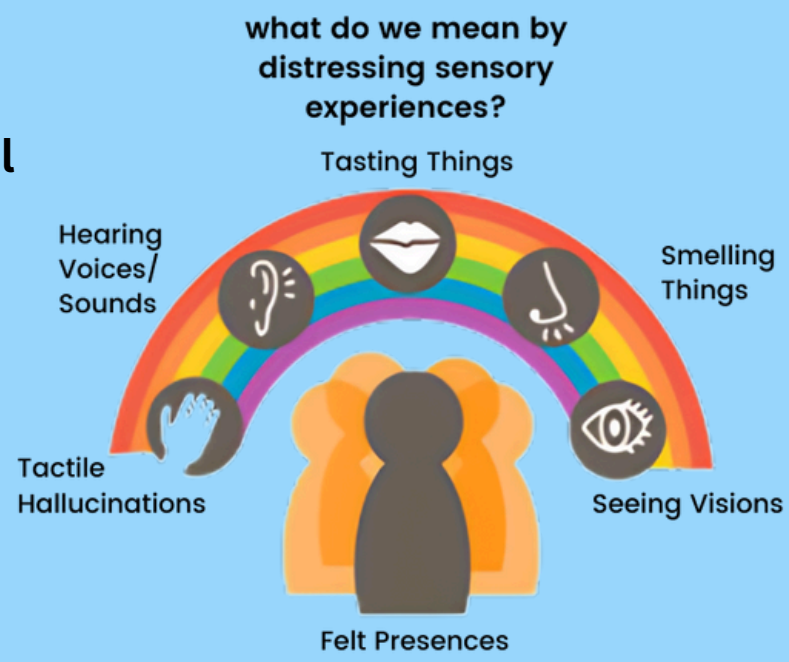
co-produced with young people and parents

This Communication Guide presents what young people and their parents find helpful and unhelpful when discussing experiences such as hearing voices or other sensory perceptions.

By gaining insight into the words and approaches that feel supportive, we aim to create a resource for CAMHS workers, helping them navigate these conversations with sensitivity and understanding, engaging with young people in a way that respects their experiences and promotes meaningful dialogue.



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PLEASE NOTE: this is a guide co-produced with young people and parents to help CAMHS practitioners think about how they communicate with individuals and families with multi-sensory experiences. It is not a script or rule book!

THANK YOU!

Thank you to the young people, parents, and staff that have contributed to the planning and creation of this guide. Thank you to the Lived experience advisory group and the parent advisors groups from the ChUSE trial for co-producing this guide with us. Thank you to Voice Collective. Thank you to Emma Paxon for the illustration graphics.

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Preferred Terms or Phrases

MULTISENSORY EXPERIENCES – LIKED BY SOME BECAUSE IT ENCOMPASSES MORE EXPERIENCES THAN HEARING VOICES

Unusual sensory experiences – although it may be intended to be kinder it can be perceived as devaluing the YP experience or imply they are 'weird' for having these experiences

Voice hearing – limited, there are more experiences relating to senses as well as beliefs

Psychotic symptoms – refreshing to be recognised their experiences after years of being unsure

Psychosis – can be affirming but also scary, first focus on describing and understanding the experiences, and use the words that the YP uses

KEY POINTS

- Sometimes "stigmatizing" labels feel more honest than overly softened terms
- There is variation in which terms people prefer
- Building authentic relationships is more important than using a certain term over another

"I think we should avoid using 'nicer sounding' terms, sometimes labels with more stigma are better suited to describe my experiences – some people like clinical language, others don't. Use the language that people use for themselves"

TERM OR PHRASE	WHY IT'S UNHELPFUL
Delusional	Feels dismissive, stigmatizing, and invalidates lived experience
Compliant / Non-compliant	Suggests control rather than collaboration; can be weaponized
Imaginary (without context)	May feel invalidating or infantilizing
Lacks insight / poor insight	Implies judgment; often used unfairly to justify decisions without consultation
Patient denies	Casts doubt and feels accusatory, forcing individuals to "prove" their experience
Limited capacity	Leads to assumptions about decision-making; often cited without adequate context

ULTIMATELY, IT'S NOT JUST THE WORDS WE CHOOSE THAT CONVEY MEANING – THE BEHAVIOURS WE EXHIBIT AND THE APPROACHES WE TAKE SPEAK VOLUMES.

- Even when documentation is written for professionals, it should be assumed the young person or family may read it.
- Language has emotional weight – avoid anything that frames someone as being difficult, unreliable, or manipulative without context or support.
- Pay attention not only to words, but also tone, body language, and intention behind communication.

WHAT ABOUT ASSESSMENT QUESTIONS?

"I think the first session shouldn't be something heavily on risks assessment and filling out forms. It's necessary trust is being built in the first session without using clinical language bluntly"

"There are times where so many questions are asked about your situations like "how often you self-harm" and "how supportive are your parents" without building trust first."

"I had a psychiatrist who at our first appointment asked me 'why are you here?', and I started telling him about my history – he stopped and said "I know your past, I read your file, I'd like to know what brings you here today" – I found this to be so validating of my present worries, it was reassuring to know that he knew my history, and validating that he wanted to know how I was feeling in the moment. It made me like him which then made it easier to build a relationship with him."

"Especially being asked to explain history immediately without any time to build rapport. Even simple things like 'how was your day', I remember I had one CAMHS worker who would always have a box of fidget toys and we would talk through them at the start to find ones I liked and it helped me build rapport with her because I felt like she cared about what I thought and liked. Also even when she was not the person I was there to see she would say hi to me in the waiting room and check in on me, again making it feel like she cared and not that I was just a patient to her."

KEY THEMES

THEME	NEGATIVE EXAMPLE	POSITIVE EXAMPLE
Communication Style	Stigmatizing language, clinical jargon, interrogative tone	Use of respectful, clear terms including YP's preferred language
Trust & Relationship	Prioritizing paperwork over connection; listening more to parents than the young person	Rapport-building approach, showing genuine interest in YP and valuing their voice
Judgement & Assumptions	Presuming incompetence or malingering; using dismissive notes	Validating diverse experiences and perceptions
Stigma & Labelling	Minimizing YP's experiences; overly compliance-focused language	Encouraging YP-led language and actively involving them in their care decisions
Body Language & Tone	Hostile body language; harsh or dismissive tone	Calm demeanor, open posture, and use of supportive gestures/tools
Power & Autonomy	Coercive tactics; lack of accessible channels to report concerns	Promoting choice and autonomy by inviting YP to shape their language and treatment preferences

Negative

COMMUNICATION, TRUST, AND LANGUAGE

- Rigid communication styles, especially those relying on clinical or impersonal terminology (e.g., "delusional," "non-compliant"), can feel dismissive or dehumanising and may cause young people to shut down.
- Labelling language—such as framing behaviours or feelings as "good/bad," "manipulative," or "strange"—can increase distress, reduce autonomy, and reinforce stigma.
- Posing too many difficult questions or using a suspicious tone without building rapport can erode trust and suggest judgment rather than support.
- Trust may be undermined when young people feel sidelined in favour of their parents, or when parents are perceived to hold too much influence in clinical conversations.
- Initial sessions that prioritise paperwork and risk assessments over relationship-building can feel impersonal and hinder connection.

ASSUMPTIONS, NOTES, AND PERCEPTION

- Preconceived attitudes, especially those based on clinical notes, can lead to unfair assumptions about competence or credibility.
- Negative or subjective comments in clinical documentation—particularly regarding appearance or behaviour—can feel judgmental and contribute to lasting stigma.
- Interpreting a young person's insight or concerns as "delusional" or "non-compliant" may overlook legitimate perspectives and reduce collaborative engagement.

BODY LANGUAGE, TONE, AND APPROPRIATENESS

- Hostile or dismissive body language and tone from clinicians can be deeply damaging to young people's confidence and safety in the therapeutic space.
- Mismanagement of age-appropriate humour or swearing may alienate young people and signal a lack of cultural or developmental awareness.

Positive

CONSISTENCY AND CLARITY

- Consistent use of language helps acceptance and supports engagement.
- Scientific terms can help clarify and make experiences easier to research.

PERSONALISATION AND TRUST

- Asking what terms young people prefer for their experiences and using their language builds trust.
- Building rapport first –asking about day-to-day things or using fidget toys– helps calm nerves and shows care/interest.

INCLUSIVITY AND VALIDATION

- Recognising multisensory experiences (not just voices) ensures all experiences are covered.
- Showing genuine interest in the young person, not just their symptoms, makes them feel valued.

EMPOWERMENT AND COLLABORATION

- Involving young people in discussions about their care and language preferences increases engagement.
- Building a clear sign of respect by listening and prioritising the young person's perspective

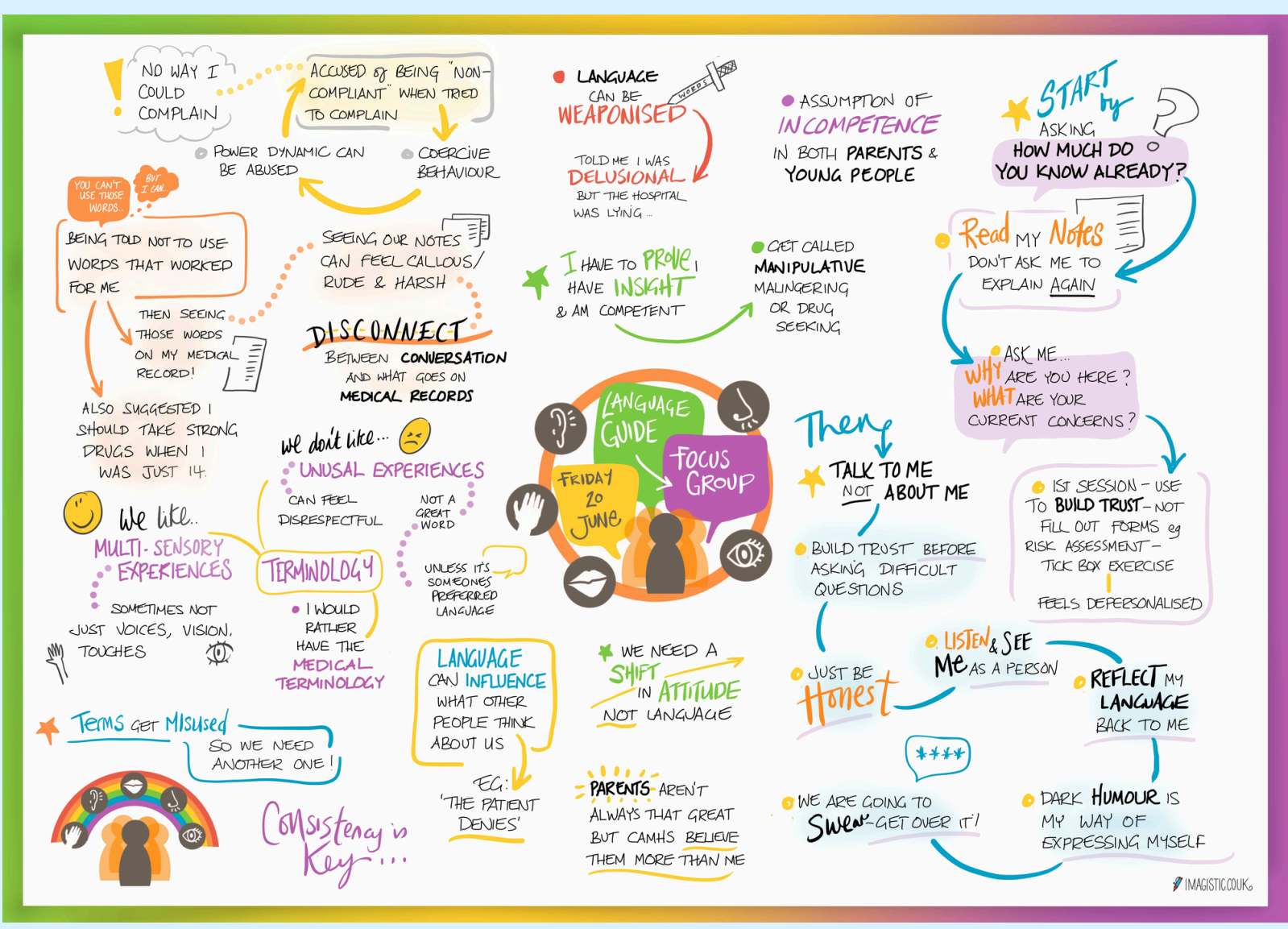
BEYOND LANGUAGE

While it's essential to use the words and terms that young people resonate with – language that reflects their experiences and identities – this alone isn't enough. The heart of truly effective communication lies in how we relate, not just what we say.

<u>Young people repeatedly share a clear message: they want to be listened to, seen, and treated like whole people</u> – not case files, diagnoses, or problems to be solved. They crave authentic human connection from practitioners who engage with openness, honesty, and warmth. This means:

- Being curious without being clinical
- Letting the conversation be led by genuine interest rather than ticking assessment boxes
- Acknowledging complexity rather than reducing it to checklists or charts
- Showing personality – yes, even humour and vulnerability – in the therapeutic relationship

AUTHENTICITY TAKES FIRST PLACE. IT CREATES SAFETY, FOSTERS TRUST, AND OPENS SPACE FOR YOUNG PEOPLE TO SHARE THE FULLNESS OF THEIR EXPERIENCE. WORDS MATTER — BUT IT'S THE RAPPORT, THE PRESENCE, AND THE REALNESS OF THE PRACTITIONER THAT MAKES ALL THE DIFFERENCE.



RELATIONSHIP-BUILDING & COMMUNICATION TIPS

- Be mindful of parental relationships – not all are safe or supportive.
- Involve YP meaningfully and transparently in conversations.
- Show genuine interest in YP's world, passions, and perspectives.
- Handle complaints with openness, without branding YP as "non-compliant."
- Acknowledge difficult experiences rather than trying to fix or dismiss them.

OTHER KEY INSIGHTS & RECOMMENDATIONS

- Humour (including dark humour and swearing) can be a valid coping tool – don't shame YPs for using it.
- Language used by mental health professionals can linger and impact trust in future relationships.
- Professionals aren't objective by default – YP experiences are deeply personal, but this doesn't mean they are automatically subjective or "less real"

TAKEAWAYS

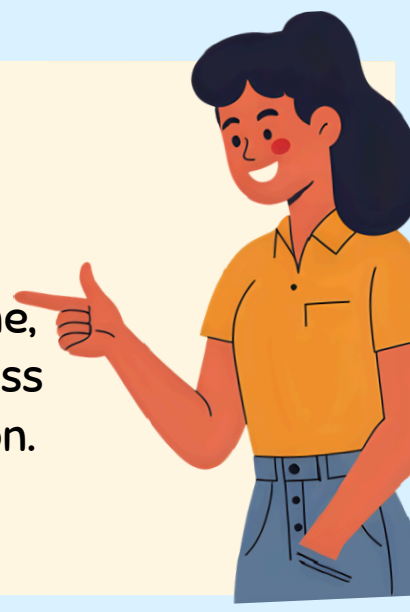
WHAT YOUNG PEOPLE WANT YOU TO REMEMBER

LANGUAGE SHAPES EXPERIENCE

The words professionals use – whether spoken or written – have emotional and psychological weight. Terms like delusional, non-compliant, or denies can alienate young people and make them feel invalidated. Language must reflect empathy, respect, and person-centred care.

APPROACH MATTERS AS MUCH AS VOCABULARY

It's not just about choosing the right words – tone, body language, and genuine curiosity and openness are equally important to build trust and connection.



YOUNG PEOPLE KNOW THEIR OWN EXPERIENCE

Practitioners should respect young people's descriptions and preferred terminology – including unconventional or evolving terms, clinical labels, or even humorous language. Let them steer the narrative and recognise them as experts in their own experiences.

REPORTS AND ASSESSMENTS CAN BE HARMFUL

What's written in clinical records and reports isn't just administrative – young people may read them, and damaging language can hurt their sense of agency and affect future care. Mindfulness in documentation is essential, both when writing it and when reading it in preparation for an appointment.

TIPS FROM PARENTS

"BE CURIOUS. VALUE SUBTLETY. HOLD COMPLEXITY"

VALIDATE

Even when the intent behind normalising certain experiences is thought to be reassuring (e.g. to manage family's anxieties or make them feel less alone), telling families that hearing voices or seeing things is "common" can come across as invalidating experiences that are very real for the child and have a significant impact on their life. This is especially frustrating when communicated in the context of comorbidities and complex presentations, such as OCD or autism. We should understand it's a fine line to thread – balancing reassurance with validation.

"I was told that neurodiverse people have distressing sensory experiences anyway, which is true and important to know, but it can feel minimising, especially after having gone through many doctors and appointments – there are many autistic people that don't hear voices as well"

Parents have often interacted with many other practitioners before you, often reporting negative experiences – try to be affirming when they raise concerns and let them know that you believe them.

"When we changed services, I started explaining our history to the clinician expecting to have to convince them about my child's difficulties. I was told: 'we absolutely believe that your child is having these experiences' and it was very affirming to hear, after being dismissed for a long time"

BE KNOWLEDGEABLE & CURIOUS

People who have distressing sensory experiences might do so because of many different reasons. It's important to be curious about the YPs experiences and challenge rigid views around certain diagnoses . This can lead to families feeling like they are not being supported in accessing useful services or interventions that would be beneficial for the child.

If the YP isn't suitable for a certain therapy, make sure you explain why, providing psychoeducation to the family when appropriate. Be curious in your own understanding of DSE and the support available outside of CAMHS and provide meaningful signposting to alternatives.

Your ability to communicate that there is more that the family can do leaves a lasting impression on the family and makes them feel like the hope is still alive.

Often this seems to fall on the individual practitioner, however, there needs to be a more standardised effort across services to embed signposting into clinical practice when support can't be accessed within CAMHS.

RESPECT COMMUNICATION STYLES

Understand different ways of communicating besides verbal communication – e.g. writing; but also for any interventions – be open about trying different approaches beyond talking, e.g. art therapy.

Crucially, offer these as options when possible so that the family can think about the best approach for their communication style.

Bring this respect into conversations with the young person. For instance, if the child names a voice, respect the name they are using to describe the voices – don't imply it's an alter ego used to get away with things.

UNDERSTAND FAMILY DYNAMICS

Working with young people means engaging with their family too. Parents may want to be involved and heard, so it's important to remember that they and their children are different individuals from different generations, with distinct perspectives. Each family brings its own unique dynamics to every appointment, so it's essential to approach the situation with understanding and flexibility.

Using Diagnostic Language with Care and Purpose

The implications and consequences of receiving a diagnosis are multifaceted and often contradictory. For many parents, clinical terminology can offer legitimacy and help them be taken seriously by professionals and systems. Yet these same terms can feel daunting or alienating, creating a sense of fear or stigma.

Achieving a balance is crucial—and that balance will look different for every family, depending on their unique context and needs. Labels can unlock access to support and services, but some families face realities that leave little choice but to embrace stigmatizing language simply because it's the language that opens doors.

INCLUDING LABELS OR DIAGNOSIS IN REPORTS MAKES A DIFFERENCE:

- when transitioning services – e.g. to adult services
- it also has implications for PIP or disability claims
- "Psychosis label was needed for this pot from the council, having this money made a crucial difference"

IT'S IMPORTANT TO ENSURE THINGS ARE PROPERLY DOCUMENTED, RECOGNISING THAT FOR SOME PEOPLE RECEIVING A DIAGNOSIS HELPS SERVE A PRACTICAL PURPOSE, SHAPED BY WIDER SOCIAL AND ECONOMIC FACTORS.

Even labels and diagnoses don't always lead to support—often they imply functionality without offering anything useful. It's important to be mindful of how language and labels can become weaponized, carrying heavy stigma without any follow-up care or assistance.

SUPPORT SHOULD BEGIN BY PRIORITISING THE YOUNG PERSON'S OWN DESCRIPTIONS OF THEIR EXPERIENCES AND UNDERSTANDING HOW THESE AFFECT THEIR DAILY LIFE. THEIR PERSPECTIVE MUST REMAIN CENTRAL. SERVICES LIKE CAMHS PLAY A VITAL ROLE IN HOLDING THESE VARIED NARRATIVES TOGETHER AND SHOULD STRIVE TO WORK IN A PERSON-CENTRED WAY—TAILORING THEIR APPROACH TO EACH YOUNG PERSON`S AND FAMILY'S UNIQUE CONTEXT.

USEFUL LINKS

[VOICE COLLECTIVE]

[HEARING VOICES NETWORK]

[INTERVOICE]

[HUB OF HOPE]

RESEARCH ARTICLES

Leach, H., Kelly, J., & Parry, S. (2023). **Compassion-informed approaches for coping with hearing voices**: literature review and narrative synthesis. *Psychosis*. https://doi.org/10.1080/17522439.2023.2253883

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