Statement of Regional Priorities for Care Market Development

Stakeholder engagement version

directors of

adass

adult social services
eastern region

connecting innovating improving

Contents

Foreword

This work began during the height of the Covid 19 Pandemic, in response to increasing concerns about care market fragility, and in recognition of the urgent need to radically transform the way adult social care is delivered.

The two White Papers were published towards the end of this work. Building upon the framework already established by the 2014 Care Act, People at the Heart of Care strongly advocates coproduction and working closely with people with lived experience to help shape the care market. This is complemented by the Health and Social Care Integration White Paper which sets out the systems required to join up health and social care service delivery around the needs of people, communities and place. We are pleased to say that our proposed vision, principles and priorities are in direct accordance with the policy framework set out within the white papers. Indeed, the vision within which this work is rooted is to ensure people have a place they call home and can live the lives they want to and do the things that are important to them, as independently as possible (Making it Real; Think Local Act Personal). Further, we have revisited the Market Development Priorities in order to ensure as close alignment with adult social care and system reform as possible in order to further strengthen them.

The stakeholder engagement process and the findings thereof in the final section provide a stark read. In July 2021 ADASS East signed up to promoting and using the Making it Real (MIR) I / We Statements as part of its improvement programme. What we now need to do is to make Making it Real a reality. Clearly there is a still a long road ahead of us to ensure our behaviour, approach and services consistently become more human across ADASS East. There is much for all of us to learn, particularly from people with lived experience of adult social care.

This work doesn't mark the end of the process. Rather it opens the way for a new dialogue with people who draw on care and support from adult social care. Seizing also the opportunity afforded by the reform agenda we need to think further about how we build on existing the coproduction and personalisation work at local and regional levels in order to make the necessary changes. The recommendations in the final section provide a good starting point for further listening, conversation and consideration in order to find ways forward that are effective and sustainable.

Finally, we are very grateful to Curators of Change and all the people with lived experience of adult social care who have taken the time to tell us so honestly about their experiences. We would particularly like to thank our stakeholders who engaged in the process from across the Eastern Region:

Robert Johnstone	Eleanor September	Mark Dale	Donna Robinson
Kadie Chapman	David Rolph	Jo Hough	Nat Clarkson

Thank you all

Julie Ogley
Director of Adult Social Services and sponsor for Market Shaping & Commissioning Network

June 2022

Introduction

The Care Act 2014 sets out the duties of LAs to help create a diverse, sustainable, high quality market for our people, including those who pay for their own care. Also, it requires the promotion of an efficient and effective operation of the adult care and support market:

Care Act 2014

In 2021 the Market Shaping and Commissioning Network ('the Network') developed a draft statement of regional priorities for care market development within adult social care (ASC) services. The draft priorities set out how support should be provided so adults of all ages with physical or learning disabilities, autism, frailty, mental illnesses or substance misuse would be enabled to live a fulfilling life and realise their potential to contribute to their local community.

As a part of this process, during summer / autumn 2021, we worked alongside stakeholders, people who access care and support services, their carers and families, to listen to and learn from what is important to them, so that we could decide whether or not the regional priorities are the right ones.

The end of this stakeholder engagement process coincided with the publication of the two white papers:

1. People at the Heart of Care: Adult Social Care Reform a ten year vision for reform – December 2021: This White Paper puts people firmly at the centre and revolves around three key objectives:

    *   people have choice, control and support to live individual lives
    *   people can access outstanding quality and tailored care and support
    *   people find adult social care fair and accessible.

2. Health and social care integration: joining up care for people, places and populations – 9/2/2022: Integration White Paper

    This white paper sets out measures to make integrated – or joined up – health and social care a universal reality for everyone across England regardless of their condition or where they live. Everyone should receive the right care, in the right place, at the right time to support them to live healthy, independent and dignified lives.

    We have therefore amended the draft Regional Market Priorities document that was produced for the stakeholder engagement process in summer 2021 with the addition of the following:

    *   feedback from the summer 2021 stakeholder engagement process
    *   updates where necessary to incorporate the requirements of the White Papers.

Who are we?

We are the Market Shaping and Commissioning Network. The Association of Directors of Adult Social Services (ADASS) asked us to develop some priorities for care market development within the eastern region. All local authorities (LAs) in the region are part of our network. The local authorities in our region are: Bedford Borough Council, Cambridgeshire County Council, Central Bedfordshire Council, Essex County Council, Hertfordshire County Council, Luton Borough Council, Norfolk County Council, Peterborough City Council, Southend Borough Council, Suffolk County Council and Thurrock Borough Council. Milton Keynes Borough Council joined the Eastern Region mid-way through the development of the market priorities.

Together we looked at the evidence on what's working and what could be improved in the care market.

This led to thinking at regional level about the kind of vision and principles that we believe should inform future care market development and the regional priorities.

As part of this process, we were very keen to listen to people who draw on or buy care services and support. We wanted to know what people think of the principles and priorities identified so far. It was and is very important to us at regional – as well as local level – to really engage with communities in order to understand what people think. To do this we recognised that we needed to start listening and engaging with our stakeholders differently.

Stakeholder engagement

To start this process, we asked Curators of Change[1] to host a workshop of a small group of people who access care and support services. The task was to sense check the principles and priorities that have been proposed before we included them in this version of the document. One of the things that this group agreed was to include reference to the Think Local Act Personal (TLAP) Making It Real Framework.

"Making it Real is not just another thing for organisations to do. It is a vision, inspiration and a guide that, if used in the way intended, will help people to lead their lives to the fullest"

Sally Percival, *Making it Real Framework*

This document outlines the

- Vision
- What the services and support are that we talk about when we say we want to develop the care market
- The principles we are committed to working with
- The priorities we think are necessary for the best future market development.
- The outcomes and recommendations from the stakeholder engagement process

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[1]   Curators of Change is driven by the desire to shift the emphasis from what matters to systems and processes, to focus first on what matters to people and communities.

The vision

Social Care Future co-produced this vision together with people who access care and support services. It is also the vision within The Future of Adult Social Care Report – **www.futureasc.com**.

'We all want to live in the place we call home, with the people and things that we love, in communities where we look out for each other, doing what matters to us...'

We know that this is not always the experience that people have and are committed to working directly with people who draw on care and support to make sure that we are all working together to co-produce care and support that is right for everyone who needs it.

There were no comments from the stakeholder engagement process that led us to consider amending the vision in any way.

The Services

What is the provider care market?

The provider care market is a term used by ASC to describe any care and support you need to be able to "live the life you want to and do the things that are important to you as independently as possible" (Making it Real October 2018).

The provider care market includes services that are provided by: local authorities, private providers or community groups for adults (age 18+ years old) and older people.

What is care market development?

Care market development is the work that ADASS, Local Government Association (LGA), local authorities and other health and care organisations do to make sure that they are 'commissioning' the services and support they believe people need to draw on or buy for themselves and are available locally.

This work is done to make sure that people with care and support needs have a wide range of options when it comes to meeting their needs.

Locally and regionally a lot of work is needed to develop the range of services provided by the care market. We want to ensure there is a much greater choice of care options to meet individual needs and circumstances. We also want to support people to have choice and control about how their care and support needs are met.

What does the care market include?

Accommodation based solutions for adults of working age and older people including those with learning disabilities, physical disabilities and those with mental ill health, to support them in managing everyday tasks and with independent living.

Carers – informal: we have included here because carers provide an invaluable level of care in the community. They provide unpaid care and support in the family home. They are usually family members but could also be friends and/or neighbours.

Care homes: homes (sometimes called residential care homes) that people live in with other people, with staff providing care and support.

Community micro-enterprises (CMEs): are very small community-based organisations delivering social care services in local communities. They employ five or fewer staff. See *Micro-enterprises: small enough to care* for more information.

Day opportunities: a planned program of activities or support for adults who require this additional support during the day.

Domiciliary care: care provided by either the local authority, voluntary community services (VCS) or private agency, to a person in the place they call home to support their independence.

Interim care: intermediate care and reablement services providing support for a short time to help the person recover and increase their independence to remain at home.

Nursing homes: care homes that also employ registered nurses to provide nursing care. Nursing homes may be privately owned or they may be run by a charity or a local council.

Technology enabled care services (TECS): includes the range of health and care technologies such as: telecare; telehealth; environmental controls; health; telemedicine.

The following are not direct services but are included as they are important because they provide money to people to enable them to purchase their own services:

Direct Payments (DPs): money that is paid to an individual (or someone acting on their behalf) so they can arrange their own support.

Individual Service Funds (ISFs): a supported way of managing a personal budget from the council. The funds can be held by a particular provider. The individual remains in control of making decisions about how they receive their support.

Personal Budget (PB): money that is allocated to an individual by the local council to pay for care or support according to results of a needs assessment.

Once a personal budget is worked out it then becomes a direct payment if that is a suitable way of people receiving their personal budget. The Care Act says a personal budget should be worked out based on unmet needs and it can either be commissioned as a direct payment, commissioned by the LA as for example a managed service, or be taken up as an individual service fund. The personal budget also includes what people are contributing themselves towards their own care and support.

Making it Real

'Making it Real' is a framework for good personalised care and support co-created by members of the National Co-production Advisory Group (NCAG) and the Think Local Act Personal (TLAP) partnership.

It includes a series of **'I'** and **'We'** statements that were co-produced with people that set out what good, personalised care and support should look like for people themselves (I statements), and from the perspective of the organisations who commission or provide care and support (WE statements), for example:

> *"I can live the life I want and do the things that are important to me as independently as possible"*

The framework is based on the following principles and values of personalisation and community-based support:

- People are citizens first and foremost

- A sense of belonging, positive relationships and contributing to community life are important to people's health and wellbeing

- Conversations with people are based on what matters most to them. Support is built up around people's strengths, their own networks of support, and resources (assets) that can be mobilised from the local community

- People are at the centre. Support is available to enable people to have as much choice and control over their care and support as they wish

- Co-production is key. People are involved as equal partners in designing their own care and support

- People are treated equally and fairly and the diversity of individuals and their communities should be recognised and viewed as a strength

- Feedback from people on their experience and outcomes is routinely sought and used to bring about improvement.

(Making it Real: Launched Oct 2018)

The _People at the Heart of Care White Paper_ specifies that a new single assessment framework will be developed by the Care Quality Commission (CQC). As part of this they will draw upon TLAP's 'I' and 'we' statements which will be used to clarify what standards the CQC expects – and what further work will be undertaken to develop the framework in conjunction with TLAP, national voices and other stakeholders.

The principles

The principles we have developed are about:

A. **What 'good market development' needs to look and feel like from the perspective of people, carers and families**

B. **What organisations and services need to do to make that happen**

During the workshop convened by Curators of Change, people struggled to understand how the principles could make sense to them. It was felt that the Making it Real statements helped people and others to make sense of the principles. As a result of this we have included some of the 'I' and 'We' statements alongside the principles.

Our principles:

A. **What 'good market development' needs to look and feel like from the perspective of people, carers and families:**

1 Person centred

- One size does not fit all. Each of us has different needs that depend on age, gender, disability, religion, ethnicity and sexual identity.

- Shaping care markets should include:
  – Knowing what matters to people and what good looks like for people
  – Putting people and communities at the centre of planning and decision making
  – Working alongside people, communities and health and care organisations who provide support
  – Supporting people to meet their needs now and in the future.

Making it Real statements

I am treated with respect and dignity.

I am supported to make decisions by people who see things from my point of view, with concern for what matters to me, my wellbeing and health.

We have a 'can-do' approach which focuses on what matters to people and we think and act creatively to make things happen for them.

We work in partnership with others to make sure that all our services work seamlessly from the perspective of the person accessing services.

2 Wellbeing and independence

- It is important that people can be as independent as possible in their own home or community home for as long as possible.

- Nursing and residential care should only be an option when the person or family want this.

- Keeping people socially connected and well, and those who support them well, is also important.

- Moving between settings (someone's home to care, or a hospital stay for example) should be easy. People should be included in any decisions about what is best for them.

Making it Real statements

I have a place I can call home, not just a 'bed' or somewhere that provides me with care.

I live in a home which is accessible and designed so that I can be as independent as possible.

I am supported to plan ahead for important changes in life that I can anticipate.

We make sure people feel safe and comfortable in their own home, which is accessible, with appropriate aids, adaptations, technology and medical equipment.

We talk to people during and after significant changes to find out if their requirements for care, support and housing have changed and to review their aspirations.

Necessary infrastructure to support person centred services, wellbeing and independence:

3 Place, diversity and innovation

- What matters to people is the most important – where they want to live, who with, and who supports them.

- The care market should include lots of different options for people. This includes what is available to people in their local area/community.

- Creating new opportunities for people and removing the barriers and blocks that stop people being able to do the things they want to do.

- Listening to what people and communities are saying and help to make things happen in ways that make sense to them.

- Test all new ideas with people and learn from them about what works best, and what does not work so well.

- Share what works for people across the region.

Making it Real statements

We see people as individuals with unique strengths, abilities, aspirations and requirements and value people's unique backgrounds and cultures.

We invest in community groups, supporting them with resources – not necessarily through funding – but with things like a place to meet or by sharing learning, knowledge or skills.

We have conversations with people to discover what they want from life and the care, support and housing that will enable this, without restricting solutions to formal services and conventional treatments.

We welcome ideas about using personal budgets flexibly and creatively.

B. What organisations and services need to do to make that happen:

4 Partnership and integration

- Coproducing with people who access care and support, communities, commissioners, providers, planners, education, LA housing and planning departments the NHS and public health from the start.

- Work with the NHS to join up the care and support that people need.

- Recognise that people's lives are not separated into health, care, private and community. People are individuals with lots of ideas about how they want to be supported to live their lives. Starting with the strengths, listening to what matters to people, sharing decision making power, valuing each other's expertise is important.

- Develop strategies that are based on what matters to people, working with what is already there and helping to keep people well and living the lives they want to.

Making it Real statements

I have a co-produced a personal plan that sets out how I can be as active and involved in my community as possible.

I know how much money is available to meet my care and support needs. I can decide how it's used – whether it's my own money, a health or social care personal budget, or a budget managed on my behalf.

We work with people to manage risks by thinking creatively about options for safe solutions that enable people to do things that matter to them.

We work with people as equal partners and combine our respective knowledge and experience to support joint decision-making.

5 Collaboration, reciprocity, subsidiarity and transparency

There are lots of common issues and challenges in relation to contracting. Local authorities should talk to each other when working with organisations who provide services across their boundaries.

Transparency and trust is very important. Local authorities should talk openly about plans, share intelligence, insight and proposals. For example:

- Be open about rates of pay and respect other providers' payment rates
- Expectations from providers
- Contract standards
- Workforce Pay

They should also talk about how we are working to join up processes across the region in relation to:

- Safeguarding
- Procurement
- Mutual Aid

Being clear about what happens at a local, regional or national level.

Making it Real statements

I feel safe and am supported to understand and manage any risks.

I know what my rights are and can get information and advice on all the options for my health, care and housing.

We make sure we share information about what we do and how people can access our service with other relevant organisations so we can all work more effectively.

We make sure that people, and those closest to them, know what to do and who to contact if their health condition, support arrangements or housing conditions are deteriorating and a crisis could develop. We respond quickly to anyone raising concerns.

6 Evidence, quality, outcomes and value for money

- Creating an automated and integrated reporting system that informs local commissioning, supports providers and helps regional level understanding, prioritisation, planning and action.

- Providing relevant up to date knowledge at local and regional level – and making sure the evidence that informs decisions is based on what matters to people.

- Making sure that 'outcomes' relate to what matters to people and what people want as the market develops. Including more non-regulated service contracts to enable micro-enterprises / community-based services to become viable service providers.

- Ensuring quality and evidence is at the heart of market development and service delivery and investing in what is known to deliver good outcomes.

- Developing new systems of care that ensure better value for money and that money is used locally and wisely.

Making it Real statements

I can get skilled advice and support to understand how my care and support budgets work and enable me to make the best use of the money available.

We make sure that our organisational policies and procedures reflect the duties and spirit of the law and do not inadvertently restrict people's choice and control.

We work in partnership with others to make sure that all our services work seamlessly together from the perspective of the person accessing services.

We don't make assumptions about what people can or cannot do and don't limit or restrict people's options.

The stakeholder engagement process showed us the importance of using the right language in order to help peoples' understanding. The Making it Real statements were helpful in translating the meaning of the principles to make them more real for people.

As a result of the stakeholder engagement process and also in view of the requirements of the Care Act, People at the Heart of Care and Health and Social Care Integration White Papers, we believe these are the right principles.

Regional priorities

The Network has identified the regional priorities we believe are necessary to make the right changes in the care market.

The priorities outlined here are informed by the vision and principles.

The priorities have been categorised according to whether they are:

A) in progress
or
B) a new development

A)   Priorities already in progress

Work has already started on some priorities which are included here for completeness and transparency.

1)   Implement the Eastern Regional ASC Workforce Development Strategy

An ASC Care Market Workforce Development Strategy was approved in October 2020. Six priorities for action were identified: recruitment and retention; parity of esteem; career pathways; sector promotion; skills and values; and wellbeing equity and diversity. In view of the requirements of the Health and Social Care Integration White Paper this work is now developing into coproducing a joint care and health workforce development plan with health partners and Skills for Care at Integrated Care System (ICS) and regional levels.

2)   Develop the Regional Provider Assessment Market Management System (PAMMS) market intelligence system to also include market insight tool and reporting

This will give us much more information on what is happening across the care market in the region so we can understand better what is going on and what the issues are.

It includes the capacity for the LAs and the region to do demand and capacity tracking, a benchmarking function, a provider risk dashboard, differential costs of care, a standardised approach to performance monitoring, and information on providers such as ownership and financial structure.

In line with People at the Heart of Care White Paper requirements the PAMMS system will improve the quality and availability of data regionally, locally and at individual provider levels.

3) Share local authority care market and digital innovations strategies and market position statements (MPS)

This is ongoing work to log and share care market innovations regarding care market sustainability and development and MPS so we can each learn from what is working well in other local authorities across the region. In addition, according to the People at the Heart of Care requirements regarding Fair Cost of Care (FCC) each LA will be required to develop a Market Sustainability Plan by October 2022.

4) Lobby national level for the necessary change

A National Commissioning Network has now been established. This is chaired by the chair of ADASS East and attended by two representatives from ADASS East's Market Shaping & Commissioning Network. There is therefore now a stronger voice from the East at national level to influence change.

5) Stakeholder engagement on market priorities

A stakeholder engagement process on the regional priorities for care market development ran from July 2021 to January 2022 with the purpose of listening to people who have used the services, their carers, local communities and providers. Sensemaking and stakeholder events were held in September / October 2021 and a joint markets / personalisation and prevention regional network workshop was held in January 2022 to share the learning and consider recommendations for moving forward. The outcome of this process is reported in the final chapter.

6) Create a regional approach to housing

In February 2022 the inaugural meeting of a newly formed Regional Housing Group was held as the first in a series of phases of work. The Best Practice Guide will be launched at a showcase event in October 2022 aimed at cross sectoral public and private partners. At this event consideration will also be given to the next steps required for a partnership approach to housing development at Regional, Integrated Care System (ICS) and Local Authority level in accordance with the housing requirements in People at the Heart of Care and the Integration white papers.

B) Newly identified priorities

7) Develop the specialist skills of commissioners involved in care markets and housing in order to ensure the choice of systems and services needed are provided so that people will have a place they can call home, not just a bed or somewhere that provides care

Contribute to and support the Regional Building Positive Futures Programme which provides ongoing learning through action learning groups about a range of different topics related to innovative commissioning and personalized care.

We will actively engage with the work of the LGA to develop resources and tools to improve care market commissioning.

We will also encourage the take up of training and development opportunities for new market commissioners, including commissioning for wellbeing programmes, secondments, development opportunities, coaching and mentoring. This priority is also in line with the requirements of People at the Heart of Care White paper in order to strengthen market shaping and commissioning capabilities to deliver the vision for reform – which comes with funding to strengthen commissioner capability.

8)   Agree common regional market commissioning approaches

This will include provider uplifts, intelligence sharing, identification of provider at risk, markets risk etc. We can learn from existing approaches across the region. We will consider how to include the community voluntary sector (CVS) in this as we expand from the traditional provider base to new providers and care models. The regional Fair Cost of Care work, to be completed in October 2022, will also help inform this priority.

9)   Establish a regional purchasing consortium

Using an existing supply organisation where possible. Possible options include bulk purchase of provider supplies, energy consortium, benefits for market care sector workforce, support for providers to reduce costs, low-cost loans, buying buildings and renting back, lending capital, capital investment to support market reshaping, and so on.

10)   Agree a regional approach to collaborative commissioning with the NHS

Reshaping the market is part of the agenda for the Integrated Care Systems (ICS) and we need to develop collaborative approaches between citizens, local authorities, health and the community and voluntary sector (CVS). The LGA is currently developing a guide to NHS collaborative commissioning which will help inform this process.

11)   Co-produce a regional provider engagement process

As part of Priority 1 – regional workforce development we recently undertook a survey of providers and care staff regarding the conditions that are necessary for staff recruitment and retention and plan to use this as a basis for onward work with care providers.

The Stakeholder engagement process showed us that we have the right priorities and that people would like to participate in how these are developed.

Outcomes of the Stakeholder Engagement

"We felt safe to share our lived experiences because of the accessible and rewarding methods in place to allowing us to feel valued for the contributions we were making. We felt lived experiences were the cornerstone to achieving results that benefit more people including systems, especially those geared to improving lives"

Donna and Eleanor *– Coproducers December 2021*

Summary

This final section has been coproduced by Curators of Change[2] and the Markets Network. It provides a high-level summary of the stakeholder engagement process, summarises the feedback from the listening process, makes clear recommendations and outlines some next steps. For full details of the stakeholder engagement process and outcomes please refer to Annex B.

These key messages and recommendations are relevant to all ADASS East Networks. They are designed to bring about changes to peoples' experience of care across the region.

The engagement process highlighted that person centred care and working is not currently peoples' experience of care. Further, what emerged overall, was an understanding of the huge gap that exists between the market development priorities as written and the reality of people's experience. The overall challenge across ADASS East therefore is to create the right conditions to enable person centered ways of relating, caring and working.

In order to make improvements there was clear agreement on the need to coproduce in future, working with and alongside people who draw on services and their families to enable the best care and support to be designed and delivered. Coproduction is not a magic formula or a one-size-fits-all solution. It is something that emerges from making the space to listen and working together in partnership in order to create the right, more human, conditions.

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[2] Curators of Change is a small enterprise of people with diverse and lived experience of care and support. Our ethos is one that brings the human element of change to the fore, and creates space for people to reflect on the wider and system changes that need to take place from a much more human perspective. Our aim is always to come alongside and connect with the existing networks and seek out people with lived experience to be part of the process of change in the areas we are invited to work.

Key recommendations

1. any actions and plans should be developed in coproduction with the people who draw on services and support.

2. we need to create a level of accountability with the people who have given, and continue to give, their time to share their stories and participate in this work to date.

What we did

To start this process, we convened a small group of people to sense check the principles and priorities. It was suggested that it would make sense to look at the principles through the lens of the Making It Real Framework. Using Making it Real statements we produced both a stakeholder and an Easy Read version of the Market Priorities document in order to maximise access to the documents.

From July to October 2021, we spent time listening to people who access care and support services, their carers and families, and a wide range of other stakeholders. We listened to them with a view to learning what is working well, what is not working so well, and what is most important in relation to the development of the regional care market. Some of the people involved in the process have worked alongside the Curators of Change team to ensure that the voices of people who access services and support across the region are being included in the spaces that matter most.

To do this we delivered a series of facilitated workshops, asked for feedback via an online questionnaire, and used Community Reporting[3] to gather and learn directly from the stories of peoples very real and current experiences.

In January 2022 the results of the stakeholder engagement process were presented to the Market Shaping & Commissioning Network and the Personalisation and Prevention Network to which the markets network and the chairs of other relevant networks were invited to consider what people said, think about how they need to respond and come up with recommendations.

What people said to us

Listen more:

All those who participated in the storytelling process and workshops were clear they valued being listened to. They felt their insights and experiences were acknowledged and that officers genuinely reflected on what they had told them.

Be more human:

Many of the stories and experiences shared and explored during this process highlighted how inhumane current practice could be, even when organisations thought they were doing a good job. Putting the person into personalisation was a recurring theme as people said that person centred practice had become just another 'system' that was not working!

> *"Culture of fear – people being left behind, voiceless"*

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3   Commuity Reporting – a way of capturing, recording and gathering lived experience stories

Build trust and relationships:

The engagement process created a safe space where everyone could be open and voice their concerns. People shared the things that really mattered to them and this gave them a sense of purpose and started to build trust in the relationships between people who draw on services, providers and commissioners.

Start with a blank page:

The proposed priorities for market development were seen to be the right priorities, but people wanted to contribute to how they would be achieved. There was a fundamental question over how to define what is available in the care market and who is best placed to work on this. One challenge is to consider how people with lived experience and their families can coproduce commissioning mechanisms that would impact on service quality, such as inclusions in provider contracts and in monitoring of performance.

Cocreate the right conditions to truly coproduce:

The Regional Care Market Priorities are not wrong – but the stakeholder engagement process has shown us that HOW they are being delivered is not working – so what do we need to do to change this? WHAT is proposed is largely ok – HOW it is done is the thing that has mostly surfaced during this process.

> *"Good point about commissioners paying lip service to person centred care.*
> *We are a long way from this in reality"*

> *"I would love to sit and have a chat with her [my SW] – I don't believe she is a bad person"*

How should ADASS East respond?

- **Invest in the process of coproduction** across the region with the people who access care and support, and be accountable to them for creating the conditions that enable people to 'live the lives they want to and do the things that are important to them as independently as possible.'

- **Recognise we won't always get it right.** Be willing to test things, and to get it wrong. Have an open and no blame culture.

- **Create more space for conversation.** More informal spaces and networks with less hierarchy.

- **Work more with stories.** Hearing people's stories was a powerful way for commissioners and providers to understand the impact of their work. There was a desire to work more with stories, including with local organisations that are already doing this, e.g. Healthwatch and ACE Anglia.

Some recommendations:

Establish a regional coproduction advisory group / assembly / forum with clear terms of reference and an appropriate support mechanism in place e.g. Curators of Change or similar organisation. Objectives to include:

1. lead the creation of a regional coproduction charter / citizens charter in consultation with wider stakeholders. The purpose would be to give power to people and communities to make change happen.

2. lead the development of a guide to coproduction that reflects the views of people truly at the heart of care. Ensure that it builds on the I and We statements, and show that coproduction needs to **be facilitated** in a way that creates better relationships and that it will influence both regional and local level coproduction principles, work and practice.

3. liaise with regional networks to support their thinking / learning / approaches to coproduction and establish what might be most helpful for them (may wish to refer to learning from York & Humber and West Midlands approaches).

4. support people with lived experience to co-chair, facilitate and participate in networks and events and support networks to provide the necessary flexibility and support for this to happen. Support may include peer to peer, training, action learning and mentoring approaches.

5. coproduce a reward and recognition policy to facilitate people with lived experience to attend / support meetings.

6. support the development of more flexible approaches to self-directed support that put people at the heart of care.

7. strongly encourage LAs to undertake local accounts.

8. being empowered to request LAs to demonstrate how they are delivering on Making it Real in assessments, reviews and in effecting the necessary culture change in operational teams, and also how it is meaningfully used to support coproduction.

9. support the Building Positive Futures Programme development as a means of supporting the development of a diverse care market and care market commissioner development.

10. help create lived experience resources / stories for networks. Support networks to share stories from people with lived experience.

Glossary

Taken from **Think Local Act Personal**'s online *Jargon Buster*.

Commissioning	The process of planning services for a group of people who live in a particular area. It does not always mean paying for services, but making sure that the services people need are available in that area.
Independent living	The right to choose the way you live your life. It does not necessarily mean living by yourself or doing everything for yourself. It means the right to receive the assistance and support you need so you can participate in your community and live the life you want.
Integration/ integrated care	Joined up, coordinated health and social care that is planned and organised around the needs and preferences of the individual, their carer and their family. This may also involve integration with other services for example housing.
Market development	The way in which a council looks at what people's care and support needs are in the local area, considers what care and support services are available in that area, and works out where the gaps are and how they can be filled. The aim is to make sure that people can find care and support that meets their needs, and that a variety of options are available to suit people's individual circumstances and preferences.
Market position statement (MPS)	A description of what care and support services are available in a particular area, what services will be needed in the future, and what the commissioner will do to make sure that the services people need are available (regardless of who funds them). Every council has to produce a MPS, which should contain detailed information on what is needed in the area and what the council's plans are.
Provider	An organisation that provides services, such as care and support services.
Stakeholders	People or groups who have an interest in what an organisation does, and who is affected by its decisions and actions. When an organisation such as your local council or NHS trust is planning to make changes to the way it works or the services it offers, it may hold a consultation with stakeholders, to find out what you think and what your experiences are.
Wellbeing	Being in a position where you have good physical and mental health, control over your day-to-day life, good relationships, enough money, and the opportunity to take part in the activities that interest you.

Stakeholder Engagement Process

This Annex includes more detailed feedback from the engagement process and an overview of the research methods.

The main period of engagement was from July until October 2021. From May until July, Curators of Change worked with the Market Development Priorities Network, and people with lived experience from across the region to re-write parts of the market development priorities document, and translate this into an easy read version.

The period October 2021 to March 2022 has been analysis, sense checking, and working with the network and working groups to refine the information to present to the Personalisation and Prevention network.

Stakeholder engagement

Curators of Change worked alongside the Market Shaping Network and a small group of people with lived experience to gather lived experience stories and host a series of listening events and workshops that created space for some open and honest conversations with people who access care and support, service providers and other stakeholders.

These focussed on:

- what matters to people
- what those who participated thought about the vision, principles and priorities

We also designed an online qualitative survey, however the number of responses, even though well promoted, was low. The quality of the responses was good, and this added another layer of feedback to the overall process that was rich and valuable. This also allowed us to gauge how people ranked the Market Development Priorities.

Curators of Change have engaged with nearly 170 people across the region from all the main stakeholder groups, including 15 people who have shared their experiences and stories as part of the community reporting, 10 of whom have worked alongside Curators of Change to support and attend workshops and meetings. It is hoped that these people will form the core of an emerging coproduction advisory group / assembly to support the ongoing Market Shaping Network as well as other networks.

Overview of key engagement events

Date	What we did	Aimed at	How many people
24 May	Reviewed the draft priorities document with people who access care and support from across the region	People who draw on care and support (coproducers)	6 participants
May – July	Drafting documents, etc...	ALL	12 in total
26 July	Two workshops to explore what is working in relation to the care market from the perspective of providers of care and support, and wider stakeholders	Morning workshop – aimed at providers Afternoon –aimed at a range of stakeholders including people who draw on care and support	10 in total
10 August	Two story gathering workshops. Recorded zoom sessions where people were invited to share their stories and experiences, and give consent for Curators of Change to use the stories in sense making workshops – a process where we collectively identify key thoughts and themes from the stories	Carers, and people who accessed care and support, shared their stories. 1 Commissioner	42 in total
8 September	A repeat of the workshops on the 26 July	Morning – providers Afternoon – wider stakeholders	16 participants
27 September	Sense making workshops where we played extracts from the stories and invited participants to reflect on what they were learning, how it made them feel and how it resonated with their own experiences	Members of the Market Development Network, and coproducers	
13 October	Brief review of story extracts at the start of the Regional Network meeting, as part of our update	Members of the regional network	

Date	What we did	Aimed at	How many people
18 October	Conversation of Change event – played a 15 minute film of story extracts. Reflected on learning and developed the conversation into the practicalities of what needs to change in order to develop the market	Open to all stakeholders	17 people
Ongoing	Survey Easy Read Survey	28 individual responses 4 group responses 4 Easy Read responses	32 + group responses
Story gathering	Capturing Community Reporter stories for sense making and conversations of change. Powerful often 'hard to hear' stories of the impact of good and bad experiences of care and support	9 people in the workshops 6 peer reporters trained and shared their stories 6 other stories gathered	20+ stories gathered to date
26 January 2022	Presented back to the Personalisation and Prevention Network. Sense checked with them and the Markets Network. Agreed priorities to be included in the final chapter of the Market Development Priorities document	ADASS East Network Members	20+

The engagement events and stories led to a lot of very rich feedback about peoples' experiences of care and support. This has been summarised as part of the appendix in relation to the principles and priorities.

The principles – what people said during the scoping, sense making and conversation of change workshops...

Overall, it was felt that the principles and priorities developed by the Market Shaping Network are not wrong. They clearly state what needs to be done to ensure good market development regionally.

However the findings very clearly demonstrated that the current experiences of people whether they were supported by or worked in 'the system' were a long way from achieving the priorities.

1)   Person centred

Story tellers talked about their frustration of social care not being person centred, this was picked up on by participants in the sense making workshops too. "You can really hear the frustration that each individual has experienced with the system" and the feelings of "frustration, disempowerment, bewilderment"

This prompted feedback in the workshops about how big the gap was between the principle of being 'person centred' and the reality of people's experience.

People also talked about their *fear* – the fear of asking for help, and support being taken away, fear of reading emails or receiving post from the LA and the power of space where people were free to have conversations about good care and support.

"Many people with eligible needs are still on arranged provision where there is no personalisation or coproduction. And even those with access to self-directed support are most often not given the freedom and control they deserve and desire"

"Good point about commissioners playing lip service to person-centred care. We are a long way from this in reality"

"I would love to sit and have a chat with her [my SW] – I don't believe she is a bad person"

"Culture of fear – people being left behind, voiceless"

2) Wellbeing and independence

The strongest theme to emerge was about how inhumane things feel to people, carers and families.

People's frustrations were clear, they often described a lack of 'humanity', words like belittled, feeling small, having to fight... "having to develop a ferocious persona to be heard..."

Parents described how they had failed themselves and their adult children. This was hard for those working in social care to hear – saying things like:

"I feel embarrassed to be part of a failing system"

"Difficult to hear, we need to support people before crisis point"

This also resonated in relation to other service areas "although a different client area, this really resonates with Older Peoples Social Care".

3) Place, diversity and innovation

During the sense making workshops one participant commented on "the importance of family carers and how they're not valued"

People talked often about how difficult 'the system' is to navigate: assessment, review, waiting times, panels etc... again the theme of it being an 'in-human' experience was common.

"Accessing support needs to be simple and easy – people are desperate to access the help they need yet there are so many barriers. The system is contributing to dehumanising individuals at a time when we ought to be truly there for people"

4) Partnership and integration

Peoples' stories highlighted how current structures pay 'lip service' to being person centred. The experiences were described in the sense making workshops as 'fragmented and disjointed' and that 'multiple assessments shouldn't be necessary'.

Stories highlighted the familiar experience of people 'falling between the cracks' of mental health and learning disability services.

Other people talked about the amount the amount of hierarchy and bureaucracy that gets in the way of more integrated ways of working.

> *"If family members have had to fight so hard to get the support that they need they are going to be very reluctant to let any of this go even if it is no longer needed"*

5) Collaboration, reciprocity, subsidiarity and transparency

During the conversation of change people talked about the need to remove the 'closed shop mentality from the local authority' and to be more open, honest and relationship focussed.

A strong desire the continue the coproduction work started as part of this process – this isn't explicit enough in the draft priorities and principles.

People talked a lot about increased use of DPs ISFs and micro enterprises. Parents talked about wanting to be free to be parents rather than carers.

It's not just the WHAT but also the HOW – be more human, ditch the badges at meetings, and asking for forgiveness rather than permission (being less risk averse), were things that were talked about during sense making and conversation of change events.

Language was a key theme that emerged, as a principle this one is again not wrong, but the words used in relation to this principle are jargonistic.

> *"His message re the importance of coproduction was really powerful and key to us improving the outcomes that people achieve from accessing services!"*

6)   Evidence, quality, outcomes, and value for money

Again, people talked a lot about the de-humanising experiences they had, and the fact that they were made to 'fit what was on the shelf', and parent carers talked about their 'failure' to get the support they needed for their adult children. Many of the people we spoke to are not getting support when they need it, let alone support that could be deemed quality and value for money.

"Earlier support, but the right type of support to enable people to be as independent as possible. Potentially this should reduce the longer term need for formal commissioned provision"

"You just get to that point when they wear you down so much you give up and in a way it feels like that's what they want you to do and yeah its just exhausting"

"Good point – if we want different outcomes we HAVE to question everything and do things differently"

The draft priorities – what people said during the scoping, sense making and conversation of change workshops...

As part of the online survey, we asked people to select their top 3 priorities from the 11 priorities in the document. They are included below in order of being ranked. However, this was not a big sample so is not necessarily representative of the wider audience for this work.

1) Implement the Eastern Regional ASC Workforce Development Strategy

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"Flexibility of staff" "Up the status of social care and make a good career structure and payment structure for care staff" "More social workers" "Be supportive and perhaps offer a helpline" "Carers being appreciated for the work that they do" "Listen. Professionals need to listen to the individual who they are trying to support. Care should be done with rather than done to" "People with direct payments can't offer the same incentives as bigger providers" "Long term funding, not yearly – but 3 yearly"	Put compassion back into the work – **be human and kind.** **Listening more** – this is what gives people the most purpose Moving away from trite expressions like 'person centered care' and **having a more holistic approach**... **We are a long way from working in ways that are person centered** – this needs a rethink – what does this actually mean?

2) Develop the Regional Provider Assessment Market Management System (PAMMS) market intelligence system to also include market insight tool and reporting

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"All Healthwatches are interested in hearing individual experiences of services and support – and will collate feedback and follow up"	**There was no specific feedback on PAMMS.**
"Is there a danger that commissioners will continue to block buy based on prices or because they are not listening or working in coproduction with people"	There was feedback related to outcomes – **and the need to change the way we do things in order to achieve different and better outcomes!** The danger is that we report on what is there, and what we 'know' rather than create space to be truly responsive to what matters to people and supporting them to 'live a good life'.
"Can we encourage providers to bid collaboratively"	**A desire to work more with stories** and organisations who are already working with stories like Healthwatch, ACE Anglia.
"Not great when the charities are expected to fill in the 59-page document! Procurement and commissioning rules make it difficult for smaller groups"	An emerging theme includes **the amount of reporting and form filling that smaller organisations and charities don't have the capacity to do.**
"Lack of data sharing"	**Where is the data that evidences what authorities are not doing** – a number of people reported that they were told their authority doesn't do ISFs for example even when they should be offering them.
	Learning and reporting is not only for people who work in services but also for people who access them – how accessible is this information to people?
	Better quality assurance across services, improve basic standards all round.

3) Share LA care market and digital innovation strategies and market position statements

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"To improve communications across the board but ensure that those with no access to technology don't fall through the gaps!" "Digital isolation" "Lack of technology" "Digital services to improve social care for those who have access" "People and digital investment"	**People talked about being 'stunted through digital'** – some people who access services can't use/afford the tech so they are losing contact with services. **Personal budgets need to include digital access and training**/help to use it.

4) Lobby national level for the necessary change

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"A joined up national coproduction model" "An end to the postcode lottery" "More money in social care system"	

5) Stakeholder engagement on market priorities

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**

Key themes emerging from the **Conversation of Change workshop** 18 October

"More joined up peer support for providers to work towards improvements"

"Empower more people to use their voices"

"Build better relationships, trust providers more"

"Listening into action – staff events in the hospitals re discharge"

"Training to help our staff move forward in understanding the sector"

Providers need to work with staff to work differently.

Resolve issues with other departments – e.g. legal commissioning frameworks – **involve us in the design process.**

Rebuild trust and relationships – trust people with lived experience and providers to spend personal budgets in ways that make sense to people.

Move away from silo approaches and work together to remove system blocks

6)   Create regional approach to housing

"Housing and care"

"Stronger focus on housing – it's so important"

"Lack of info re live-in carers" people given DPs didn't have enough info or support to be confident about what they were doing

"More choice with housing and more person centred housing. Home should be a place we are living not to be signposted to"

People are often dumped in residential care – no luxury of a conversation beforehand"

"People coming into residential care are often very poorly – most people are left in their own homes without the quality of support to live a good life"

"People who pay privately come into residential care sooner than people referred by social care, or come via hospital"

"The approach to the care market is dependent on the senior leaders – you get what there is – in residential care its very structured, set rate, no flexibility why it could be more or less"

"In res and domi care the conversation always ends up being about the rates of pay and not about the quality of care – around the units"

"In residential care we never get CHC in spite of the level of need of people"

Better support for people to move out of their parental homes – how does the system help people to move out of the parental home?

How 'ferociously' carers have to fight to get support for their adult children to live independently of the family home

We must invest more in DPs and ISFs to ensure people have the freedom and flexibility they deserve.

Focus on quality of life – not minutes or hours in care.

Pots of money – rather than individual placements to allow people and providers to be more flexible.

Need to take a holistic view and understand the impact on the wider family of having their young people living at home.

Better information about support options, but from a place of **better understanding what people want**...

7) Develop the specialist skills of commissioners involved in care markets and housing in order to ensure the choice of systems and services needed are provided so that people will have a place they can call home, not just a bed or somewhere that provides care

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"Continuity of social work support" "Thinking bespoke and outside the box" "More opportunities for people who look for support services and people who provide support to have meaningful direct conversations" "Seeing care workers as skilled professionals" "More support for people to advocate for themselves and their families" "Courageous leadership" "Being approachable" "Professional trust" "Holistic support – not just task driven"	Everything **needs to be RELATIONSHIP based.** Let's explore the relationship next… **Adopt Making It Real –** **Simplify contracts with providers** – use Making it Real statements/outcomes. Be clear about the fact that **we can't know what outcomes people want to achieve until they have achieved them!** If we want different outcomes, we have to question everything and do things differently… Lack of vision – good people are trying to do the right thing but caught up in issues/fire fighting so losing sight of goals for individuals – SWs can see what would be beneficial for people but can't get agreement for these things to be funded as assessments are 'too detailed' and therefore 'restrictive'. **Need for genuine personalisation** – not the system version. **Support to live an ordinary life** – services and support that are closer to real life!

8) Agree common regional market commissioning approaches

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"An end to one size fits all approach" "End the postcode lottery" "Holistic support – not just task driven" "Easier referrals to the community sectors, direct payments support so people are independent" "Local authorities making procurement of services equitable" "Prevention and delay should be at the heart of social care offer" "Listen and provide the right care and support for everyone. For the elderly bring back the home help!" "Is there a danger that commissioners will continue to block buy based on price because they are not listening to or working in coproduction with people" "Can we explore how to encourage providers to bid collaboratively" "Not great when the charities are expected to fill in 59-page documents etc! Procurement and commissioning rules make it difficult for smaller groups" "There is never enough money but there will never be – how can we use the resources we have more effectively?"	**Greater openness, honesty and transparency** – space where everyone can contribute to decisions, and responsibilities are laid out! **A more human approach built on TRUST and relationships** – including trust of people with lived experience and providers. **"Every party to be seen and treated as equals** **Circles of support** – more of this kind of approach **Professional advocacy** should be a right! **Adopt place-based approach** **Greater emphasis on micro-enterprises – rather than block provision** – again the emphasis here is on the conditions – the HOW we support people rather than WHAT! **Put personalisation into personalisation** – people were open during the conversation of change about how person centred practice had become just another 'system' that was not working! **Better use of ISFs and DPs** – and the support needed to encourage take up. **Flexibility not just around spending PBs but also flexible attitudes.** **Resolve issues with other departments e.g. legal commissioning frameworks.** **"Earlier support, but the right type of support to enable people to be as independent as possible. This should reduce the longer term need for formal commissioned provision potentially"**

9) Establish a regional purchasing consortium

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"An end to "one size fits all" approach" "Get rid of Panels and REM" "End the postcode lottery" "LA not willing to set up ISF packages for people" "Not easy for people who have a DP to know what support is available to them" "Unclear commissioning strategies" "Lack of awareness of what is available int the market place"	Local coproduction that helps shape the care market – f**undamentally who should define what is available in the market in the first place?** **Coproduction of standards** is key. **Stop being faceless** – over the last 5 years many LAs have sought advice from consultants and they have progressed with what is known as the 'Apple' model – which is the faceless organisation. **Get people in the room around the blank page approach** Even those who access self-directed support are most often not given the freedom and control they deserve and desire. **We must invest in direct payments and ISFs and the relationships and flexibility that are essential to making them work!** *"Earlier support, but the right type of support to enable people to be as independent as possible. This should reduce the longer term need for formal commissioned provision potentially"* Local authorities and CCGs (etc) **to adopt the I/WE statements and use them in assessments for PBs**. Simplify contracts with providers, focus more on the conditions as outcomes rather than outcomes (we can't know what outcomes will actually be until we get there).

10) Agree regional approach to collaborative commissioning in the NHS

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"Stop silo working" "Enhance relationships between health, care, voluntary organisations and at a local level too" "Parity of esteem" "Holistic support – not just task driven" "Secondary MH services embedded into primary, such as GP surgeries, with less clinical approach" "Equal access to health care for service users" "integrated care system/access so that people only have to tell their story once" "Have ONE comprehensive assessment process" "Co-diagnose and joint pathways for families and individuals" "Bring health and social care together under one umbrella" "A lot of older people don't want to go via social services, they only want support via their GP" "People feel like needing social services is a failure on their part"	**Work with Making It Real** – adopt I/We statements – actually using the I/We statements in assessments for personal budgets Focus not only on the what but on the HOW – **what are the conditions that will bring about the changes** people really want to see? Open honest conversations, flexibility on how budgets are used and stop moving the goalposts… **"The system is not joined up around individuals' needs"** **Better quality assurance across services** – improve basic standards all round – **let's work towards true integration** of health and social care with less silo working and fewer system blocks.

11) Co-produce a regional provider engagement process

Comments from stakeholder workshops on 26 July and 8 September – **What are the biggest priorities for you/What do you most want to see change?**	Key themes emerging from the **Conversation of Change workshop** 18 October
"People need a forum that gives them TEETH to challenge and make change – challenging councils that don't adopt coproduction models" "Social workers be enabled to take time to get to know the people they advocate for" "Empower more people to use their voices" "Ensure inroads into coproduction do not fall back again" "Provide personalised care, based on very specific individual needs" "More collaboration and coproduction" "It feels a bit like who knows who when it comes to which organisations and charities get to provide or respond, and it's not always the best for people – we need to listen to the little charities and groups more"	If we want different outcomes, we have to question everything and do things differently" When peoples' voices are heard it gives them a sense of purpose – and what people need most is to feel a sense of purpose. Please listen to us and stop seeing us as obstructive – really listen to people and coproduce True co-creation and coproduction is essential (with those with lived experience) – investment in coproduction and the relationship between people and services. Listen to what really matters and work with peoples' own wisdom and strengths, advocate where necessary – creating spaces to genuinely listen to and work alongside people in receipt of support (not tokenistic) Commissioners really listening to what matters to people.

Key learning from the stories

One of the methods used in the research was community reporting (more info below). Fifteen people trained as reporters and shared their story, or just shared their stories with one of the Curators of Change trained reporters.

These consisted of open-ended dialogue interviews with people who have accessed a range of care and support services, including carers. The findings from the stories supported the feedback from the various focus groups and the survey, and were central to the sense making and conversation of change processes.

These stories were hard to hear at times, although there were some moments where the experience of the storytellers was more positive.

Overview of key learning

Overall the storytellers were weary of working against the systems of care and support that are there to help, and afraid of challenging, often using words and phrases like 'having to push and push'; 'struggling to cope'; 'frustrating'; 'battle'; describing their feelings of being tiny, being fobbed off and not listened to.

However there were some positive reflections from people too. One storyteller describes her experiences of good care and support that enable her to live the life she wants to, being independent and being well supported at home by friends and family. This storyteller's strong support network was fundamental to her wellbeing, however even in this story there was frustration relating to Carers Allowance and means testing being unfair.

Carers of young people with disabilities talked openly about the frustrations they face getting support in relation to their adult children being independent. The strain on families was clearly evident as the storytellers talked about their frustrations and lack of appropriate support. One mum talked about wanting a 'gentler transition' and a mentor to help her son even begin to think about the options open to him. 'He is not in crisis – he knows he is comfy and we will support him but he needs to slowly become independent. I've tried to explore so many ways – I applied for social housing and they accepted him but he isn't ready… but he will only get help if he moves out' This highlights how 'stuck' some people are, but also highlights the need for a different kind of support for families in similar situations. "All I want is for my son to be happy and safe."

Other carers shared their experiences, one shared how the process for getting appropriate housing for her brother is terrible; professionals just don't turn up for meetings or keep cancelling them and months pass with no support or action. "My brother is having to come and live with me at weekends because mum wants to be a mum NOT a carer"; "He's a young lad and he wants to be with people his own age who are better matched". Another talked about how she has "failed abysmally since her daughter finished college" to find solutions for her daughter.

One mum shares her sadness at her son being sent away to school as a child "My son was sent to an out of county placement before inclusive education, this was quite challenging because we had children to have them in our lives full time but he was sent to residential school" As an adult her son has lived at home, and they have benefitted from direct payments. However now she wants to not have the responsibility of managing a direct payment and for a 'person centred' provider to take on the provision of care and support for her son. Something that will free up her relationship with her son, but also cost the local authority more money.

Some of the storytellers were direct recipients of care and support. The views were mixed, a clear recognition that when care and support is good and personalised it works well, but when things 'go wrong' the impact can be devastating. One direct payment recipient talked powerfully about her experiences of care and support and the difference it made to her life. "Having a direct payment has been life changing, before I had one I was incredibly isolated in my home". Alongside the impact of the lack of trust when 'professionals' made decisions about her care and support without talking to her. "Suddenly out of the blue I got an email after I had asked for help it said: your care has been cut. I know you won't be happy with this, I am going on holiday now." The recipient went on to say: "I don't think social services realise how much fear there is, I will never phone social services to ask them a question because I worry it will trigger a review".

One gentleman describes how life changing his experience of direct payments was, enabling him to live life, travel, work and have complete control of his life at the time he most needed it. Another says "I just want them to actually listen to us. I don't want them to sit there in judgement and go back to the managers and say, ooh, how many hours can we cut here?... They don't fully understand the complexities of someone's needs... if you do one thing wrong, they come down on you like a ton of bricks". He goes on to say "Social services don't seem to be able to communicate on a human level – the systems and processes get in the way... It's like they've taken their normal head off and put their social services lack of humanity, lack of empathy head on". This lack of humanity was something that was expressed by most of the storytellers in one way or another.

One of the storytellers worked as personal assistant he says "to be a good PA you need to have a good listen and be a good detective because you need to find out for yourself what the actual needs are not what a social worker has said" and continues "its mixed. Being a PA on an individual level the work is very rewarding but there is next to no support from social services, it's as if I don't exist"

Finally, some of the story tellers talked specifically about coproduction, and the difference it can make. One person who had a diagnosis of his mental health condition later in life explained how things fell into place for him in a "Eureka" moment. But how he then experienced the hierarchy and bureaucracy in the system, how he has struggled to be heard and often felt invisible. The solutions for him were very simple "if we want a different outcome, we have to do things differently" he explains, and how surprised others in the room were when he said this! He goes on to explain how coproduction brings us together as humans. Brings unlikely people into the conversation and how this can create different outcomes. It would be good, he says, to work both regionally and nationally in coproduction to share solutions – this would enable us to deal with things more quickly. He ends by saying seeing changes as a result of having his voice heard has given him psychologically a sense of purpose "that's why coproduction has been rewarding".

About the Research Methods

Community Reporting methodology overview

Originating in 2007, Community Reporting has been developed across Europe as a mixed methodological approach for enhancing citizen participation in research, policy-making, service development and decision-making processes. Central to Community Reporting is the belief that people telling authentic stories about their own lived experience offers a valuable understanding of their lives.

Community Reporting has three distinct components – story gathering, story curation and story mobilisation. Through gathering, curating and mobilising stories from our growing network of Community Reporters, we seek to inform policy, processes and practice.

Diagram 1: *Community reporting cycle*

Mobilising stories
e.g. responding

Gathering stories
e.g. probing

Curating stories
e.g. sense-making
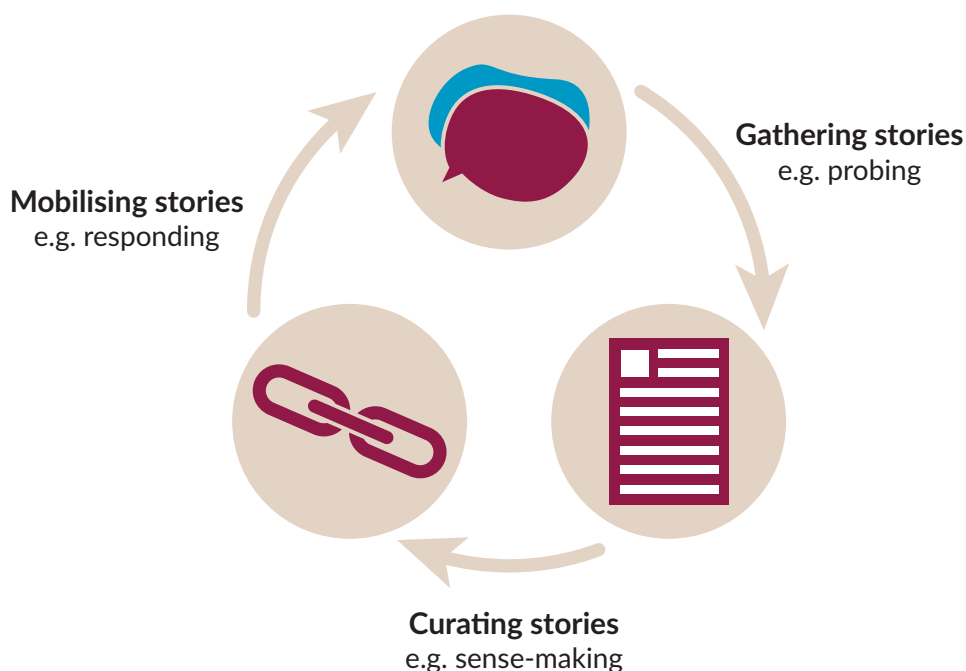
Storytelling techniques

Within Community Reporting there are three key storytelling techniques adopted. The techniques are:

Snapshot stories: these stories engage people in talking about their perceptions on a particular topic.

Dialogue interviews: these stories take the format of peer-to-peer 'interviews' that do not have pre-determined questions. Instead, an opening question (i.e. a conversation starter) is asked which enables the storyteller to start to tell their story. The Community Reporter recording the story then asks any questions within this storytelling process that naturally occur to them and interacts with storyteller to support them to communicate their experiences. In essence, the structure of this practice mimics our day-to-day conversations and the questions and interactions that take place are those that occur naturally as the story progresses. The storyteller is largely determining the 'agenda' of the conversation, whereas the Community Reporter is the 'agency' facilitating the conversation.

Personal monologues: these stories are people's own recordings of themselves talking about a particular topic, experience or life journey.
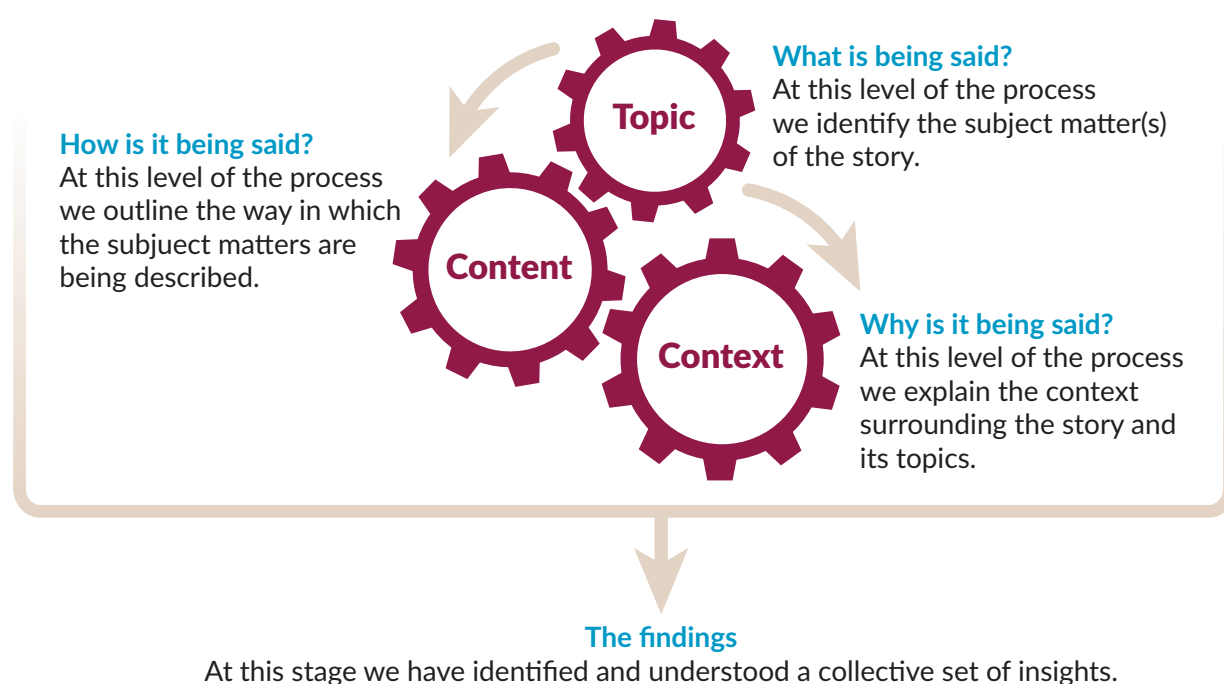
Responsible storytelling

Is embedded into each Community Reporting activity. Responsible storytelling accounts for the ethics and values of Community Reporting; ensures appropriate content of people's stories; ensures the necessary permissions and consent are gained; and puts people's online and offline safety at the heart of the practice.

Story analysis technique

This process happens at three levels: the first is the 'Topic' level and this is concerned with identifying the subject matter(s) in a story. The second is the 'Content' level and this is concerned with outlining the way in which the subject matters are being described. The third is the 'Context' level and this is concerned with explaining the wider context in which story is being told.

Diagram 2

How is it being said?
At this level of the process we outline the way in which the subjuect matters are being described.

Topic

Content

Context

What is being said?
At this level of the process we identify the subject matter(s) of the story.

Why is it being said?
At this level of the process we explain the context surrounding the story and its topics.

The findings
At this stage we have identified and understood a collective set of insights.

Story mobilisation techniques

Story mobilisation processes connect the learning from stories to people, groups and organisations that are in a position to use this knowledge to create positive change. There are many ways in which we mobilise the findings from our stories and curated content, both online and offline.

A key aspect of our story mobilisation processes are Conversation of Change events. Conversation of Change events use Community Reporter stories and other stimuli to prompt a dialogue between various stakeholders that seeks to catalyse change. When we talk about dialogue we mean the sharing of understandings, learnings and ideas.

Adopting facilitation techniques informed by aspects of Open Space Technologies, Brené Brown's (2012) vulnerability research and story dialogue techniques (adapted from Labonte and Feather, 1996), the stories and the key insights within them are used as stimuli for conversations between people with multiple perspectives.

(*Source: Peoples Voice Media; Institute for Community Reporting*)

Focus groups

These were an additional space to the story workshops and community reporter process designed to allow an exchange of knowledge based on a grounded approach and to allow for an open response to questions from which feedback is coded and themed. These facilitated spaces provide another level to the knowledge exchange process that can support new ways of thinking and doing things. Feedback was captured in the words of respondents using the chat function and Flinga boards (online white board).

Survey

A survey was created based on similar lines of enquiry to the focus groups. Allowing for open ended responses, with some space for people to indicate which priorities were most important to them. This is not the preferred methodology for this type of work, but it did allow an additional layer of sense checking the feedback from the stories and focus groups.

About Curators of Change

Curators of Change is a small enterprise of people with diverse and lived experience of care and support. The team includes people with lived experience of caring, mental health, long term conditions, as well as working in the field of change and change management.

Our ethos is one that brings the element of change to the fore, and creates space for people to reflect on the wider and system changes that need to take place from a much more human perspective.

Our aim is always to come alongside and connect with the existing networks and seek out people with lived experience to be part of the process of change in the areas we are invited to work.

The team that worked to support ADASS:

Isaac Samuels is an established community campaigner and coproduction advisor. He has worked for 25 years within the health, social care and housing sectors supporting those at risk of disadvantage due to social, political and environmental barriers such as poverty, health and or disability, to live their best lives. He does this by supporting people to share their lived experience in order to shape policy and reach their desired life outcomes irrespective of the systematic barriers they may face.

Isaac has lived experience of his own inequalities associated with his own health and social care support needs. He is passionate about supporting others to overcome these particular barriers.

Sally Percival started out her working life as the manager of a hydrotherapy unit in a rehabilitation hospital but her path changed after having children. Sally's son, A, was diagnosed with autism and a learning disability at the age of three; through this diagnosis she started The South Lakeland Autism and Asperger's Syndrome Support Group in 1995, and supported Our Lives Cumbria, a family leadership organisation which tells authentic stories about directing your own support. A has a joint social care and health personal budget as does her step daughter H who also lives with her. "Self directing our own budgets and support has given us choice and control over our lives and this has made an enormous difference to family life." Sally truly believes that: "the happiest of people don't necessarily have the best of everything; they just make the most of anything".

Kate Sibthorp – my daughter, M is my inspiration. When she was ten, the White Paper, Valuing People, was published and I had great hopes for her future. Nearly 20 years later, people with learning disabilities still don't have enough choice and control and are often not included in society. I'm a big fan of Making it Real and 80+ fabulous I and We statements: stop me and try one!

My professional background is more years in local government than I care to remember, managing public sector housing in the capital and moving into organisational learning and development in Manchester.

Cat Duncan-Rees is an enterprising and energetic practitioner running her own business. With more than 20 years' experience of facilitating organisational and workforce development for a wide range of public sector organisations. Cat is also a national 'coproduction' expert, a Pirate and Camerado!

Cat founded Curators of Change in 2017 based on years of insight and experience of managing and observing the effects of good strategic and change and organisational development in public sector organisations, including health; social care; BBC Sport; Think Local Act Personal and a range of community and voluntary organisations. Curators of Change is driven by the desire to shift the emphasis from what matters to systems and processes, to focus first on what matters to people and communities.

In addition to this work with ADASS East, Cat's current work includes: Senior Community Facilitator supporting the community development fieldworker team with Winning Hearts and Minds (Manchester Active); Associate work with Ideas Alliance and Peoples Voice Media; Red Quadrant (Commissioning Academy); Be More Pirate development work.

ADASS East Market Shaping and Commissioning Network