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Luton Dementia Coproduction Project
Carers Survey

To identify and implement practical solutions to the needs
of carers of people living with dementia



Why was this survey conducted?

- Luton CCG (GP and Nursing services) identified that there was an increase in the number of carers caring for people living with dementia who were attending surgeries when they reached crisis point.
- The project was set up to use the coproduction process to look into the number of those caring for people living with dementia reaching crisis point
- The results will influence commissioning and improve the quality of services from health and social care which in turn will improve the quality of life for the person being cared for and the carer themselves.
- The survey was not conducted under 'pure' research conditions but rather the opinions of the carers involved. Carers were trained to carry out the survey as it was recognised that carers carrying out the interviews would have empathy with their situation

Co-production initiatives

- ☑ define people who use services as assets with skills
- ☑ break down the barriers between people who use services and professionals
- ☑ build on people's existing capabilities
- ☑ include reciprocity (where people get something back for having done something for others) and mutuality (people working together to achieve their shared interests)
- ☑ work with peer and personal support networks alongside professional networks
- ☑ facilitate services by helping organisations to become agents for change rather than just being service providers

- 76 carers were interviewed
- The youngest interviewee was in their 20s and the oldest 90+
- 73.7% of the respondents were female and 25% male and most were of white/English origin
- 39.5% of respondents were caring for their husband, 21% for their mother and 14.5% for their wives
- Of those being cared for 36.7% were suffering from Alzheimers, 31% from vascular conditions and 10.4% from both Alzheimers and vascular
11.7% of respondents were unaware of the type of dementia suffered by the patient
- 68% of carers were living with the person suffering from dementia
- In terms of severity 32.9% deemed the condition to be moderate, and 21.1% as severe

Carers were asked the following two simple questions:

- Q1 - What are the things that you find most difficult or worry about?
- Q2 - What are the one or two things that would support you in your caring role - maybe you think, if only I had that, it would make so much difference?

Over 55% of respondents claimed that they were having a good day when being interviewed, with 17% claiming it was a bad day.

Results

Q1. What are the things you find most difficult or worry about?

Daily living – changes in the ‘dependence’ and level of function of the person living with dementia

- 27.93% - carers
- 19.7% - focus groups
- 16.8% professionals

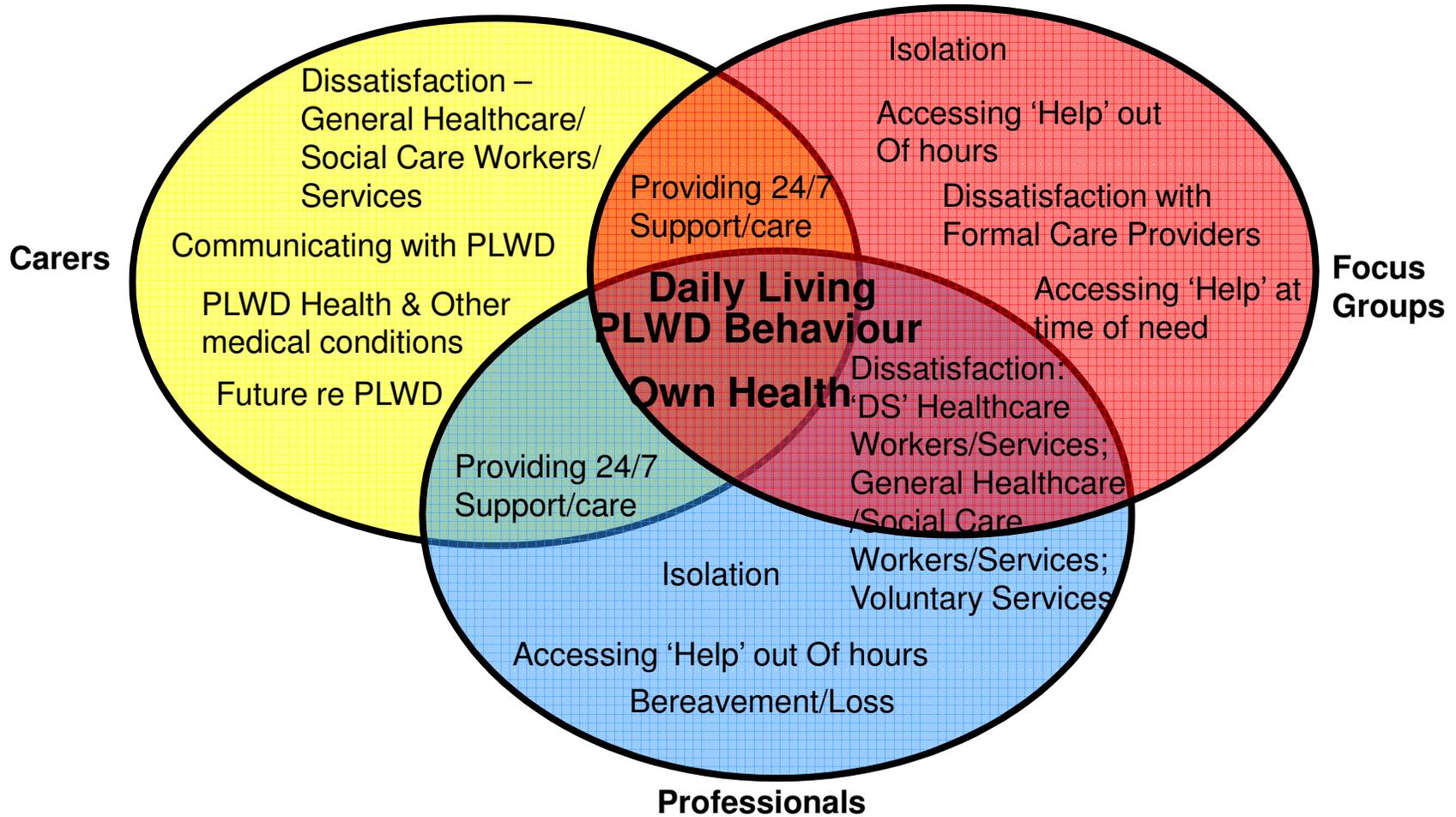
Person living with dementia behaviour including wandering/getting lost; own (carers) health, fatigue and tension (joint 2nd responses)

- 14.33% - carers
- 13.4% - focus groups
- 16.8% - professionals

Providing care for person living with dementia 24/7 and/or providing ‘other’ support

- 3.62% carers
- 8.9% focus groups
- 9.1% professionals

STRESSES



Results

Q2. What are the one or two things that would support you in your caring role - maybe you think, if only I had that, it would make so much difference?

20.2% - 40 responses – most requested service - short break/respice

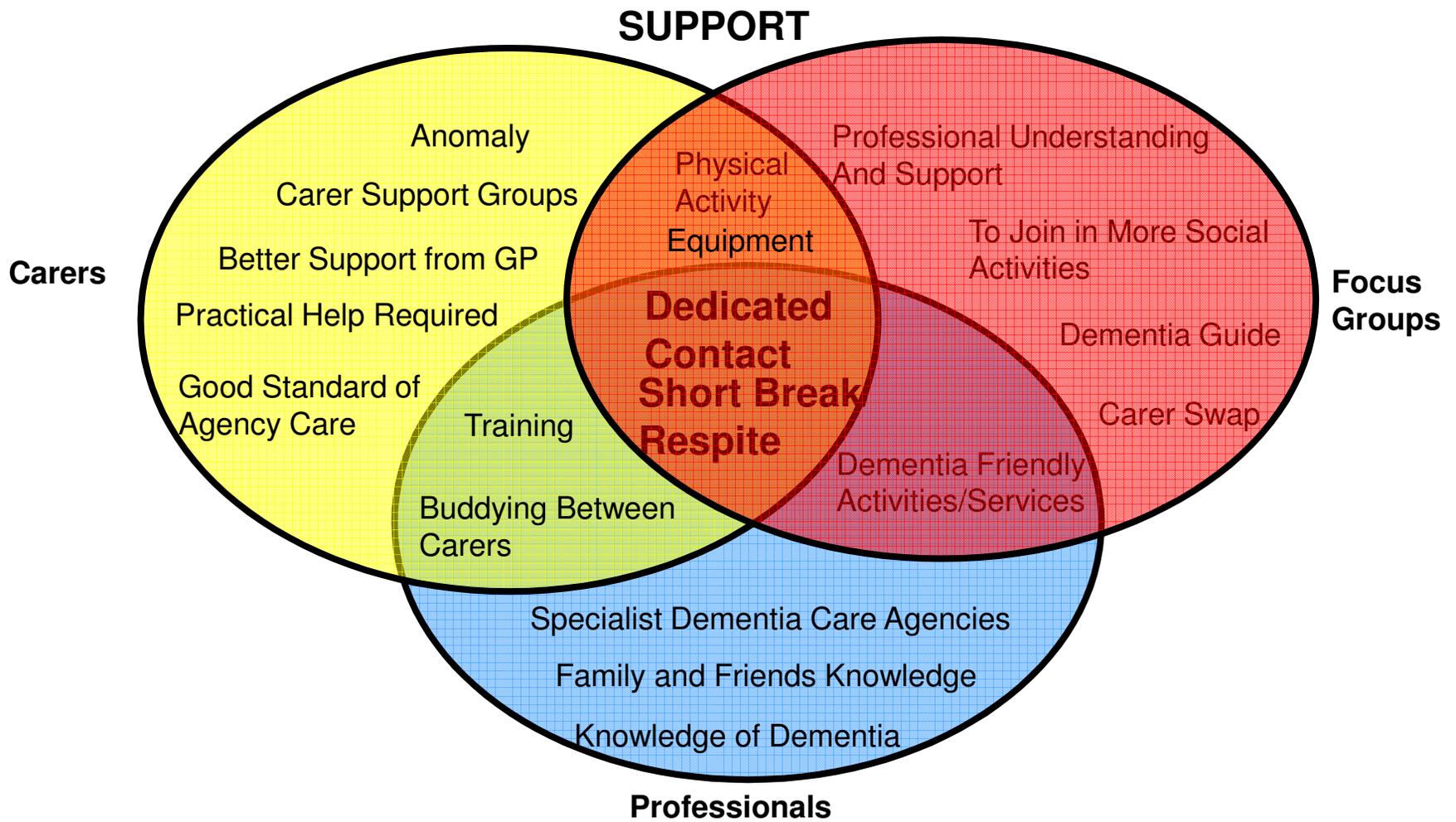
Grouped into this category are:

- requests for a sitting service support for person cared for to enable carer to undertake household chores
- request for overnight care/respice

14.6% - 29 responses - second requested service - dedicated contact

Grouped into this category are:

- out of hours
- dementia nurse specialist



Outcomes

- ☑ Strong partnership working & relationships
- ☑ Service re-design is being informed through co-production
- ☑ There is a higher level of commitment to resolving key issues
- ☑ Carers of people living with dementia have been given a voice

Challenges

- ☑ Competing agenda's
- ☑ Creating a shared vision and understanding
- ☑ Participation – carer support needed to facilitate this
- ☑ Number of meetings needed to keep on track
- ☑ Managing the co-production process/project focus
- ☑ Increasing demands on carers in their caring role
- ☑ Engaging with people from ethnic minority communities

Luton Co-Production Dementia Project

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