



***Telling it as it is: influencing commissioning
and models of care & support***

DAA quarterly meeting

Salford

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Life Story Network CIC

- A social enterprise company based in Liverpool;
- We promote the value of narrative approaches, including life stories, to improve the quality of life and wellbeing of individuals and keep them connected in their local communities;
- Extensive experience in consultancy, developing strategies & training, with a particular expertise in dementia;
- Committed to cultural transformation and improvement, taking a 'holistic' & 'whole systems' approach.

I'm going to talk about ...

- Devolution – or delegation?
- Our approach
- Some important ingredients of whole systems working
- Our work in Rochdale
- The engagement process we used
- Some key themes
- Measuring success

Devolution or delegation?

Some inherent tensions:

- Accountability remains with NHS England
- Seeking permission – or acting autonomously?
- Local v national priorities?
- Scaling up what works – without imposing a single model on the system
- Core objective – achieving future savings or producing better outcomes for the local population?

Some important ingredients of a whole systems approach

- Giving people with dementia and family carers a voice and a seat at the table
- Engagement – or equal partnership?
- Individuals, groups and organisations
- Thinking beyond health and social care
- Getting out and about, feeling safe, taking part, being made to feel welcome, staying connected ...
- Transport, leisure, culture, housing, customer care
- Technology, social media – but not for everyone

Our work in Rochdale

We were commissioned to review the existing Dementia 'offer' and identify gaps and areas for further development:

- Undertake a documentary review of the current policy context and examples of good practice / models;
- Identify linkages between current services, opportunities for greater integration and service gaps;
- Find out what matters to local people with dementia and family carers – a specific focus on BME communities;
- Produce a strategic report with key recommendations and an outline implementation plan.

Engagement process

Purpose:

- ✓ Ensure that the strategy **reflects the voice and contribution** of people living with dementia, family carers and local people
- ✓ Provide people **with the time and a safe place** to say what they would like to have in place locally – what does good look like, what can we do differently;
- ✓ Give commissioners & providers the opportunity to **hear directly** from people with dementia & carers
- ✓ **Secure ownership** across the whole system
- ✓ Identify **community assets** beyond health and social care
- ✓ Provide **local traction, leverage and the evidence (*business case*)** for the necessary changes and realignment of current financial investment / services

Engagement process

- Must start with older people, people with dementia & family carers
- Listen to what really matters to local people living with dementia and their carers
- May need various approaches – reaching out as well as including people in events
- Includes practitioners, clinicians and managers
- Multi-agency – NHS, local authority, voluntary, community & independent sectors; commissioners & providers; housing, transport, emergency services
- Building block of developing effective strategy and competent, resilient communities

What people told us

- *It was vascular dementia and there was no treatment – go back to the GP if there are any problems.*
- *I was asked ‘do you know what Alzheimers is?’ and I answered yes, and was then told that is what your mum has and here is a prescription. Then we left!. Not satisfied at all – no compassion or offer of any support.*
- *“The GP gave the diagnosis, have never been seen in the memory clinic. GP was very matter of fact and printed a dementia sheet from his computer – myself and my family were very upset.*
- *GP was good – referred to memory clinic, got speedy appointment - no complaints!*
- *I would like more social interaction and to meet other people, often feel lonely. Dementia advisor is arranging a for a support worker to take me to a lunch club and referred to companion support services.*

What people told us

- *I was admitted three months ago with an infection. The first ward was too busy and didn't understand needs. Felt intimidated and that I was like a nuisance. Moved to the Oasis Unit which was fantastic!*
- *Total lack of respect when trying to sort out a missed appointment / lost referral. I felt that no one wanted to take responsibility or provide help*
- *The last few months have felt very lonely. Was left to get on with it without knowing who to contact or what to do. I have reduced my hours at work to enable me to carry on in the caring role as everything was getting too much for me.*
- *I have struggled for the last year not knowing who to turn to or if I was doing the right things for my husband. Having no professional support has been very difficult. I have often felt stressed worn out, but not known what to do for help.*

What people told us

- *I hate going home as I don't know what I am going to be faced with. He assumes what is happening on the TV is real and shouts and screams at the TV. He throws things around. I don't know what kind of mood he is going to be in – sometimes he is so angry and other times so apologetic. I have come to the point where I have looked at care homes in Islamabad, Pakistan as I don't feel I can cope anymore. My children have their own lives and families, so although they visit they can leave but it's me that deals with this on a day to day basis.*
- *Home visits from the dementia advisor are important, more relaxed and people not overhearing your conversations.*

Some key themes from the work

- Quality & availability of post-diagnostic support, including peer support
- Finding the way around 'the system' & knowing where to go for help
- Support for self-funders – often ignored
- Support to carers, including carers' assessments
- Role of primary care – gateway to assessment
- Integrated information and data systems (across police, fire service and NHS / Social Care) especially regarding frail elderly, social isolation and loneliness, appropriate discharge
- Needs of particular groups – younger people, learning disabilities
- Shared ownership & leadership across the system – organisational leadership less relevant in achieving sustainable change
- Sharing resources, working collaboratively, joining up services

Measuring success

- Some conventional performance indicators (diagnostic rates, emergency admissions to hospital, admission rates to residential care ...) only tell half the story
- Lived experiences of people with dementia and family carers
- Engagement is not enough
- Involvement as equal partners
- People with dementia and carers tell it as it is – if we ask them and listen to what they have to say!

Now over to Rochdale for the next exciting instalment!

Thank You!

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