

Lived Experience Network Event Civic Centre, Carlisle

Friday 20th September 2024



Cumberland Community Voices

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**tabletop discussions of LE progress to date –
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Foreword

The citizens of Cumberland are experts in what it is like to live here, they love this place, care about it like no one else can and really do have a vested interest. This is their home, their services and their future. It's time for us to take a bold new approach to involving them in the next chapter for Cumberland.

It is widely agreed that the voice and experiences of local citizens should be harnessed to help develop and shape local services. Cumberland Council has a strong belief that citizens should be the heart of all that we do. Incorporating lived experience into the way we shape, and design services can lead to improved outcomes, early interventions and prevention as well as better informed decision makers.

The Network of Lived Experience does not seek to replace the plethora of organisations in the Voluntary, Community, Faith and Social Enterprise sector who are rooted in their own field, nor the Teams of professionals working within Council services with existing connections with those with lived experiences, rather to add to it and enhance it in a focused way. Following discussions it became apparent that there are many organisations in Cumberland who are actively including lived experience within their decision making.

In collaboration with Cumberland Council, Healthwatch Cumberland created an event inviting organisations together to explore what is working well, what could be better and how lived experience can influence us all when it comes to service improvement.



This report will highlight the discussions that took place, the themes and attitudes on the day and the aspirations for what is next.

We would like to thank all attendees and participants for their valuable contributions, thoughts, experiences and reflections.

healthwatch
Cumberland

Event Details



Location details

The Cathedral Room

Civic Centre

Carlisle

Date

20th September 2024

10am - 4pm



Cumberland Community Voices

A group of over 50 lived experience practitioners gathered in Carlisle Civic Centre to share their stories and experiences from the Voluntary Sector, The Council and other Health and Care organisations.

After sharing their experiences, the delegates participated in tabletop discussions to discuss what had worked and had not worked and to raise issues that they want the Lived Experience network steering group to bring to the attention of the Council and the NHS services.

The capture of the real-world experiences is a vital input into the improvement of Health and Care improvement.



Showcase

We heard some incredible stories from 17 colleagues from across Cumberland, these are just some of the big takeaways we noted. A more detailed record is included in the long report which will be made available.

The Well Communities

- Addicts are best facilitators for addiction events
- Most staff are recovering addicts
- Collaboration with professionals/statutory services is essential

Silent Footprints

- Attendees own experience, not talked about in public
- Easier to share experience with others who have been through it

Patient Voice Volunteer

- Good networking with the University
- Can inform service development
- Can't go it alone, collaboration is a must
- World falls apart after 1st diagnosis
- Respite and emotional support essential

Carlisle Youth Zone

- Youth participation lead is key role
- Young people have strong opinions to be heard
- Provides 'healing for YP and adults
- YP decide the projects to be funded and help with writing the bid
- YP Help create strategies for YP support
- 2,000 YP can vote with their feet, therefore research must be inclusive

Carlisle Foodbank

- Space to talk to professional help eg Mind with consultation hub – valuable research resource
- Safe space
- Stigma is a barrier to help
- Linked to CCC health and wellbeing team
- Multi agency referral

Age UK North Cumbria

- Linked to CCC Health and Well being
- Combatting poverty
- Multi agency referral

Links with Healthwatch ageing well

Cumbria CVS

- Bridge between statutory services and voluntary sector
- Potential to be a hub for voluntary sector lived experience?
- Facilitating Lived experience is not a role/job!

The Happy Mums Foundation

- Provides mental health support for new mothers
- Has a hub
- Community engagement co-Ordinator
- Mums share their maternity experiences with other agencies
- All staff have MH training
- Mums coached to become volunteers

Volunteer at Ehlers Danlos Support UK

- 1st full time co-ordinator for the condition in Cumbria
- No clinical specialist in Cumbria
- Lived experience of the condition not used by the NHS

SENDAC

- Included in Service redesign with Local authority and NHS
- Annual survey triggers selective deep dive which informs areas for improvement
- Provides feedback to families
- Have been able to influence service change
- Not enough support from funders/statutory services
- Work with professionals to redesign services
- Goal to have parent/carers standard participation on redesign of services

Triple A Project

- Lived experience is at the heart of all they do
- Autistic people empathise with non-autistic people but non-autistic struggle to empathise with Autistic people
- Trainers are autistic
- 1 to 1 support
- Use social groups with facilitators who have used the service
- Autistic people 9x more likely to commit suicide

People First/Healthwatch

- People First have an expert hub
- Lived experience are included in expert hub

Cumberland Council

- Development offered for carers
- Lived Experience informing support for carers
- Mantra –everyone is a professional!

Andy's Man Club

- Takes users complaints and turns into a movement for change from within – voice of the service use
- Service users are a source of lived experience within the community

Cumberland Council – Ambassadors for Care

- Lived experience in care
- Codesigned brief for social workers
- Young people workshop defined what good social care should look like
- Young People access to their own personal record was a game changer

Community Panels

- Lived experience stories identify good and bad practice in services
- Panel with multiple agencies encourages communication and understanding
- Community network engagement –in investment plan – what do you want your neighbourhood to look like?
- Use external private sector organisations to fund projects e.g. Sellafield, Carlisle Utd
- Care experience is a protected characteristic

Angel Advocates

- New Charity
- Works with CVS
- Recruiting advocates to help people



Big Takeaways

People with Lived Experience are best facilitators to enable open discussion

Co production – Young People decide what to fund

Trusted space – no stigma

Lived Experience is at the heart of all we do!!

Proactive use of Lived Experience in service development

Lived Experience can support service funding from private sector

Lived Experience informs policy

Lived Experience provides bridge with service focus

Lived Experience educates service providers – language & behaviour

Lived Experience works well with multi –agency collaboration

Networking with Academia, Statutory service and Voluntary Sector

Culture Shift

Partnership

Coproduction

Making a difference



Key Themes

What worked

Recognition of Lived Experience:

Acknowledging the value of lived experience was appreciated.

Community and Peer Support:

Organisations like Andy's Man Club and the 12 steps programme provided effective support

Flexibility in Crisis:

The removal of bureaucratic barriers during crisis like Covid-19 and floods enabled quicker, more effective responses

Collaborations:

Partnerships and co-facilitation efforts built trust and improved outcomes. For example, CVS and Shared Lives initiatives were positively mentioned.

Inclusive Practices:

Efforts made to make services more accessible (e.g., easy-read documents, safe spaces) and training for staff contributed to positive engagement.

Genuine Co-Production:

Involving people with lived experience in meaningful ways built trust and yielded better results.

Key Themes

What Didn't Work

Return to Rigid Policies:

After the pandemic, reverting to rigid strategies and policies hindered progress.

Sustainability Issues:

Overreliance on crisis funding without long-term plans made many initiatives unsustainable.

Lack of Collaboration:

Charities were competing for funding rather than collaborating, and town councils.

Inaccessibility:

Both physical and digital inaccessibility were barriers, particularly for those experiencing digital poverty.

Tokenism and Retraumatization:

Participants felt their contributions were sometimes tokenistic and retraumatizing, especially when no real change followed.

Lack of representation and Feedback:

Opportunities for feedback were inadequate, with many feeling that their full stories weren't captured or valued.

Suggestions for Improvement (Even Better If):

Improved Access to Funding:

Broadening access to commercial funding and having the council act more like a co-operative could help sustain initiatives.

Meaningful Collaboration:

Increased collaboration across the third sector, and ensuring that GPs and social workers better signpost services, was suggested.

Inclusive EDI Policies:

·More inclusive equality, diversity, and inclusion policies were called for, particularly in recognising contributions and providing safe spaces.

Honest Communication:

Building better, more honest communication and following up on feedback were seen as vital for improvement.

Trauma Informed Approaches

Ensuring the safety of individuals after sharing their lived experiences and taking a trauma-informed approach were emphasised.

Ideas Going Forward

Improving Communication:

Using evidence and reports to communicate and shape services, with forums for discussions and debates with professionals, would enhance understanding and action

Involving Experts by Experience:

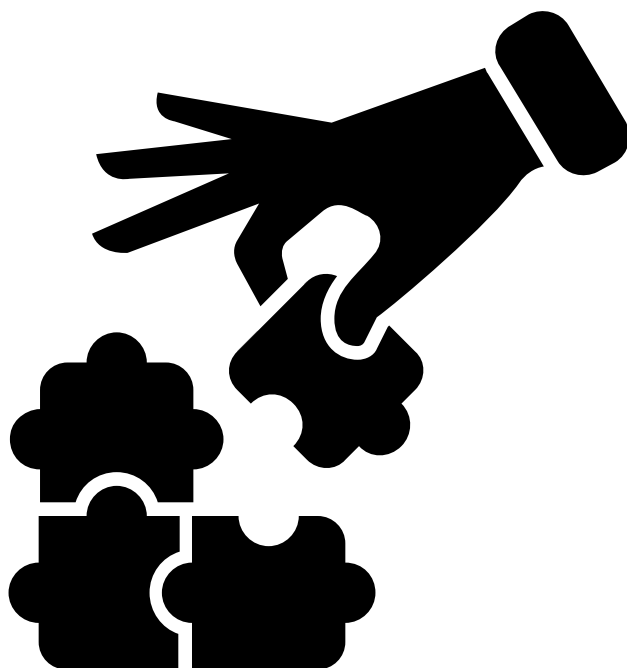
·Ensuring that people with lived experience are involved in panels, recruitment, and policy development was suggested to keep decision-making grounded.

Pioneering Change:

The feedback emphasised being more pioneering in how organisations value lived experience, with calls for a system-wide pledge to ensure this.

Decision-Maker Engagement:

Participants wanted more opportunities to meet decision-makers and bring lived experiences to the forefront of discussions.



Conclusion

This feedback reflects a strong desire for more inclusive, sustainable, and collaborative practices. Attendees appreciated genuine co-production efforts and accessible, flexible support during crises but expressed frustration with post-crisis policy shifts, lack of sustainability, and insufficient feedback mechanisms. Going forward, there is a clear call for better communication, more involvement of people with lived experience in decision-making, and innovative, trauma-informed approaches.

Action Plan

1. Expand Funding Access

- Action: Explore opportunities for commercial funding beyond local authority sources.
- Action: Organise events where commissioners and third-sector organisations collaborate on identifying and applying for funding.
- Action: Enable funding for participation by third sector partners (eg. backfill).

2. Promote Collaboration Across the Third Sector

- Action: Establish a regular forum for third-sector organisations to share knowledge and work towards common goals.
- Action: Encourage collaboration between GPs, social workers, and third-sector organisations to ensure services are well signposted.
- Action: Development of Lived Experience Hub

3. Ensure Inclusive Equality, Diversity, and Inclusion (EDI) Policies

- Action: Review current EDI policies to ensure inclusivity and accessibility, incorporating feedback from lived experience networks.
- Action: Provide ongoing EDI training for staff to ensure a welcoming and inclusive environment for all.

4. Foster Genuine and Honest Communication

- Action: Introduce a “You Said, We Did” mechanism to close the feedback loop, ensuring that people who provide input see the outcomes of their contributions, with a view to move this towards “We Said, We Did”.
- Action: Ensure immediate feedback is provided where possible, rather than retrospective feedback.

5. Embed Trauma-Informed Approaches

- Action: Develop and implement trauma-informed training for staff who engage with people sharing lived experiences, ensuring safety and support are prioritised.
- Action: Create a system-wide pledge for valuing and protecting people's lived experiences, ensuring safeguarding measures are in place for those sharing their stories. This could be developed alongside a co-production charter.
- Action: 'Promote' people with Lived Experience to lead sessions and ensure pre/post support alongside with empathy and understanding.

6. Include Experts by Experience in Decision-Making

- Action: Formally integrate Experts by Experience into recruitment panels, public engagement, and policy development processes.
- Action: Ensure that Experts by Experience are involved in public-facing events, allowing them to plan and showcase initiatives.

7. Improve Accessibility

- Action: Ensure that all documents (policies, event information, etc.) are co-designed with lived experience contributors and are accessible to a range of abilities and communication needs.
- Action: Address digital poverty by offering alternative means of providing feedback and information, including non-digital formats.
 - Needs to work with poverty across the sectors
 - Needs to be made up of several organisations – equivalent to poverty truth commission

8. Health Involvement

- Action: Promote to Integrated Care Board (ICB) for greater involvement in the Lived Experience Network, focusing on aligning health services with co-production practices.

9. Monitoring and Evaluation

- Set up a regular monitoring group to track progress on these actions.
- Evaluate outcomes through feedback from lived experience networks and adjust actions as needed.

Feedback

Chris Jones-King, Director of Adult Social Care and Housing for Cumberland Council, said:

"The Power of Lived Experience event was a fantastic opportunity to start conversations around collaboration and coproduction with local community support groups. It cannot be understated the positive impact these groups have in supporting communities in the Cumberland area through a huge variety of situations, and we are incredibly appreciative of the work they do. We look forward to working with these groups and Healthwatch Cumberland in future and would encourage anyone who is a part of a local community support group to get in touch if they would like to be involved. Individuals can also attend our local community panels."

Lindsay Graham, Director of Healthwatch Cumberland, said:

"This event is the start of a long journey to truly recognise, value and support the amazing work people in Cumberland do, by using their own lived experiences to influence and drive change. It was a privilege to listen, and we are grateful to all those who attended. We now have to work together to make Cumberland a place where local people are involved in the shaping, monitoring, and commissioning local services. I am excited to see where this goes!"

The steering group reflected that the workshop demonstrated that the sharing of lived experience through storytelling is an essential element of qualitative research into the underlying causes of ill health.



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