

Lived Experience Engagement and Employment Framework

“The art of conversation is the art of hearing as well as of being heard” - William Hazlitt



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Thank you to all the contributors who shaped this document

The framework has been shaped by the insights of parent carers and young people in Kent and Medway, and colleagues and partners across Medway Council, Kent County Council and NHS Kent and Medway. We are grateful for the time offered in particular by young people, parent carers and the voluntary sector in support of this first edition. Thank you to Medway Parent Carer Forum, Kent PACT, Peer Associates at Involve Kent, Activmob, staff from East Kent Hospitals University NHS Foundation Trust, Think Local Act Personal ('TLAP') who have provided specific areas of input and/or feedback. Thank you to the Western Australian Mental Health Commission who responded with additional information about designated/non designated perspectives (roles) to a request for citation information.



Part 1: The Framework

Purpose and use of the framework

Across NHS Kent and Medway, Kent County Council, and Medway Council, strategies and other documents recognise the importance of working with people who live in local communities and/or use services.

This framework supports those commitments and brings together common terminology and positive approaches to working with people with lived experience. It contains common terms and provides explanations for them; includes values that are respectful and inclusive of people with lived experience; provides relevant knowledge; and gives some points to consider when carrying out engagement and participation activities. These topics are also important when people are employed to draw on their lived experience.

The framework was developed with reference to existing literature and good practice guidance and provides an approach to the inclusion of lived experience within strategic and operational functions of Kent County Council, Medway Council,

and NHS Kent and Medway. It is not designed to be prescriptive, but to provide a guide and baseline to those working or engaging with people with lived experience.

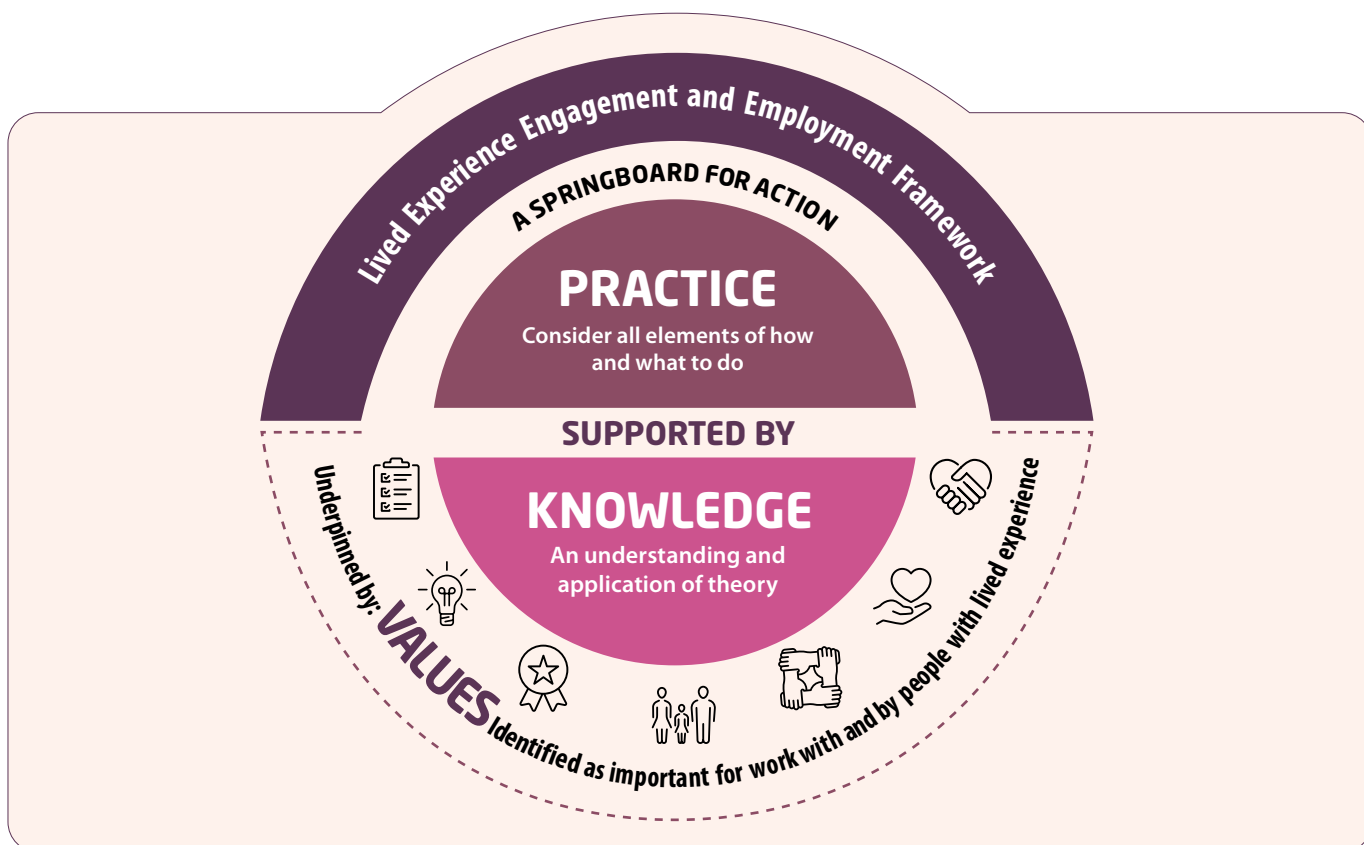
Understanding and aligning with the content of the framework will help with the inclusion of lived experience and removal of barriers, while protecting people's information. It will support both working with people who are employed to use their lived experience, and engaging with people who want to provide feedback and insight.

Internal guidance

Additional resources to support those planning for engagement or employment will be available via training and / or further information. Please use the contacts at the end of this document for further information.

Framework Structure

The framework is structured to include the practice that is important when working with people with lived experience, and the knowledge and values that apply.



Definitions used in this framework

For the purposes of this document, the following definitions apply:

Lived experience means having personal experience of something – an example could be a health condition or using support services. It might be as a family member or carer, or as the person with the health condition. It might not be related to health but to something like homelessness.

Learned experience refers to knowledge of something through education or work/volunteering.

People can have both **lived** and **learned** experience.

Family and carer lived experience or **first person lived experience** can be used to identify a difference in the perspective being used.

A **designated** role is one in which people are employed to draw on their lived experience – this means that one of the criteria is to have relevant lived experience which is relevant to the role. Assumptions should not be made that people holding a **non-designated** role do not have relevant lived experience, but the two roles are different in approach.

The lived experience workforce refers to people employed into designated lived experience roles.

Participation – People are supported to take part in an activity, or activities, (which may be one off or time limited) in which the person/people with lived experience is/are an active part of making or influencing a decision (through sharing experiences and/or or direct feedback on suggestions). An example might be a participation worker facilitating a series of workshops in which people with lived experience attend alongside people seeking decisions, or attending a regular forum (e.g., Youth Voice). The power balance is not decided by the activity type.

Engagement – this may be for a fixed period, or can describe the longer term activities, plan, or strategy for building a relationship with your stakeholders, and gaining and / or maintaining their interest. There may be a different approach for different groups, for example considering engagement with different people and communities (e.g., children and young people). Usage might include 'we have developed an engagement strategy for the X project'.

Communication – for best practice, reference to communication should mean a two way process back and forth between two parties, which offers and invites genuine discussion.



Framework Values

These values were created collaboratively to inform the way that we work together as and with people with lived experience.



Accountability



Being open to accepting responsibility and challenge.
Being honest and transparent.
Actively reviewing and improving.

Ambition



Seeking to make improvements.
Driving change.
Being open to innovation and change.

Bravery



Recognising that sharing your story and/or your needs is brave.
Being ready to challenge stereotypes and stigma.
Asking questions and providing honest answers.

Inclusivity



Welcoming all voices.
Recognising and removing barriers to engagement and participation.
Using a person centred and strengths-based approach.

Integrity



Acting in the best interests of people.
Delivering what you promise and promising only what you can deliver.
Appreciating the skills of others.

Kindness



Understanding different experiences and perspectives.
Prioritising wellbeing.
Being aware that people may be experiencing undisclosed difficulties.

Respect



Recognising the right to participate in decision making.
Appreciating the value of different points of view.
Uniting people who may not agree.

Positive, timely and meaningful communication underpins all of these values.

Key Concepts

Holding knowledge and understanding of the following areas (amongst others) is important when working with people:

- Working with people with lived experience should be supported by **training or assistance** from other teams within your organisation, or via external organisations if necessary. These might be teams that can offer advice about legal requirements to consult, or teams that already work with people and can help with your planning or activities.

- It is important to understand **intersectionality** which recognises that people's experiences are lived through not in isolation, but in the context of other experiences, relationships and identities.

- A **trauma-informed** approach will support the wellbeing of everybody who is taking part in engagement and participation, including people facilitating this work.

- Understanding responsibilities to make **reasonable adjustments** under the Equality Act will help to reduce barriers to participation – how to support disabled people to take part comes into planning.

- **Healthcare inequalities** are described by the NHS as 'unfair and avoidable differences in health across the population, and between different groups within society.' Understanding these can help with planning and with representation of different experiences.

- The **social model of disability** evolved as an alternative to the medical model, which considers that disability is caused by a person's condition or impairment. The social model sees people as disabled by the way that society runs, and that identifying and removing barriers is the appropriate response. Definitions of the medical model and the social model are included in the Glossary. Although there are other models of disability, the most commonly used one in the UK is the social model. This framework is designed to ensure that the approach and language used when engaging with disabled people reflects this.

- **Communities** – "A community is a group of people who have common characteristics or interests. Communities can be defined by: geographical location, race, ethnicity, age, occupation, a shared interest or affinity (such as religion and faith) or other common bonds, such as health need or disadvantage. People who are socially isolated are also considered to be a community group." (NICE, 2017)

- **Confidentiality and Information Sharing** – this requires knowledge of the concepts and how legislation and good practice is applied within your organisation through policy and procedures.

- **Demographic data** refers to information available about the different populations and groups of people nationally or within your local area. This can be useful when looking at whether views are representative of the wider community.

Types of engagement

Sharing decision making between organisations and the people that use them

What are we calling this type of engagement?

Information

A provision of finalised information, which is not currently available for revision.
What might it look like? Examples include: Newsletters / Websites / Posters / Leaflets.

Involvement

People with lived experience shape or provide feedback on an aspect of a project or service.
What might it look like? Examples include: Asking people using the service to look at a leaflet design for readability; offering a choice of operational times; asking for general feedback.

Collaboration

People with lived experience work together with people with learned experience to move a project forward.
What might it look like? Examples include: A series of focus groups, a one off event led by a facilitator, the design and creation of information with a group of informed people (who understand the project).

Co-production

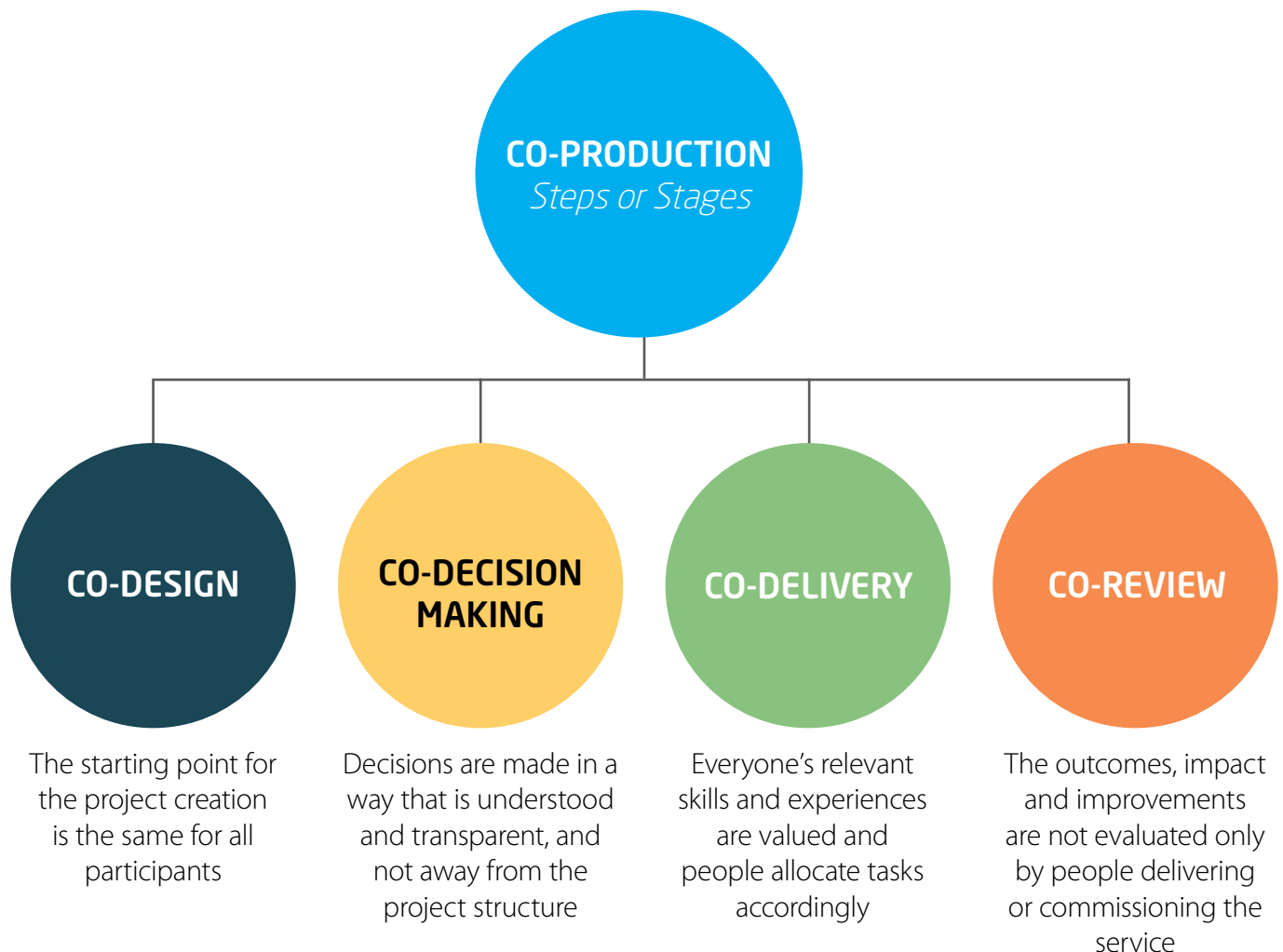
A process in which people use their lived and learned experience and knowledge to make decisions together, on an equal power sharing basis:
• Co-design • Co-decision making • Co-delivery • Co-review
What might it look like? Examples include: Workstreams for large projects, inclusion in steering groups from inception, inclusion at the same point as those with learned experience.

Consultation

A planned request for views and opinions on a specific subject, where these will shape or inform the outcomes.
Avoid the term unless referring to a formal Consultation.
What might it look like? Examples include: A consultation document explaining proposals and rationale. Feedback mechanisms such as a questionnaire. Promotion of the consultation via a range of methods which may include: social media, posters, emails, media releases, and targeted communication with service users and other stakeholders.
Note: there will usually be a planned timescale.

Remember: it should always be clear how people's input has been used and what the end result was. Provide this feedback to those that took part.

Co-production in more detail



“ Co production is a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. ”
(NHS England, 2023)

Co-production requires time, and a commitment to working together as equal partners. Explaining it as four parts or stages as above helps to demonstrate how people are included from the beginning through to review.

Considerations for types of engagement

There are a number of factors which will be important to consider. The first is any statutory or local policy driven requirement for consultation or public involvement – see internal guidance in the full framework for a brief overview and follow organisational standards for these. The values and guidance in this framework can be used to complement any existing organisational process.

The internal guidance references national documents and the principles for consultations. The following provides an overview of what to consider when planning to engage with people:

Impact:

How much of a change or difference will this decision or project make?

Public funding:

How much public money is being spent?

Flexibility:

How much has already been decided at a national level? This includes co-produced guidance or decisions.

Timeframe:

How much time is available before the launch day or decision needs to be made?

Prior knowledge:

What existing recent information is there from previous or consecutive engagement?

Proportionality:























The engagement activities should be proportionate to the cost and impact of the project/decision.





















Putting the values and knowledge into practice

Engagement

Although this section refers to engagement with people who use services, as opposed to the lived experience workforce, many of the thinking points will be relevant to employed colleagues.

PRACTICE AREA	APPLICABLE FRAMEWORK VALUE/S				
Ensuring the organisational or team culture is open to lived experience voice.	 Ambition	 Accountability	 Inclusivity		
Making sure planning is based on understanding timescales and scope of the project.	 Inclusivity	 Respect	 Integrity	 Ambition	
Understanding what may motivate people to take part.	 Respect	 Bravery	 Kindness	 Ambition	
Ensuring recognition and/or remuneration is considered.	 Respect	 Integrity			
Thinking about how meaningful representation can be achieved.	 Inclusivity	 Respect	 Integrity	 Bravery	 Ambition
Understanding, identifying and addressing barriers to participation.	 Inclusivity				
Knowing how to facilitate participation and engagement.	 Accountability	 Ambition	 Integrity		

Putting the values and knowledge into practice (Engagement) - Continued
























PRACTICE AREA	APPLICABLE FRAMEWORK VALUE/S				
Ensuring wellbeing.	 Inclusivity	 Kindness	 Accountability		
Supporting volunteer and workforce development.	 Integrity	 Ambition			
Understanding the value of peer support.	 Respect	 Inclusivity			
Building the plan to include reviewing the outcomes and the engagement experience.	 Integrity	 Accountability	 Respect	 Ambition	 Inclusivity
Understanding GDPR and the use of personal information.	 Integrity	 Bravery	 Accountability		
Providing feedback.	 Integrity	 Accountability	 Respect		








Employment

This section focusses primarily on people employed to utilise their lived experience (in addition to other skills and experiences required for the role).

Note: People are often employed in roles they have applied for as a result of their own experiences and background, even if there is no explicit requirement to draw on these. If disclosed, additional wellbeing support may be required. Colleagues in non-designated roles with lived experience have the potential to be an ally to lived experience colleagues but disclosure of lived experience is always a personal choice for colleagues in non-designated roles and should be carefully considered. The objectives and perspectives drawn upon will be different for these roles.

PRACTICE AREA	APPLICABLE FRAMEWORK VALUE/S				
Ensuring the function of the role is clear from the job description onwards; including any additional skills or training that may be required (including once employed).	 Inclusivity	 Ambition	 Inclusivity	 Bravery	 Integrity
Clarity on designated/non designated roles.	 Respect	 Accountability	 Kindness		
Valuing the potential impact of the roles and ensuring this is widely understood.	 Ambition	 Respect	 Bravery		
Understanding and addressing dual relationships.	 Integrity	 Kindness	 Accountability		
Appreciating that disclosure is situation specific and always belongs to the employee.	 Respect	 Accountability			
Making sure that reasonable adjustments are considered wherever necessary.	 Accountability	 Inclusivity	 Integrity		
Ensuring wellbeing of employee and colleagues is considered at all times.	 Inclusivity	 Respect	 Kindness	 Integrity	

Putting the values and knowledge into practice (Employment) - Continued

PRACTICE AREA	APPLICABLE FRAMEWORK VALUE/S				
Ensuring that training and development opportunities are made available to support career progression.	 Respect	 Integrity			
Finding and promoting allyship and champions.	 Respect	 Integrity	 Ambition		

Capturing your actions

“The successful alignment of coproduction, quality improvement and experience of care requires a cultural change and needs to be driven from the highest level in an organisation or system.”
(NHS England, 2023)

The starting point suggested by the framework is consistent consideration of how to include lived experience perspectives within projects; and recording and reviewing this.

Understanding what ‘good’ and ‘effective’ engagement looks like can only be achieved through understanding what has been tried, how this was experienced by people, and what the outcomes were for the project. This is true both of engagement and employment.



For this first edition, the framework suggests that services and projects start recording and reviewing the following:

- **How was the inclusion of lived experience planned?**
- **What level of engagement (or employment) was the aim?**
- **What level of engagement or employment was achieved?**
- **How did you measure this?**
- **What would you do differently to achieve a better level of engagement (is/was this possible?)**
- **What difference did the inclusion of lived experience make? This could be a change to process/culture/understanding and the overall outcome for the project.**
- **Did participants (practitioners and people with lived experience) feel the activity was proportionate to the resources used (e.g. time) and outcome?**
- **What was the experience like for people with lived experience? Did they agree with your assessment of the level of engagement?**

Part 2: Resources

Language guide

Values represented:

Inclusivity



Ambition



Bravery



The organisations will have their own communications teams, which will advise on house style (standardisation requirements re: language, grammar and spelling for that organisation). However, there are some general concepts which can be used when thinking about engagement with people with lived experience, bearing in mind that these will often be useful approaches for everyone involved.

On an individual basis, and always when referring to their own support, health or care needs, people should be free to use, and have used, the terminology they feel comfortable with. The only rare exception would be if this is widely accepted as offensive and would not be appropriate for council/ ICB staff or members to use.

Some of the conversations with people with lived experience which shaped this guide have given different views on the use of language, but the consistent themes have been:

- Use clear and plain language, avoiding ambiguity.
- Support people to learn some of the terms so that they are equal in meetings (this seemed to be more relevant for regular commitments, than for a one-off consultation).
- Provide a glossary, if producing something which needs to use technical language or acronyms.



Language guide - Continued

Acronyms

Acronyms are easy to adopt when they are in everyday use in roles or services. However, it's very hard to remember what they mean for people who don't use them often, and they may have a completely different meaning in a different context. Acronyms can also reduce people to a collection of letters - referring to children and young people as 'cyp' for example, should be avoided. If it is not possible to avoid their use, circulate a list of common acronyms and explanations with agendas, minutes or invitations for meetings. During online meetings a method to explain acronyms that are used by participants should be considered (for example, would using the chat function to explain them be appropriate?).

Identity first language or person first language

"Person-first language introduces a person before any description of them. Examples include person with a disability, patient with cancer, and child who has cerebral palsy. Person-first language is intended to emphasise the fullness of a person and to avoid defining them exclusively by their disability or condition. Identity-first language involves stating a descriptor of a person first, as in autistic person and blind child. This is often done with the idea that the characteristic in question is an integral part of a person's identity and community membership and should be emphasized rather than minimized." (thesaurus.com, 2021)

Differing communities will prefer person first / identity first language and establishing this (e.g., via third sector or house style guides) should be part of planning. However, identity first language is preferred and should be used for participation and engagement with autistic people (Society, n.d.).

Associations

Holding an awareness that some words and phrases may have unintended and/or negative associations is important, to avoid unexpected responses. For example, the word 'user' for people with addictions; the word 'register' may make people wary; or they may have alternative meanings elsewhere – the term 'local offer' (for information on special educational needs and disabilities) is also in use in some social housing contexts for example. Good practice would be to ask people with lived experience to design or support communications, and to respond to insight as it is provided.

Metaphors and similes

It is important to keep in mind that while useful to make a point, or to add humour, metaphors in particular may only work for a specific audience familiar with the subject, or require additional processing time. Similes have the potential to be confusing, especially if someone does not have the same life experience or use of language. Clear language will exclude unnecessary additions, and avoid confusion if a literal interpretation is applied.

Note: a metaphor is the use of one thing to represent another ('they are a whirlwind' meaning 'they are very active') and a simile compares things ('their house was as clean as a whistle').

Neurodiversity

Definitions are included in the Resources section with thanks to the Kent and Medway Partnership for Neurodiversity (2023).

Language guide - Continued

Service user

The terms service user, customer and client all have limitations. People may not feel like customers or clients if they are waiting for a long time to access a service, and have no choice in how, when or what they receive. 'Service user' can reduce someone solely to their relationship as a recipient. Phrases recognising more than this aspect of someone are preferable – for example 'People who access the service', and use 'people' wherever possible.

The government (Cabinet Office and Disability Unit, March) and NHS (NHS England, n.d.) have produced guides which address language to use in reference to disabled people, and on making communication accessible to people with learning disabilities and autistic people which provide easy to follow reference guides.

Current language usage

Being aware of current language, and using it, is a step to holding sensitive conversations. Checking relevant organisations for up to date guides is useful. One example from Mind's language guide (when talking about mental health) is the use of 'a bit OCD' in reference to being tidy or liking cleanliness (Mind, 2023).

Using language which could imply blame or fault onto others, should be avoided. People are generally busy, getting on with their lives and the onus is on services and organisations to make the provision of feedback a meaningful activity. Terminology can be alienating – phrases such as 'hard to reach' can be replaced with more neutral terms - 'under-represented', if this is accurate compared to demographic data for example. 'Not heard from' can be clumsy wording when referring to a group including people who do not speak/ speak in some situations.

This [blog](#) on the [UpRising](#) website, by Haleema Ali, talks about the being 'hard to reach'.

Using gender inclusive language, and which does not assume traditional family relationships avoids

Referring to lived experience roles

Communication with a third sector organisation around titles suggested there was no clear preference for the types of roles which should always include lived experience outside of peer support and caution about titles being explicit reflected concerns such as being seen through the lens of lived experience only or being seen to speak for all people.

At this stage of development, the framework would suggest the continued use of familiar terminology such as expert by experience; peer supporter/peer support worker or 'lived experience lead for ...' with further work recommended for future reviews.

placing assumptions on people we engage with, and their own identity and relationships. The UN describes gender inclusive language (United Nations, n.d.) as 'Using gender-inclusive language means speaking and writing in a way that does not discriminate against a particular sex, social gender or gender identity, and does not perpetuate gender stereotypes.' Guidelines are available on the UN website for further reading which recommend avoiding specifying a gender where it is not relevance to the communication. (United Nations, n.d.)



Glossary and frequently referenced concepts

Term	Definition
ABCD	Asset Based Community Development – a way of acknowledging and using the strengths of the community to contribute to solutions.
EbE	Expert by Experience.
Family carer lived/living experience	Indicates that the experience is that of supporting or caring for someone with a health or social care need and or experience of receiving support. Experience of services will sometimes be direct (e.g., when advocating or receiving support for the caring role). Note: Young Carers is a specific term, see below.
First person lived/living experience	Indicates that the perspective is of someone with a health or social care need, or who has experienced services directly (not in a caring role).
ICB	Integrated Care Board ('statutory organisations bringing the NHS together locally to improve population health and care' (NHS, 2023)).
ICS	Integrated Care System ('a geographically based partnership of health and care organisations' (NHS, 2023)).
Lived or living experience	Knowledge and experience gained which is personal (may be past or ongoing).
Learned experience	Knowledge and experience gained through study, work or volunteering.
Models of disability	Two main models relating the experience to being disabled – these are the medical and social model <ul style="list-style-type: none"> • Medical model: "The medical model looks at a person's impairment first and focuses on the impairment as the cause of disabled people being unable to access goods and services or being able to participate fully in society." (Parliamentary and Health Service Ombudsman, 2015) • Social model: "The social model was created by disabled people themselves and looks at the barriers erected by society in terms of disabled people being able to participate fully in day to day life." (Parliamentary and Health Service Ombudsman, 2015)
Protected characteristics	Under the Equality Act 2010, specific protection against discrimination is given to the characteristics of: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion and belief; sex; sexual orientation.

Glossary and frequently referenced concepts - Continued

Term	Definition
System	'In relation to integrated care systems (ICS), this refers to the level of the ICS, typically covering a population of 1–3 million people. Key functions at the system level include setting and leading overall strategy, managing collective resources and performance, identifying and sharing best practice to reduce unwarranted variations in care, and leading changes that benefit from working at a larger scale such as digital, estates and workforce transformation.' (The King's Fund, 2024).
'The organisations'	Kent County Council; Medway Council; Kent and Medway ICB.
Unconscious bias	Beliefs or assumptions that lead to prejudice or preference for a person/group/entity.
VCSE	An acronym for voluntary, community, and social enterprises, also referred to as 'the third sector'.
Young Carer	Someone aged under 18 years old, who helps to look after a disabled relative, and/or a relative with a long term physical or mental health condition, or an unhealthy relationship with drugs or alcohol.

What is a Parent Carer Forum?



A Parent Carer Forum is a group of parents and carers of children and young people with special educational needs and / or disabilities. They are parents and carers of children and young people aged 0-25 years old, although often people will remain in touch or connected to their forum. The group provides a formal way for people to work

with local authorities, Integrated Care Boards (ICB) and local services to improve services and commissioning.

Parent Carer Forums are funded by the Department for Education, through an organisation called Contact. They can be in various forms – examples include a charity, or a Community Interest Company ('CIC'). There will only be one Parent Carer Forum in each local authority area, although other groups may also exist to provide feedback.

Parent Carer have two broad offers, which are (1) providing a way for parents and carers to work with strategic partners and practitioners and (2) providing signposting and information for parents and carers.

Usually, a Parent Carer Forum holds an Annual General meeting ('AGM') which gives an overview of who is who, and what activities and decisions they have made in the previous year. These will be advertised in advance and anyone can attend.

What is a Parent Carer Forum - Continued

Working together

“Our role is to be the voice of parents as a whole... we take the collective voice”.

Parent Carer Forums have a Memorandum of Understanding between the local authority, the ICB and the forum, which sets out how they all expect to work together. They are part of a National Parent Carer Forum, and have access to resources and training as well as opportunities to apply for funding for specific projects.

Parent Carer Forums inform and influence strategic and operational service commissioning, design, and developments to improve the experiences of families in their local areas.

They do this by gathering the views of local families and then working in partnership with local authorities, education settings, health providers and other providers to highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made.

For local authorities, and ICBs, they will be able to share the views of their members, as well as helping to find people to contribute to a specific project through these members and connections with other groups and organisations.

Parent Carer Forums will have volunteers or paid staff who are also parent carers who organise opportunities to get involved, and help to circulate information. They may have a social media presence, a mailing list, or in-person events. Each forum will do things slightly differently.

Providing signposting and information

“We are a friendly bunch of people who’ve been through it ourselves.”

Sharing information about local events as well as opportunities to feedback is part of a Parent Carer Forum’s support. For parents and carers, their vast knowledge of the local area can help to connect people with groups and activities relevant to their needs. They can also provide ways to meet other parents and carers, and to get together for peer support and understanding.

Parent Carer Forums don’t provide individual case support as part of their main offer, but they will have relationships with services that they can signpost members on to. Some Forums may have additional funding to provide this type of service, and will make this clear to people wanting to join. There are no charges to parents and carers who join Parent Carer Forums, although some meet up activities may have a small cost.

“We’re open to everyone... you don’t need a diagnosis to be a forum member.”



Tips for practitioners working with forums

“Please promote what you are doing, new initiatives don’t always seem to be shared.”

“Involve us early on, if you’ve chosen what you are going to do, why ask us?”

Neuro-affirming language

In 2023, the Kent and Medway Delivery Partnership Board for Neurodiversity agreed the following definitions for use. This Framework shares these definitions to further collective understanding and consistent use of language.

Note: Definitions have not been amended for this framework. Definitions relevant only to the Partnership Board for Neurodiversity have been removed.



Term	Definition
ADHD or Kinetic Cognitive Style (KCS)	Means people whose neurocognitive functioning diverges from dominant social norms by experiencing attention differences, and/or diagnostically labelled as having “attention deficit hyperactivity disorder” or “attention deficit disorder”, people who experience ADHD or ADD are part of the ADHD Neurominority Group.
Autistic People	Means people whose neurocognitive functioning diverges from dominant societal norms by being Autistic, and who are part of the Autistic Neurominority Group, where Autistic experience includes: differences in the processing of, and experience of: sensory, social, emotional, cognitive, behavioural, and communication of information.
Co-production or Collaboration	Refer to non-tokenistic, full-inclusion of Independent Neurodivergent Experts/Leaders/Advisors; this means equal and equitable collaboration between Neurotypical and Neurodivergent individuals (recognising the automatic power imbalances between Neuromajority and Neurominority members), involving joint decision-making on e.g., goals, processes, and outcomes ¹ , recognising that Neurodivergent people can also be experts/professionals in their own right, and should not be reduced to “experts by experience”.
Independent Neurodivergent Advisor	Refers to individuals appointed in accordance with this Agreement to the Delivery Partnership Board who are: Learning-Disabled; Autistic; or Autistic and Learning Disabled; or otherwise neurodivergent, and does not include individuals who cannot be classed as an Independent Neurodivergent Advisor as outlined here (e.g., this role does not include neurotypical carers; professionals; or advocates). The role of the Independent Neurodivergent Advisor is further detailed at Schedule 5.

¹ <https://www.liebertpub.com/doi/10.1089/aut.2020.0050>

Neuro-affirming language - Continued

Term	Definition
Identity-First/IFL Language	Refers to wording about a person that leads with a description of them in the context of a disability, medical conditions (including mental health conditions), or other physical or cognitive difference. Autistic people generally prefer Identity-First language and people with learning disabilities, or learning-disabled people neither preferred nor rejected, provided the principles of the social model of disability are applied. Examples include terms like Deaf person, Blind person, and Autistic person ^{2 3} . Generally speaking, the Autistic community prefer identity-first language, and there is evidence Identity-First Language when used to describe Autistic people is less stigmatising than Person-First Language ⁴ , and should be adopted by medical professionals (with the caveat for a need for language training delivered by Autistic people). Since 1985 people with learning disabilities have also defined themselves within a context of disability as disabled people, with the onus on non-disabled people to make adjustments and accommodations with regard to people being learning-disabled, rather than physically-disabled. Identity first language appears neither preferred nor rejected by people who are learning-disabled, or people with learning disabilities provided people are supported within the social model of disability. The terms are therefore used interchangeably throughout this partnership agreement.
Learning Disabilities or Learning Disabled	Refers to people disabled by way of dominant social norms related to learning and retention of information, throughout their life. For example, in understanding complicated information, learning some skills, looking after themselves or living alone. Learning disabilities starts either in utero, or in early childhood but might not be recognised until adulthood.
Multiply Neurodivergent	means to have neurocognitive function/s that diverge/s from dominant societal norms in multiple ways. For example a person who is Autistic and Learning Disabled is multiply neurodivergent; as is someone who is Autistic and experiences anxiety and psychosis.
Neurodivergent Representative	Means people employed, or paid for, or supported in accordance with this Agreement to the Delivery Partnership Board who are Autistic; Learning-Disabled; Autistic with learning disabilities with their supporter or carer as indicated by the person The role of the Neurodivergent Representatives is further detailed in Schedule 5.
Neurodivergent or Neurodivergence	Means having a brain and body that functions in ways which diverge from dominant societal standards of normal, which is a result of innateness or genetics, or produced through brain altering experience, or through a combination of the two (2).

² <https://www.thesaurus.com/e/writing/person-first-vs-identity-first-language/>

³ Resources supporting preference, but importantly wellbeing properties, of identity-first language: We are Autistic <https://aucademy.co.uk/2021/11/25/resources-supporting-preference-but-importantly-wellbeing-properties-of-identity-first-language-we-are-autistic/>

⁴ <https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.12706>

Neuro-affirming language - Continued

Term	Definition
Neurodiversity or Neurodiverse	Refers to the social model of human diversity of human body-minds. The human species is made up of those who are Neurotypical and able to perform Neuronormatively, and those who cannot perform in Neuronormative ways as expected by society currently. Those who cannot function or perform in a Neuronormative way are today's societally Neurodivergent. In a group of two or more people where one is Neurotypical and one is Neurodivergent, the group can be said to be Neurodiverse.
Neurominority or Neurominorities	Means a population of Neurodivergent people who share a similar form of neurodivergence and is one of the forms of neurodivergence that is largely innate or genetic and is inseparable from who they are and the form of neurodivergence they share is one to which the neurotypical majority tend to respond with some degree of prejudice, misunderstanding, discrimination and/or oppression.
Neurotypical and Neuronormative	Refer to those in society who currently are able to perform and function in an expected and Neuronormative way.
Person-First Language/PFL	Refers to wording that introduces a person first and then follows with a descriptor in relation to a disability, medical condition (including mental health conditions), or other physical or cognitive difference. Since 1985 people with learning disabilities have also defined themselves within a context of disability as disabled people, with the onus on non-disabled people to make adjustments and accommodations with regard to people being learning-disabled, rather than physically-disabled. Identity first language appears neither preferred nor rejected by people who are learning disabled, or people with learning disabilities provided people are supported within the social model of disability. The terms are therefore used interchangeably throughout this partnership agreement.

Resources for people with lived experience (a starting point)

If you are working with people who are keen to find opportunities to become involved beyond your service or project, or who would like some additional support there are some resources available. This is a non-exhaustive list, please add your own findings:

Opportunities

- Involvement with NHS England:
[NHS England » Patient and public voice partners \(PPVs\) and people with lived experience](#)
 - NHS England Patient Participation Involvement Policy: [ppp-policy-edit.pdf \(england.nhs.uk\)](#)
 - Link to InTouch newsletter (NHS England): [NHS England » How to get involved](#)
 - Parent carer forums:
Medway Parent Carer Forum - [Welcome to The Medway Parents & Carers Forum \(medwaypcf.org.uk\)](#)
Kent PACT - [Home - Kent PACT \(kentpactnew2022.co.uk\)](#)
 - You will find KCC's public consultations, and other engagement activities, on its online engagement platform called Let's talk Kent: [www.kent.gov.uk/letstalk](#).
 - Youth Councils: [Medway Youth Council | Medway | England Kent Youth County Council - Kent County Council](#)
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Resources to support people with lived experience

- Guides for organisations and individuals on supporting someone to tell their story (HSC Public Health Agency, Belfast, 2017):
[Guide to speaking publicly about self-harm/suicide/mental health issues | HSC Public Health Agency](#)
 - Guide for individuals wanting to share their story (Shaping Our Lives, 2023):
[Lived experience guide \(shapingourlives.org.uk\)](#)
 - Mind Action Wellness Plans: [mind-wellness-action-plan-workplace.pdf](#)
 - My Involvement Profile (on this page/to support people to outline their needs and preferences):
[Share your lived experience - Shaping Our Lives](#)
 - NHS Peer Leader Programme: [NHS England » Peer leadership](#)
 - Charlie Waller PLACE (for people providing parent carer support): [PLACE - Parent Support Network | Charlie Waller](#)
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Additional resources for practice (a starting point)

Children and young people

- Kent Youth Charter (explains how young people would like to be treated and link leads to co-production training): [The Kent Youth Charter - Kent Resilience Hub](#)
 - Lundy Model (adopted by Kent County Council I-Thrive and Participation team): [Participation Framework | Hub Na nÓg \(hubnanog.ie\)](#)
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Current use of language

- 'Why language matters' (NSPCC blog): [Why language matters: why to avoid the term 'victim' to refer to children who have experienced abuse | NSPCC Learning](#)
 - Inclusive language guide from Bradford District and Craven Health and Care Partnership: [Inclusive language - Your reference guide by ReducingInequalities - Issuu](#)
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Lived Experience in the workplace

- [Working definition of trauma-informed practice - GOV.UK \(www.gov.uk\)](#)
 - [Involving-people-with-lived-experience-in-the-workforce-2020.pdf \(tnlcommunityfund.org.uk\)](#)
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Local Government Association Guides

- Link arrives at 'resident communications' and two resources: [Resident communications | Local Government Association](#)
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NHS Guides

- NHS Bitesize Participation guides: [NHS England » Bite size guides to participation](#)
 - NHS training (registration and eligibility requirements): <https://www.futurelearn.com/courses/working-with-people-and-communities-to-improve-health-outcomes/1/todo/165427>
 - Kent and Medway ICB Toolkit: [Engagement toolkit for commissioners :: NHS Kent and Medway \(icb.nhs.uk\)](#)
 - FutureNHS workspace 'Start with People' (registration required)
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Representation

- Listen, a short film by CommunicationFIRST: [LISTEN Movie - Audio-Described Version \(English\) - YouTube](#)
- Kimberlè Crenshaw speaking on intersectionality: [Link](#)
- Mind's guide to reasonable adjustments: [Link](#)

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Contacts



Project team:

Queries regarding the development of the framework

stories@kent.gov.uk

To provide feedback:

<https://forms.office.com/e/QjJR2bDr6n>

Note: If you require an alternative method of feedback, please contact Mhairi or Tamsyn at stories@kent.gov.uk, who will then get in contact with you and make alternate arrangements.

Lived Experience Engagement and Employment Framework

“The art of conversation is the art of hearing as well as of being heard” - William Hazlitt

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Kent and Medway

