The role of Dementia Support Workers in the community in removing the barriers to isolation for people with dementia following diagnosis

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objectives

- Identify the need for people to have easy access to care, support and advice following diagnosis
- Development of Dementia Support Workers
- Role to provide named contact for people with dementia and their carers
- Provide information and signposting to local services
- Identify issues and facilitate engagement with specialist services for support and care
Dementia support workers

- Five DSW recruited and trained (southwest hub)
- Communication skills, understanding of dementia and needs of carers.
- DSW – one to one, suitable venue, discuss diagnosis and needs
- Journey with families provide timely, individual signposting and information
- Aid persons understanding to remove isolating barriers
- Carer benefit – better informed to support
The Research Question

- Identify the barriers and facilitators for the DSW and in using the service
- What hinders their role, what helps?
- Focus groups and interviews with DSW’s
- Interviews with people with dementia and their carer’s
- Interviews with stakeholders
- Documentary analysis
- Mapping referral routes and signposting
Realist Evaluation Framework (Pawson and Tilley, 1997)

- Not about x causes y - need to understand not describe real people and real services
- Start from premise that involvement in a service is a choice
- Understand more about what led a particular person with a particular set of circumstances to make their particular choice

Central question: ‘What works for whom and in what circumstances’
Referrals

- Client record system provides detail relating to referral
- Provides view of service delivery, client information
- Demographics, routes of referrals, who contacts, the reason
- Carers, family, GP’s, CPN’s, PWD
- Majority by face to face at home, library, memory cafe
- Provide single personalised contact point
- Proactive to avoid a crisis
Families using the service

- “You need professionals. We’re ok physically, medically, it’s the emotional support.” (carer)
- “You’ve offloaded baggage, you can move on.” (carer)
- “It’s the weekend you need something like the Samaritans when I feel like I can’t take anymore and he’s driving me nuts.” (carer)
- “He’s in his man cave, he knows you’re at the entrance and no-one can get to him.” (daughter)
Reason for referral and information provided

- Befriending/memory cafe/ Alzheimer Society services
- Health, living well, emotions, relationships
- The future, finance, day care, home support, voluntary services
- Diagnosis, transport and driving
- Emotional support

Service users felt listened to and the information enabled access to other services
There were three people talking together about how frightening the telephone was and I never heard anyone talk like that before. I’d never heard somebody say I’m terrified of the telephone what if I pick it up? What if I can’t remember what the person is ringing about and I can’t take the message? What if it’s the grandkids and I can’t remember their name?” (DSW 002)
Promoting the service and meeting the needs of the population

- Biggest minority – Polish support for the future
- Attempt to work with communities through sheltered housing schemes
- Network with AGE UK, Dementia Action Alliance, Plymouth museum and the arts memory cafes, CMHT’s, GP surgeries
- Prompts better liaison and service delivery
- Break down barrier to diagnosis
Promotion through GP Surgeries which population access

“Their appreciation of what we can offer because a lot of the time they are saying the time they make to get a referral for diagnosis can be 6 months and that is a huge difference in someone’s life. We don’t have to wait we can actually start to help.” (DSW 004)
What works for who and in what circumstances?

- Face to face not always possible – busy professionals
- More visible information for professional stakeholders
- Careful consideration to respecting autonomy of the person with dementia
- Provision of adequate support to the carer and their family whether needs are congruent or conflictual
- Clear demarcation of roles and capabilities
Respecting autonomy and the tension in meeting needs

“There comes a point when you have to accept what they say. Just give then the option that if we can be useful at all this is how you contact us. That is all we can do because we can’t make them.” (DSW 001)

“The wife (who had dementia) was nonchalant like my daughter has arranged this, I haven’t. The daughter was really keen and it’s meeting all three needs because you want the daughter to go feeling better but you don’t want the wife to feel that she is having services shoved down her throat.” (DSW 003)
Facilitators

- Competency in dementia and approachable
- Strong links with primary care, voluntary and community sectors
- Priming local service users about a new service before it begins
- Clear definition of new worker role and how this fits into existing care pathways and interacts with services to maximise acceptance of role by others
Limitations

- Signposting only as good as the services people are referred to
- Type and degree of information required over time by service users impacts on DSW case load.....

“You could be a real problem for someone if you start making promises. You can’t, it can be devastating. You have to be honest about what you can provide and follow that through as far as you can.” (DSW 003)
Recommendations

- More Dementia Support Workers will be needed due to expanding demographics
- The co-location of DSW in GP surgeries so the service is more visible
- Seamless integration and close links with services
- Inform that services are there – safety net
- Information to include local events and activities for carers
Thank you for listening

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