Making Connections
24 February 2015
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Welcome and Introduction

Scene setting

Who we are

A network of individuals and organisations dedicated to champion the use of narrative practice, including life stories to enhance the care and support for individuals, family carers enabling them to live independently as valued citizens in their local communities.

Promoting a model of ‘citizenship’ and ‘inclusive communities’ underpinned by ensuring that a person’s human rights are recognised and respected.
DAA
Liverpool Dementia Action Alliance

• 2013 – Year of Action on Dementia

• May 2014 – launch of Liverpool DAA

• Over 30 members

• Five groups:
  SURF
  Transport and environment
  Community engagement & education
  Diversity
  Dementia reference group

• Initial funding from CCG
Your Community Matters™

• PM’s Challenge
  – Care and Support Compact
• Refining the organisational model
• Refining ‘Family Carers Matter™’
  Led to
• Successful proposal to DH for further funding 2012-13 (1)
What we set out to do

• Explore the concept of the care home as a community hub by supporting their engagement with the wider community, including family carers, volunteers and young people in education or who are unemployed, as a way of keeping people with dementia connected

• Work with the home care sector to promote life story work and relationship-based care

• Work with the housing sector to develop the capability and capacity of communities to support people with dementia and help keep them connected
What did we learn about the care sector?

• Care homes as ‘the hub’ in the community – is this realistic, given the capacity, dependency levels and resources?

• Facilitating communities to engage with care homes – rather than vice versa

• Home care staff worked in isolation – but doing life story work increased positive contacts with families

• Opportunity for underpaid and undervalued staff to recognise and validate their crucial role – keeping people independent

• Training increased their confidence to advocate on their clients’ behalf
What did we learn about young people?

• Real interest in connecting with older people

• Using life stories is a valuable way of doing this

• A way of inspiring them to take up social care as a career, using workplace opportunities to engage in a meaningful way

• Our training helps them develop inter-personal and communication skills
What did we learn about housing?

• Varying degrees of knowledge and activity on dementia

• Clear demand for further training – an open door

• Recognition by RSLs of their responsibilities towards their tenants with dementia in general housing stock as well as in specialist housing – need for more collaborative approach within the sector

• Enthusiasm of tenants and the potential to develop community capacity through them

• Training increased tenants’ confidence to advocate on their neighbours’ behalf and challenge negative attitudes

• Key role of the sector in developing dementia-friendly communities
What did we learn about communities?

• A desire amongst tenants and neighbours to support each other

• An appetite to learn more about dementia in order to really understand it, challenge negative attitudes, change behaviours and know how to provide practical help and support

• Solutions to create dementia friendly communities lie within the people and organisations within communities – assets to be built on

• Our contribution has been significant in bringing about a recognition that people living and working in the community have the ability to affect positive change

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Your Community Matters – Phase 2

- Housing providers recognise they have a role in supporting the dementia agenda
- They have difficulty in assessing which training, initiative or resource is most useful & appropriate to their organisation – moving from awareness to understanding
- Focus on Anfield in Liverpool to map what it’s like to live with dementia there
- Project under the remit of the Liverpool DAA
What did we learn in Anfield?

- A good place to live and a supportive community
- Lots going on – but not joined up
- Information about resources and how to get help is difficult to access
- A need to raise awareness and understanding about dementia locally
- Housing sector is key – the eyes and ears of the community
- Sector not always at the table with strategic health and social care partnerships
- Survey of housing staff confirmed the need for bespoke training for those dealing directly with the public/tenants

Next steps
- Community mapping exercise to pull together resources
- Further community event to present results
Family Carers Matter in Hartlepool

• Funded by Northern Rock
• Built on a previous project with family carers, focusing on practical and positive responses to difficult behaviours of people with dementia
• Aimed to help rebuild relationships through shared experience of developing life stories and providing a focus for conversations
• Training programme for family carers, followed by recruitment of volunteers from participants to deliver training to others – sustainability
• Evaluated project using a quality of life questionnaire
What did the evaluation tell us?

- Improved understanding of behaviours – not wilful or intentional – *I’ll approach mam in a different way*

- Reduced frustration of family carers and increased their tolerance levels – *I’ll encourage mam to tell me what she wants to tell me, not bombard her with questions*

- Helped carers define what they wanted from the relationship – not just as a carer – *with a fresh pair of eyes*

- Increased enjoyment of spending time with person with dementia – *a pleasure not a chore ... we’ve found each other again*
Transport Matters

• A priority for older people generally and for people with dementia

• One of the five DAA sub groups

• ‘Getting out and about’

• Staying healthy, active and connected

• Getting lost is both a fear and a reality

• People lose confidence after diagnosis and may withdraw
What have we done?

• Consultation with people living with dementia and their carers

• Initial seminar to get feedback and gauge interest from the sector

• Larger event to share learning and get strategic support

• Piloted bespoke training
What people with dementia and carers told us

- Train timetables are difficult to understand
- Buying tickets is difficult – pressure to use machines or book on-line. Ticket counters not very inviting
- Platform changes are a nightmare!
- Staff are not always visible to ask for help
- Most bus drivers are helpful but some drive too fast and brake hard
- Seat belts on priority seats would help people feel safer
- Carers who don’t qualify for a pass and accompany disabled or older people pay full fare
What the sector told us

• Policies about disabled customers do not include dementia
• Some companies have provided dementia awareness training to staff
• Responses to people in difficulty are limited
• Not everyone identifies themselves as disabled so staff have to be alert to the possibility
• Merseyrail is looking at how to improve signage at stations
• Incidents are rarely logged and no data is routinely collected
• There is scope for contact details to be logged when a Merseytravel pass is issued
• The sector is keen to rise to the challenge
Working with Virgin Trains

- First company to take up offer of free training session
- Planned content to meet their specific needs
- Attendees wanted to be there – keen to learn
- One day course covering dementia and how to respond better in their job role – wide range of staff
- Seen primarily as a customer care issue
- Used their experiences to illustrate techniques
- Very positive feedback – their evaluation and our own
- They want more!
Next steps

• Working with city council and British Transport Police on ‘safe havens’ for people in difficulty

• Exploring carer concessions, emergency contacts and staff training with Merseytravel

• Working with Arriva buses to develop dementia training for staff

• Working with Unite to explore training for black cab drivers

• Contributing to the national dementia-friendly transport working group

• Securing project management time – this is a huge but vital agenda!
Thank You!
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