Carers workshop – 20th March 2025

Eastern Region Carers Network, online meeting. March 2025
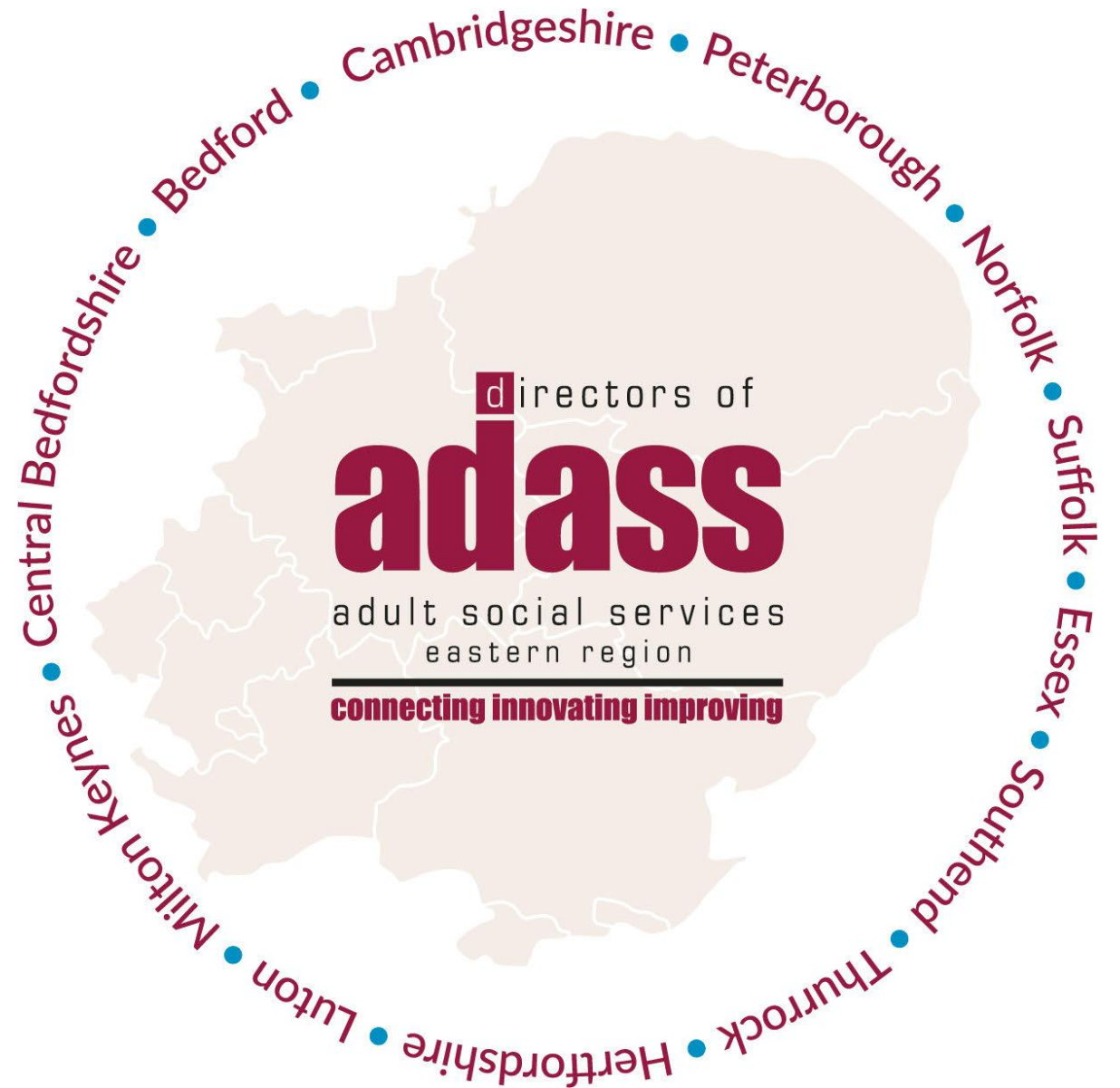
Mendonça 2025

Context

- The event was co-produced with the carers network, involving carers over the past year.

- Carers Leads extended invitations to carers organisations and carers, ensuring they were briefed on the context.

- A total of 40 attendees participated, with 10 out of 12 councils online, carers organisations, and at least one carer from each local authority, though corroboration of the exact attendance from carers was challenging e.g. we often couldn't tell through email addresses provided alone

- The purpose of the event was to discuss how we have taken into account the feedback from carers throughout the year and to highlight key initiatives we have implemented at a regional level, while also offering a platform for carers to share their stories.

- It was apparent, there was an imbalance between the professionals discussing their work and the opportunities for carers to share their experiences, which is a lesson we will take forward.

- We used Microsoft Teams for the event, which posed difficulties for those without a Microsoft Teams account.

Quotes and reflections

Listening

- "We want to be listened to and advice sought"
- "sometimes we feedback language isn't right and we are not always listened to"
- "Carers want a space to say what we feel"
- "Carers need to be listened to and their knowledge truly valued"

Language

- Language is important and shows respect – we don't use glorious ordinary language

- "What does local offer mean"

- "How do operational staff address the challenges around language and respect for carers?"

Support

- "Taking a long time to get a carers assessment which for me, ended in a carer breakdown and triggered safeguarding". It's important people know from the outset how long they need to wait for a carers assessment and risks considered.

- "Respite doesn't mean I need respite for my wife, I need respite with my wife"

- "We are in a state of crisis, begging before support happens"

- "Carers need tangible support which makes a real difference to their quality of life (not simply e.g. a manicure)"

- "Offer carer advocate services to carers in crisis (they are too exhausted to represent themselves). Ideally this should be another carer who can fully 'get' this issue"

Peer to peer spaces

- "the best peer support comes from unpaid carers rather than the system". Peer support helps with navigation and language

- "I would prefer to go to a group which has activities which I enjoy"

- "I have tried to get to zoom groups for parents of autistic people. What has been provided is face to face meetings which are not near by my home. I am aware Zoom doesn't suit everyone but there is the anticipation that everyone has to be local and face to face"

Policy

- "Politicians focus on working age adults, how many carers are working?"

- "Unpaid carers are a workforce using a business organisation approach – all age carers strategies must contain at least two elements, a workforce development plan and action plan which is monitored"

- "Moving Care Closer to Home is going to bring a huge workload"

- Could we use the investment grid at a regional level to help prioritise what needs to be done and have a smart plan"

Respect

- "It's me who has the degree in my sons, I have all the experience that they need to consider"

- "We don't use carers in our own organisations to support other carers"

- "I'm here with my work hat on but I am also a carer". Acknowledgement that we needed more carers on the call.

- "Carers are the experts. They should co-produce services so that services reflect genuine needs of carers"

- "Carers need Social Care and Health Workers to talk to them as human beings (not in LA/Health language and jargon)"

Information and advice

- "As a carer – the key from the Care Act is that you have to be willing and able, not just able"

- "We need to ensure that social workers are aware that there is no responsibility on unpaid carers to care for family members/friends and it's a much broader approach"

- "We need better support to diverse communities"

- "It's the so what, what difference does it make to people who are caring"

- "How many sites have an organisational chart on their website" – who to speak to and what this can provide?

- "Sharing information about the Care Act, Care Act eligibility is a must" – carers don't always know about the Care Act and lots of people haven't had a carers assessment

- "After 20 years, still stumbling across organisations who can help"

Training

- "Professionals need to be trained on how to relate to carers. It should cover empathy, language used and imparting of knowledge e.g. explaining that carers can do as much or as little caring hours as they feel they can, informing them of key legislation. LA/NHS staff are inadvertently creating a barrier to carers accessing help due to the language they use"

Next steps

- The feedback we have received from carers, carers organisations and carers leads will be a catalyst for regional improvement across the next year.

- Through the Regional Carers Network, we will evaluate the insights gathered across several pieces of engagement work including the regional event and explore three or four areas we can work together on during 2025/26.

Useful links

- Over a Brew coproduction coffee sessions: https://adasseast.org.uk/co-production/over-a-brew-virtual-coffee-sessions

- Working Together for Change: https://adasseast.org.uk/?s=working+together+for+change

- Information in relation to Mobilise: https://adasseast.org.uk/?s=Mobilise

(New report to follow and will appear soon)

- Language matters to carers video: https://adasseast.org.uk/videos/1661-insensitive-language-can-undermine-people-who-care

- Publications on a page over the years with clickable links including reports in relation to carers: https://adasseast.org.uk/?s=publications