Kent and Medway Mental Health NHS Trust
Learning Disabilities & Autism (LD&A) Programme

Meeting summary — Cross-Services LD&A Community of Practice, Session 3

Date	Wednesday 1 July 2026, 12:00–14:00 (Microsoft Teams)
Co-leads	Ruth Germaine and Dr Chloe Farahar
Attendance	~33 present (Session 2: 43); the smaller number was expected — several people had already flagged they could not make this date, so it is not a real drop
Purpose	Third session of the cross-services pilot: hear back on pace and structure, walk through the draft Charter, and open a shared conversation on language

Context

Session 3 was the point where this Community of Practice stopped being an idea and started to feel like a practice. Two sessions of setting the foundations — why we are here, who we are, the words we use — meant some professionals were ready to move faster. But this space moves at the pace of our lived experts, and that is deliberate: how we run the room *is* the learning. The session did three things. It fed back honestly on the tension between those two paces and named what has changed as a result. It walked the whole community through the draft Charter for the first time. And it opened a conversation on language — the everyday words that either open participation or quietly shut it down.

What follows is a summary for our system and service partners. As always, personal disclosures shared in the room are held with care and are not reproduced here.

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1. “We heard you”: pace, structure, and honesty

We opened by naming a genuine tension. Our professionals told us the pace felt slow — we are still, three sessions in, agreeing what we are for. Our lived experts told us the opposite: sessions felt too busy, with too much information and too many activities to process in one sitting. Both are true. Rather than split the difference, we were clear that we will always go at our lived experts’ pace, and we asked professionals to stay with us, because working out how to adjust our own settings *is* the work the wider system needs to do.

What we have changed, and why:

- **Longer sessions.** Two hours rather than 90 minutes, so there is time to prepare, process and follow up, rather than rush.

- **A bi-monthly rhythm from Session 4.** Every other month for the whole community, with a lived-expert-led prep meeting in the month between to shape the next session and support facilitators in their role.
- **Better-sized breakout rooms.** Groups of six to eight with a named facilitator — small enough to feel safe, large enough that no one is put on the spot to fill a silence.
- **More structure in the rooms, and more honesty about access.** We are working to do better on predictability, and to say so plainly when we fall short.

Felicity Head, a lived expert and co-facilitator, gave the reflection that anchored this. In an earlier session, three people had been dropped into a breakout room with no prompt and “a big well of nothing” to build on — and, as they put it, a room of people who each needed someone else to get them started. Their point landed sharply: a standard GP appointment is often exactly that same problem, an empty void handed to the patient to fill. Designing the void out of our own room is a rehearsal for designing it out of services.

Felicity also sharpened what we mean by action. It is not enough for change to be visible; visible action can still be “smoke and mirrors”. It has to be real and beneficial. That distinction now sits at the centre of how we hold ourselves to account.

2. What we carried forward from Session 2

Session 2 held 43 people from Session 1 — no drop-off — and left us with five thematic threads: three deepening, two new. One concrete outcome from that room is worth repeating, because it is the point of the whole enterprise: one service wanted to re-evaluate its assessment pathway and needed lived experts; another already ran a lived-expert panel for exactly that; they had never met. The connexion was made simply by putting the two people together. Nine of twelve respondents left with a concrete next action.

The five threads:

- **Lived experience leadership** — made operationally visible, with lived experts leading and shaping as facilitators, not sitting on the edge.
- **Intersectionality** — named as a structural demand. Black and brown Autistic people and people with a learning disability remain under-recognised and under-represented, and building that representation is a stated priority we will keep returning to.
- **Anti-talking-shop** — the demand for action that is real and beneficial, not merely apparent, and the honesty to name when a system genuinely cannot move something.
- **System knowledge and mapping** — new. Systems do not always know what other systems do; mapping this together lets us support one another and problem-solve as a collective.
- **Accessibility** — new, and named alongside an honest acknowledgement that a request had not been upheld and predictability had slipped.

The closing mood in Session 2 was hopeful, motivated, and calling for action.

3. The draft Charter

The whole community saw the draft Charter together for the first time. It is built from everything people have told us across the earlier workshops and Sessions 1 and 2, and it is explicitly a living document. One line from the workshops sits at the top of it and captures the intent: “this feels like we are doing it.” Two versions were circulated — a long read and a plain-English easy read — so people can revisit it in whichever form works for them.

What it says

- **What we are:** a Community of Practice for everyone working with, supporting or living alongside Autistic people and people with a learning disability in Kent and Medway. We learn with and from each other, and that learning changes what we do.
- **Who we are:** lived experts — Autistic people, people with a learning disability, people with ADHD — families and carers, and staff across health, social care, education, mental health, the voluntary sector and local authority. Many of us hold both professional and lived expert identities. Reaching black and brown communities, primary care and others facing a barrier is a stated priority.
- **Our purpose:** understand what matters and get it into everyday practice; build shared knowledge across services; listen to voices that are underheard and act on them; rebuild trust; and connect people across Kent and Medway who need to know each other.

Five values

- Lived experience shapes our structure — the agenda, language and decisions, between and within sessions.
- We listen to learn — knowledge and experience across roles and lives is equally valid.
- Action and change — visible, traceable action, however small.
- Safe and brave — space for honesty and uncertainty, receiving what people share with care.
- Language shapes participation — we use language that respects identity and opens participation, and we keep learning about it together.

The word “brave” prompted the most useful disagreement. It is in the Charter because a lived expert used it in this room, and we build the Charter from people’s own words. But, as Felicity and the lived experts’ Friday group set out, “brave” can be belittling: it can frame necessary self-advocacy as though someone is being plucky in the face of a scary world, rather than doing what is necessary. That the word made it in, and is now being questioned, is precisely how a living document is meant to behave.

The poll on whether the draft reflects what people told us returned mostly “fully” and “mostly”, with some “partly” (around 20 responses). We were clear that “partly” matters most: the odd point only one person raises is often the important one, and there is room to add to the Charter now, in the chat, or through the lived experience prep meeting before Session 4.

4. The words we use

The language conversation was framed carefully, drawing on the National Autism Training Programme. We want to balance two things that pull against each other: not causing distress through careless word use, and not shutting down conversation by making people so frightened of getting it wrong that they say nothing. Everyone in this room is here because they want to do better. The phrase we offered to hold both together was: “now I know better, I’ll do better.”

We distinguished micro from macro injurious language. Macro language is the big, obviously harmful stuff. Micro language is the everyday word or reaction that seems small in isolation — but you might be the tenth person that week to say it, and the pinpricks add up. The words we put up to react to included burden, trauma, cure, complex, treatment, capacity, challenging behaviour, high/low functioning, strong, and brave/resilient.

Where the discussion went

- **Resilient.** The word people struggled with most. Margaret Dean — a lived expert and Autistic person whose PhD examined the lived experience of suicidal Autistic adults — put it starkly: efforts to “increase resilience” often just hide our autisticness and teach us non-autisticness, which raises suicide risk. Reducing suicidality means reducing the *need* to be resilient and having others do more of the coping, rather than asking us to absorb more. Corrinne Hall added that “resilient” can quietly validate giving someone less support. Chloe’s question — are we not allowed to be soft, to be sad, without being tough? — captured the mood, echoed by a parent in the chat: “I’m often told I’m strong. No — I’m just doing what I have to do.”
- **Strong / brave.** Karen Ertsaas, a parent of an Autistic daughter, described how being called strong, brave and resilient can invalidate a person: the seriousness of how they feel is not taken on board precisely because they are seen as coping. Her daughter does not want to be resilient.
- **Challenging behaviour.** Steve Chapman, a long-standing learning disability advocate, said the phrase sends a cold shiver down his spine. All behaviour is communication for a reason; the response is to sit with the person and find out why, then work out how to support them — not to label the behaviour and move on.
- **Complex.** A double-edged word. It can honestly acknowledge that several things are moving and intertwining for a person — or it can be a get-out clause, a way of calling someone “unknowable” to cover a lack of time taken to understand them. As Chloe put it, a lot of who services call “complex” is just everybody she knows.
- **Medical language, ingrained.** A neurodivergent-heavy team of occupational therapists reflected the opposite problem: medical language is now so embedded that patients themselves use it, and staff can struggle to reach what a person actually thinks and feels underneath it. OTs tend to do well with our populations precisely because they look at the environment, not the person, as the thing to adjust.
- **Person-first versus identity-first.** We go with the language of the person — always. But being led by their language does not mean being incurious about it: sometimes distancing from “Autistic” reflects an internalised, negative view of the self

that is worth gently noticing. Rebecca Masalovich made the essential companion point — people are allowed to change their language, and we move with them.

Two structural cautions came through the discussion. Annie Cardinal noted that even as we move from deficit language toward need, we risk simply pigeonholing people in newer words; and Chloe pointed to how the language of the adversity paradigm has already been co-opted and drained of its original meaning. Better words do not stay better on their own.

5. Breakout rooms: language in practice, and the accuracy problem

The breakout question asked people to think of a conversation where language got in the way — theirs or one they were part of — and to name what would have helped and the one thing that would have made it different. Across the rooms, one theme rose above the rest: accurate, verbatim reporting, and the harm of getting it wrong.

Being spoken to, and being recorded accurately

- **Group 1 (Rebecca Masalovich).** Speak to the person the appointment is for, not their carer or parent. Do not assume all Autistic people or all people with a learning disability need the same things — well-intentioned decisions, based on the last person a professional worked with, can miss the person in front of them.
- **Connor Johnson.** “Engaged” and “engagement” are often an inaccurate account of what actually happened. A child who did not answer one question at one moment is not a child who cannot; writing notes that avoid assumptions about motivation or ability, while still being useful to other professionals, takes conscious effort.
- **Diane Weekes.** Think strengths-based, not deficit-focused; needs-based, and mindful that needs are fluid and lifelong. Challenge people using unexplained language and ask them to explain it — while remembering that language is individual, so getting to know the person comes first.

The inaccuracy that changes care

The main-room group (with Helen Carter and Karen Ertsaas) surfaced the sharpest examples. Helen described a dietitian assessing her situationally mute daughter for ARFID entirely through leading questions — “do you have cereal?”, a nod written down as fact — producing answers the clinician wanted rather than the truth. Only Helen’s presence corrected the record: her daughter does not eat breakfast or lunch. Separately, a passing “yeah, I like badminton” became “participates in badminton regularly” in a CAMHS report, for a child who had played twice in a year. The mechanism matters: a nod may be masking, a survival instinct to agree, a crisis that makes the question unprocessable, or simply not yet knowing one’s own answer — none of which is untruthfulness.

Chloe’s own example made the principle concrete: a young person who said “not being wanted” had it written down by a teaching assistant as “neglect” — two entirely different things. Verbatim reporting is not pedantry; it is the difference between hearing a person and overwriting them. For non-speaking and situationally speaking people, the chat box is their voice, and we read it word for word.

Good practice, and a systemic warning

- **Kate Foggon.** Put patients' words in quotation marks and attribute them; describe what you see rather than judging it. "Poor eye contact" is a value judgement; "looked to the side rather than at the clinician" is not. "Poor play skills" asks who gets to decide what play should look like — lining things up is meaningful play.
- **Wendy Wright.** A care needs assessment where the person described a fixed routine and fixed interests, and their mother strongly disliked that framing. Wendy recorded the person's own words and separately recorded that the parent disagreed and how she would have put it — holding both, and staying open to revising it later.
- **Felicity Head.** Even verbatim words can be misread by a reader, however carefully crafted. And there is a darker catch-22: a person with repeat trauma from being misunderstood can foresee that asking for help might trigger a safeguarding response, whose misunderstanding could then trigger the very thing they were trying to prevent — which blocks them from asking at all. It makes systems self-defeating.
- **Robyn Swirles.** A note of caution on AI. Tools like Copilot help with minute-taking and processing, but outputs are not always re-checked, and wording can be quietly amended or misconstrued — again with safeguarding consequences. Felicity added the recruitment evidence: AI filters trained on the internet's anti-autistic content have been shown to screen Autistic applicants out, invisibly, inside a black box.

Kate also named the honest bind everyone recognised: sometimes deficit language is still required to unlock support. Where that is unavoidable, being honest with the person that this is why we are using it is the least we owe them.

6. The room, in its own words

Check-in. Arrivals ranged from excited, curious, open and calm to overwhelmed with work, exhausted, a bit rushed, headachy and confused — an honest spread. Of the people who told us who they were, around 12% identified as Autistic, alongside people with a learning disability, family members, NHS and health staff, and several who selected "other" (we will make the next poll more reflective).

One thing I learnt / one thing I will do differently. The takeaways clustered tightly around allyship and accuracy:

- "Listen more carefully to the words the person uses, and document accordingly."
- "Challenge language more" — and ask safe colleagues about their language, gently, to educate.
- "Check that I have interpreted a person's words the way they intended them to be understood."
- "Always be sensitive to how a person sees themselves, and reflect it accurately — in conversation and in writing."

Several people asked to hear more in future — Margaret Dean's research on Autistic suicidality; a talk on the children and young people's system transformation in Kent; and overviews of individual teams and services and their move into KMMH. One chat comment framed the whole system-mapping case neatly: systems do not always know what other systems do — and it would do them good to learn.

7. How the Community of Practice works from here

- **Bi-monthly sessions from Session 4 (August).** Proper time to prepare, digest and follow up. Dates to be confirmed.
- **Lived experience prep meetings in the off-months.** Lived-expert-led, shaping the next session — a core part of how we run, not an add-on. The first is in July.
- **Sub-groups.** Smaller groups can take specific pieces of work forward between sessions as they emerge.
- **Future session formats.** Sharing good practice; case-study problem-solving on anonymised, tricky cases; resource sharing; and hearing directly from lived experts. Anyone willing to present a tool, project or approach is warmly invited.

Two live threads sit underneath this. First, sustainability: Ruth has carried much of the operational load and will not be able to continue at that level, so we are actively looking for system and service partners to help run the Community of Practice — it is not a heavy commitment, and sign-up is moving to a form rather than email. Second, representation: concrete routes into primary care were discussed (via George Matuska's Primary Care Network connexions and existing protected learning time slots, and via quality and governance leads), alongside the standing priority of reaching black and brown communities.

Two invitations to present are already in motion: Annie Cardinal's children and young people's team (recently moved into KMMH), whose neurodivergent-affirming approach George Matuska has been impressed by; and the ARMS mental health nurse who, given only the Aucademy profile tool and no guidebook, taught herself to build a young person's Autistic profile — and found that doing so *was* the mental health intervention. Her example makes the point better than any slide: for many Autistic people, the thing that helps most is being helped to understand who they are.

Actions

Action	Owner	By when
Confirm and circulate dates: lived experience prep meeting (July) and Sessions 4 and 5	Ruth Germaine / Chloe Farahar	July 2026
Send post-session materials — slides, Easy Read briefing, note that Session 4 is planned for August	Chloe Farahar	Following session

Action	Owner	By when
Recruit system/service partners to help co-run the CoP; move sign-up to a form	Chloe Farahar / Ruth Germaine	Before Session 4
Gather Charter feedback and take it into the lived experience prep meeting	Lived experts / co-leads	Off-month (July)
Take the Black/Brown ambassador-role proposal to the planning group	Chloe Farahar	Ongoing
Progress primary-care representation via PCN links, PLT slots and quality/governance leads	Chloe Farahar / Ruth Germaine / George Matuska	Ongoing
Invite Annie Cardinal's CYP team to present at a future session	Chloe Farahar	Future session
Invite the ARMS mental health nurse to the Delivery Group / a CoP session	Chloe Farahar	Future session
Explore inviting Margaret Dean to present her research on Autistic suicidality	Chloe Farahar	Future session
Decide where to host the shared resource collection (website vs. padlet)	Chloe Farahar / Alexandra Hamblyn	Ongoing
Add poll instructions and improve poll layout/accessibility for next session	Ruth Germaine / Chloe Farahar	Session 4

Key contacts

Name	Role / organisation
Ruth Germaine	Co-lead, Cross-Services LD&A CoP (KMMH)
Dr Chloe Farahar	Co-lead, LD&A Programme (KMMH)
Felicity Head	Lived expert and co-facilitator
Margaret Dean	Lived expert; Autistic; PhD on the lived experience of suicidal Autistic adults
Steve Chapman	Learning disability advocate
Karen Ertsaas	Parent / lived experience by proxy
Helen Carter	Parent
Rebecca Masalovich	Medway Community Healthcare (Group 1 facilitator)
Connor Johnson	Medway Community Healthcare
Annie Cardinal	Lead for psychological professions, CYP mental health (KMMH)
Diane Weekes	NHS Kent and Medway ICB
Alexandra Hamblyn	NHS Kent and Medway ICB
Kate Foggon	Kent Community Health NHS Foundation Trust

Name	Role / organisation
Wendy Wright	AHP / assessment (lived experience prep group)
Robyn Swirles	CY EDSEN
Corrinne Hall	KMMH
George Matuska	RNLD Strategic and Clinical Lead (KMMH) — primary care links

Notes

The pace tension is not a scheduling problem to be solved; it is the clearest evidence yet of what the programme argues. A room that cannot comfortably hold both lived experts and professionals at the same speed is a small model of the services we are trying to change. Getting it right here is a rehearsal, and worth naming as such to sceptical partners who read “slow” as “stalled”.

“Brave” and “resilient” deserve a flag beyond the language conversation. When a person’s distress is read as strength, the seriousness of that distress is discounted — and Margaret Dean’s work ties that directly to suicide risk. This is a safeguarding point as much as a linguistic one, and it sharpens the case for the health-inequality workstream: adjusting the environment (and the people in it) rather than asking Autistic people to absorb more.

Accurate, verbatim reporting emerged as the single strongest cross-cutting theme, and Felicity’s safeguarding catch-22 turns it into a systemic risk worth surfacing to the wider system: a process designed to protect can, through misreading, deter the very disclosure it depends on. This is a concrete candidate for a shared piece of cross-service work — the kind the CoP exists to broker.

The critique of “complex” quietly restates the left-shift logic. When services call a person unknowable, they are often describing under-invested time rather than an intrinsic property of the person. Proactive understanding is cheaper, and kinder, than reactive crisis.

Finally, two risks to hold. The AI/documentation thread (recruitment filtering, unreviewed Copilot summaries) is an emerging governance issue the programme should watch. And the CoP’s dependence on Ruth is a live sustainability risk; distributing ownership before Session 4 is not optional if the bi-monthly rhythm is to hold.