centre for research on families and relationships

Best practice in learning disability and dementia: getting service user views

Dementia is a particular concern for service providers supporting older people with learning disabilities. Until recently little forward planning had been built into services to prepare for residents to grow older, and cope with medical conditions of older age such as arthritis, osteoporosis or dementia.

For people with Down's syndrome, there is a high prevalence rate of dementia as medical advances mean they, as with the rest of the population, are living longer lives. Little is known about the views and experiences of people with a learning disability who have dementia or are living with someone with dementia in a residential setting (Wilkinson et al 2003, 2004; Lyngaard 2004)

A three year research project funded by the Community Fund in collaboration with CARE[1] has explored best practice for people with a learning disability who develop dementia - looking at what enables people to remain in their own homes and communities.

Key points

A key element of this wider project was a service user advisory forum. One of the things we wanted this group to tell us was what people with learning disabilities know about dementia and what it was like to live with someone who has dementia. We learnt that:

- Service users know a lot about dementia
- Living with someone with dementia can be really hard and residential care staff do not always have enough time for other residents
- Services should think more about how dementia affects everyone – not just the person who has the dementia
- Changes made in residential settings to better support someone with dementia can create tensions and misunderstandings for other residents
- It is important for wide consultation and explanation for changes with all residents in a care setting
- Lack of consultation clearly highlights a lack of respect or understanding of the strong social relationships and their positive benefits that can exist among residents in these care settings

[1] CARE (Cottage and Rural Enterprises) are a charitable organisation providing residential and social support for people with a learning disability in England.

Background

Demographic data on ageing and learning difficulty highlight a trend of longer life. The average life expectancy of people with Down's syndrome has increased from nine years in the 1900s to over 40 years in the 1980s (Baird and Sadovnik, 1987). Demographic trends look set to continue and people are now living into their 50s and 60s. This is particularly significant when seen in the context of the number of people with learning difficulties; the exact number is unknown, but recent data indicates that within England the figure is likely to be around 210,000 people with profound learning disabilities of whom around 25,000 are over the age of 60 (Department of Health, 2001).

Research objectives

The research had a number of key objectives:

- to explore, from a range of stakeholder perspectives, the organisational, financial, social and health care issues leading to the exclusion through relocation of people with a learning disability and dementia
- to examine the experiences of service provision for people with a learning disability on developing dementia
- to explore the experiences of paid and unpaid carers when the person they care for develops dementia
- to explore and document the practical experience of service professionals in the statutory and voluntary sectors working with people with a learning disability and dementia and their families to maintain the individual in their home setting
- to identify, with the stakeholders, models of best practice and ideas of what the key supports are, to enable people to remain in their own homes and communities
- to develop best practice guidelines for service providers on key supports for people with a learning disability

Methods

To adequately address these objectives, the work was designed around 3 main phases of data collection as outlined below.

Phase one: current policy context

Detailed review and overview of current policy and practice based on interviews with local and national policy makers in England.

Phase two: ethnography - getting to know the service users, staff, families and practitioners in the system

Eight case studies focused on individuals with a learning disability who also have dementia (or are suspected to have dementia). Each case study person was visited a minimum of 5 times. Visits varied in duration and location to gain insight into range of experiences of being supported by CARE.

Interviews conducted with CARE staff (at all levels) and where appropriate, with people external to the organisation, namely family members and health and social care professionals. Issues discussed included staff training and levels of support, inter-agency collaboration/joint working, use of technology, budgets and support for family members.

Data analysis focused on examining the opportunities and barriers around supporting a person with a learning disability and dementia to remain at home. From this a range of practical, financial, planning, organisational and staffing 'supports' were identified and recommendations made. This led to the development of a best practice pack, called DAPPER.

Phase 3: action research: testing and reviewing implementation of the best practice pack

The implementation of DAPPER was evaluated in two sites. Supports accepted in this phase will become part of an interactive training package that can be used by staff throughout CARE and beyond.

Throughout the research, two consultation groups (one comprising service users and one of university and senior practitioners/ academics/ policy makers) advised the research team to ensure that methods and findings were both practical and useful. It is the views of the service user advisory forum that are reported here.

The service user advisory forum

The service user advisory forum was set up ensure that the methods used (the questions we asked, the people we spoke to and the changes we suggested) would all make sense from a service user point of view. As well as discussing methodology in this forum, members were able to describe in detail their experiences of living with others with dementia.

Seven main issues were apparent, and occurred frequently in the discussions of panel members, and indicate their understandings of dementia. These were:

1. Confusion
2. Forgetfulness
3. Wandering
4. Health and safety
5. The impact of dementia on staff time with the person with dementia and other service users
6. "Special privileges" that may be misunderstood or interpreted
7. Organisational-level communication about, and the impact of major changes to, the physical environment

The first three of these areas cover signs and symptoms of dementia that had been noted by panel members as part of their knowledge and experience of dementia; the later ones a more systemic understanding of how dementia affects others. Members of the panel indicated fairly complex understandings of the condition and also highlighted the proactive role that residents took in supporting each other

Service users were also clear in their feelings about the impact of one person having dementia on roles and relationships within their residential settings including those with staff. Hannah articulates the tension created when a person with dementia 'takes' staff time:

> **Hannah:** *Some of us feel as if we... I know it's not right, but it makes some of us feel as though we need a few more staffing.*
>
> **Researcher:** *In here?*
>
> **Hannah:** *Not at this end, but down at the cottage end because of the way the one-to-one is on with Clare and er "I'm sorry I am doing the one-to-one with Clare" and if they are doing the one-to-one, it's like they've got only so many different things to do.*

Clearly, concerns are being raised about the impact of living with people with dementia. Residents feel that one-to-one time necessary for those with dementia is having a negative impact on other people, since staffing levels are altered to compensate for this. This is important feedback for service providers running homes with residents with mixed support needs.

In a residential setting such understandings and tensions can have a major impact on social relationships and levels of support. Whilst residents are clearly supportive of each other there are also difficulties when supports for someone with dementia are perceived by others as 'Special privileges' as described by Hannah:

> **Hannah:** ... she hates going to the dinner table sometimes
>
> **Researcher:** Oh right, and why do you think that is? I am not surprised, why do you think that is?
>
> **Hannah:** ... why? I don't know. Maybe because the other one, she sees the other one that's got dementia, gets away with sitting at the little coffee table... getting her tea. And it makes her think 'well if that one can get away with it, why can't I?'

While the person with dementia is being afforded a quiet space in which to have their meal, this is interpreted as something over and above the treatment other residents get. A lack of understanding of the need for calm and quiet environments at mealtimes results in other residents feeling resentful of what is understood as a special privilege. There were similar tensions created around the changes being made to some of the residential environments in order to make them more supportive for people with dementia without consulting with other residents. Service users expressed concerns at large scale environmental and buildings changes indicating that there has been little appropriate communication or consultation with all affected service users, but a great deal of insight into the potential impact of such changes.

The data expressed by the people with a learning disability highlight the need to consider the wider systems involved when service users develop dementia. This is not just a condition that affects one person, but impacts on a range of practical, relational and organisational levels. This includes communication about changes in the environment and how symptoms may impinge on others. Critically, service users with dementia appear not to have had their diagnosis shared with them in a meaningful way. This also indicates that they've perhaps not had information/education about ageing prior to the onset of the condition to give them some context about what the condition means. Equally, it implies that residents without the condition have not had dementia explained to them, regarding their peers who do have it. Some basic education about conditions of older age for all service users may set up a virtuous cycle of understanding of dementia, to help them learn about dementia in other residents, and, potentially in the future, for themselves and that may result in more supportive social relationships within the residential settings.

Conclusion

The field of ageing and learning disability is a relatively new area for policy and practice development. The imperative for progress in this area is demographically driven, as a larger population of people with a learning disability are reaching older age. This trend has also resulted in this population also experiencing the illnesses associated with older age such as arthritis, the menopause and dementia. Thus the policy and practice arenas are ripe for developing appropriate and effective service provisions to support people with a learning disability as they age. (Janicki and Dalton, 1999; Wilkinson et al 2004).

It is timely that we explore the views and experiences of people with a learning disability and dementia about how they feel services are best developed for their future use. In this project we employ qualitative data from people with a learning disability and dementia to explore how their views on and understandings of dementia can inform the appropriate development of service provision and care models.

The data from the panel members highlight the complexity of views that different service users report and their implications for service providers. They also illustrate the importance of relationships between residents and how dementia can have a negative and positive impact on these relationships. In the context of increased emphasis on user views in planning services and highlighting best practices, the views of the individuals reported here add a useful perspective to an under-debated area of policy and practice.

References

Baird, P. and Sadovnik, A.D. (1987) Life expectancy in Down Syndrome. *Journal of Paediatrics*. 110 849-854

Dept of Health (2001) Valuing People: A new strategy for learning disability for the 21st century. London: Dept of Health

Janicki, M.P. and Dalton, A.J. (eds) (1999) Dementia, aging and intellectual disabilities: A handbook. London, Bruner/Mazel

Lynggaard, H. and Alexander, N. (2004) 'Why are my friends changing?' Explaining dementia to people with learning disabilities. *BJLD*, 32(1): 30-4.

Wilkinson, H., Kerr, D. and Rae, C. (2003) Might it happen to me or not? What do People with a Learning Disability Understand about Dementia? *Journal of Dementia Care*. 11(1): 27-32.

Wilkinson, H., Kerr, D., Cunningham, C. and Rae C. (2004) Home for good? Preparing to support people with learning difficulties in residential settings when they develop dementia. Brighton, Pavilion Press.

Authors

This briefing was written by Heather Wilkinson, Liz Forbat and Diana Kerr
and edited by Sarah Morton, CRFR.

Latest CRFR Research Briefings

For a full list of Research Briefings visit our website www.crfr.ac.uk

Contact details for CRFR