

7 July 2014

Agenda Item: 5

REPORT OF THE SERVICE DIRECTOR OF NORTH AND MID NOTTINGHAMSHIRE

PROJECT WITH ALZHEIMER'S SOCIETY TO DEVELOP PERSONAL BUDGETS FOR PEOPLE WITH DEMENTIA

Purpose of the Report

1. To update the Committee on the achievements and successes of the partnership project between the Council and the Alzheimer's Society to develop Personal Budgets for people with dementia, and to recommend that the Committee receives an update report on progress with Personal Budgets for people with dementia in 12 months.

Information and Advice

2. The context of the project was the identification at a national level of the low level of take up of direct payments and personal budgets for people with dementia and their carers highlighted by organisations such as the Alzheimer's Society and the Association of Directors of Adult Social Services.
3. The Care Act 2014 also places new and extended responsibilities on Councils including:
 - provision of comprehensive information and advice
 - arranging and making available services that prevent delay or reduce the need for higher levels of care and support
 - supporting a market that delivers a wide range of high quality services so that people have choice
 - identification of people in the local area who might have care and support needs that are not being met.
4. In commissioning this project the Council has responded to the challenges set out above and recognised that improvements are required along a range of fronts to improve delivery of personal budgets for older people with dementia. The project ran from July 2013 to May 2014.
5. The project built on good practice and achievements already in place within Nottinghamshire to transform and personalise adult services and to improve the early diagnosis and support for people with dementia and their carers.

Key priorities for the project

6. These were:

- identify and overcome barriers experienced by people with dementia and their carers in accessing personal budgets and direct payments
- develop accurate recording of performance data on people with dementia to inform locally and ensure resources are available to meet current and future demand for support
- improve access to good quality information and advice about personal budgets and direct payments
- raise awareness of dementia and the support available through close partnership working with key operational staff and partner agencies, and
- build on the good practice already in place locally and nationally

Key outcomes

Identify and overcome barriers experienced by people with dementia and their carers in accessing personal budgets and direct payments

7. The Project Manager and Project Volunteer interviewed social care staff, people with dementia and carers to understand their experience of direct payments and personal budgets and the critical success factors. This work showed that:

- Direct Payments for people with dementia can assist with timely hospital discharge and prevent long term care admission. A number of case examples to illustrate this have been identified for use with staff and other organisations.

Mrs. A. is 92 years of age has memory loss, macular degeneration, poor mobility and is at risk of falls. She has been using a Direct Payment for the past 2 years and her brother acts as her Suitable Person. The direct payment enables her to employ three female personal assistants that she has got to know and trusts. They provide assistance with all daily living tasks including prompting for personal care, securing property, preparing light meals.

The Direct Payment costs £216 pw and has enabled her to continue living at home even after the death of her husband which is what she wanted to do. Mrs A feels it very important to remain at home. The care package is working really well and Mrs A. is highly satisfied.

- Direct payments for people with dementia can be very cost effective. Case studies evidence that people with dementia and other health conditions can live in the community with the right support, at comparable or less cost than in residential care

- The factors that make community and home based support effective in maintaining people with dementia at home were identified as reliability, continuity of carers, trust and consistency.

Mr D. has Lewy Body dementia and gets anxious and agitated when his routine changes. His mobility is also very slow. He has recently been discharged home after 26 weeks in hospital after being admitted with a severe leg infection causing him to hallucinate and not recognise his family. He was keen to remain independent at home as long as possible, but is aware he has memory difficulties.

A Direct Payment was put in place with his daughter acting as a Suitable Person. She is using a prepayment card to manage the Direct Payment finances. Following input from START brokerage a support agency was identified that could provide practical support and personal care and could work around his need for consistency and reliability of carers.

Total cost of Direct Payment = £175 pw.

- There were many examples of excellent practice across the county with staff working imaginatively to put direct payments in place for people with dementia. This included Rushcliffe Older Adults team, Intensive Recovery Intervention Services (IRIS) for older people with mental health problems or dementia, START, and Mansfield Community Hospital social work team.

M. is 60 years of age and has working age dementia. He lives in a remote village in Nottinghamshire with his wife who is his main carer. She needed a break from caring and M needed some social interaction. M. felt he was too young for traditional day care services.

Through the use of a Direct Payment he was able to find a male personal assistant who shared similar interests as he wanted to talk about cars and engineering. A Direct Payment Support Service was able to help them with legal issues around employment

- Brokerage has been shown to be very effective in the START pilot as way of building capacity within the wider direct payment market, achieving reductions in rates, and developing partnerships with providers.

Mrs K is 84 years old has been diagnosed with dementia and has a range of other health problems. Following a fall she was admitted to hospital and from there to a step up bed in a Care Home and at risk of remaining in long term residential care.

With input from START brokerage her husband, chose one of the three agencies that expressed an ability to offer home based support to Mrs K on her discharge. Mrs. K was discharged home with a Direct Payment with her

husband acting as her Suitable Person. The care agency Mr K chose provides daily support mornings and evenings. Total cost of direct payment = £ 147 pw.

- People with dementia and carers were very positive about their experience of having a carer's assessment and carers' personal budget. This service was generally accessed via the Carers Team at the Customer Services Centre.
 - People with dementia who lack a Suitable Person to manage a direct payment still want to have choice within the managed budget option to allow for specific requests for activities or support that will offer continuity or provide a dementia specific resource.
8. The information was incorporated into a report with recommendations about ways to streamline processes and reduce barriers to people accessing personal budgets and direct payments. This has been shared with Service Directors and relevant Group Managers.

Develop accurate recording of performance data on people with dementia

9. Research on direct payments and personal budgets for people living with dementia in England has revealed that there appears to be no data being collected about people living with dementia who are receiving personal budgets or direct payments. Preliminary analysis in Nottinghamshire identified that 143 people with a category of Mental Health/sub category - Dementia were receiving a Direct Payment in Nottinghamshire on 18th August 2013.
10. Staff guidance on correct dementia recording has now been developed and circulated to operational managers and staff.

Improving access to good quality information about personal budgets and direct payments

11. A range of reports including Improving Personal Budgets for Older People (Think Local Act Personal, January 2013) state that councils need to improve access to information, advice and guidance around personal budget options for older adults, including for people with dementia.
12. The project undertook a Dementia cafe consultation to establish what information (about services or support) people with dementia and their carers wanted and needed, plus where and how they might want to access that information. Over sixty people participated. The feedback has been summarised into a full report and makes a number of recommendations to improve access to information. A full copy of the consultation information is available on request.
13. A half day workshop took place to map information needs along the dementia pathway. The workshop identified that there was a need for additional early signposting about dementia support and as a result three Clinical

Commissioning groups (Nottingham West, Nottingham North and East and Rushcliffe) are now working together with the Council, Alzheimer's Society and CVS staff to develop a joint simple signposting leaflet. There are plans to continue this work with central and north CCGs.

14. The Alzheimer's Society commissioned In Control to complete a national audit of the type and format of information available to people with dementia and to identify any examples of best practice. The Project Manager worked with small groups of people with dementia and carers across the county to develop a Nottinghamshire County Council public leaflet on Personal Budgets and Direct Payments targeted at people with dementia. This is available as a background paper.

Raise awareness of dementia and the support available through close partnership working with key operational staff and partner agencies

15. The project acknowledged that there is a strong commitment at a senior level within the Council to raise awareness of dementia. The project has successfully increased awareness within assessment and care management teams of the dementia support services offered by the Alzheimer's Society¹ and improved partnerships at an operational level between the Council and the Alzheimer's Society are already resulting in benefits on both sides.
16. Alzheimer's Society dementia support workers are key providers of information, advice and guidance about how people with dementia can access services and support but were not that familiar with personal budgets and direct payments. The Project Manager and a Council officer delivered two information sessions to the dementia support workers on the customer journey and personal budgets.

"These sessions were really helpful. Personal Budgets is a term that gets used a lot and it was interesting to find out the actual meaning. I also found it very helpful to speak to a Social Worker and get information from her. I found it very helpful to see a Community Care Assessment form and to hear from someone who has lots of experience using them and how it works in practice." Dementia Support Worker, Alzheimer's Society.

17. A regional Think Local Act Personal event focussing on 'Making it Real for People with dementia' took place in June 2014 and included a presentation about this project to share the learning with a wider audience.

Areas identified for improvement

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The services available include Carer Support groups, Dementia cafes and Carer Information Support programme, Telephone support and Signing for the Brain; A Befriending service is also available but is chargeable. The Alzheimer's Society also employs Dementia Support workers who meet people at an early point in their dementia journey at Memory Clinics and provide support, information and advice to people, including home visits.

18. The project identified a number of areas where the Council can make improvements which include:

- increasing staff skills and confidence in direct payments as a positive option for people with dementia through use of peer support within and across teams by staff more experienced in setting up direct payments, and use of the case studies collected during the project.
- improving information provided at the Customer Service Centre and providing a more responsive and flexible process to meet the needs of people with dementia.
- ensuring more choice and control within the managed budget option.
- following up learning from the START brokerage model.
- introducing processes to performance manage personal budgets and direct payments for people with dementia in terms of numbers and quality to ensure take up is monitored.
- including a proportion of people with dementia in any future Personal Outcomes Evaluation Tool (POET) survey in Nottinghamshire to ensure their experience of the personal budgets process is captured and to ensure an improved evidence base of outcomes.
- continued development of the partnership between Alzheimer's Society and the Council at a strategic and operational level around the implementation of the Care Act and the effective delivery of dementia support from diagnosis through to end of life.
- continued role for the Council in shaping the development of dementia friendly personal budget implementation across the region.

Other Options Considered

19. No other options were considered.

Reasons for Recommendation/s

20. This project and the partnership with the Alzheimer's Society has been very successful. The use of personal budgets and direct payments for people with dementia is a particular challenge for local authorities and the project has shown that they can work well to divert and delay from long term care, deliver good outcomes for people with dementia and are cost effective when combined with support from carers.

21. The partnership between Alzheimer's Society and the Council has been strengthened with clear benefits on both sides. It is recommended that this is continued beyond the project at a strategic and operational level with both

partners identifying how they can work together to deliver improved outcomes to people with dementia.

Statutory and Policy Implications

22. This report has been compiled after consideration of implications in respect of crime and disorder, human resources, human rights, the NHS Constitution (Public Health only), the public sector equality duty, safeguarding of children and vulnerable adults, service users, sustainability and the environment and ways of working and where such implications are material they are described below. Appropriate consultation has been undertaken and advice sought on these issues as required.

Implications for service users

23. The project has identified that personal budgets for people with dementia can offer greater choice and control for people who require services and can support them to remain in the community. It has also demonstrated how personal budgets can support families and carers to maintain difficult situations at home.

RECOMMENDATIONS

24. It is recommended that Committee:

- a. notes the achievements and successes of the partnership project between the Council and the Alzheimer's Society to develop Personal Budgets for people with dementia
- b. receives an update report on progress with Personal Budgets for people with dementia in 12 months.

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Constitutional Comments

25. As this report is for noting only, no constitutional comments are required

Financial Comments (KAS 20/6/14)

26. There are no financial implications contained within the report.

Background Papers and Published Documents

Except for previously published documents, which will be available elsewhere, the documents listed here will be available for inspection in accordance with section 100D of the local Government Act 1972

Nottinghamshire County Council leaflet on Personal Budgets and Direct Payments for people with dementia

Electoral Division(s) and Member(s) Affected

- All