

Let's get personal

- personalisation and dementia

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Foreword

Scotland is engaged in a number of important and far-reaching policy debates. Not only are we developing the first national dementia strategy, we are also examining how social care should be structured for the future and seeking to improve our understanding of the needs of family carers.



All this is happening amidst a climate of public sector budget cuts that will have significant implications for the future of services. In addition to this, the increased demand resulting from the forecast demographic changes means that “more of the same” will not do - we must now think and learn to act differently. People with dementia and their families already do much for themselves; it would therefore be a mistake not to harness the unique strengths of the natural supports that they bring to the dynamic of service provision. However, there can be no doubt that earlier intervention and further resources are required in addition to working with the existing supports in the lives of people with dementia.

This research demonstrates that, when empowered to direct their own support, families effectively combine state resources around their own natural supports - creating truly personalised support. However, the research also highlights that this opportunity remains a well-kept secret; the availability of direct payments is being filtered through the systemic assumption that this approach is unrealistic and people are not interested in the cost or the value of their care.

We need to change the whole culture and philosophy of all front line staff and commissioners of services through transforming the system they operate within. If we continue to rely simply on individual innovators working around the current system we will never deliver choice and control to the majority. Personalisation must become the system, not an add-on or peripheral option.

Personalisation can deliver better outcomes for everyone. It fuses together state supports with the natural supports in people’s lives and will not only lead to far better and more creative support but will also deliver true value for money. The earlier we intervene and support people with dementia in this way the better, and as the case studies in this research demonstrate, we can apply a personalised approach at every stage in dementia practice.

Will we be the generation that transforms our ailing system to cope with the demands of the future, or the one that lets it regress towards care delivery by monolithic institutions and ever more depersonalised care? Personalisation is the key to coping with the demands of the future whilst treating people with dementia with the respect and dignity they and their families deserve.

Henry Simmons

Chief Executive
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Executive summary

1. Introduction

- 1.1 Personalisation has rapidly become a prominent feature of social policy discussions.
- 1.2 Personalisation provides choice and control to the social care user, with services that orientate around their lives; it can be considered a right of citizenship. It is not just about what services can do, but about ensuring that services work with the natural support provided by people's friends and family and with wider community resources.
- 1.3 However, personalisation is not widely practiced; very few people with dementia and their carers in Scotland have genuine control over the support they receive.
- 1.4 Direct payments have been the main approach to personalisation in Scotland. Alzheimer Scotland has undertaken an in-depth study into how direct payments are working in practice for people with dementia and their carers.
- 1.5 This report sets out the results of the study. It also looks at alternative approaches to personalisation of adult social care within the UK.
- 1.6 Dementia is a key health issue facing the nation over the coming decades. As our population ages, the number of people with dementia in Scotland is set to double over the next 25 years.
- 1.7 The response to current demand by many local authorities has been to restrict those qualifying for support through tightening eligibility criteria.
- 1.8 The *Changing Lives* report highlighted the unsustainability of the current social care system and the need to change in response to increased demand, greater complexity of needs and those using services having little say over how they are delivered.
- 1.9 Growing dissatisfaction has been expressed, particularly by working age disabled people, about the inflexibility and unreliability of directly-provided social care services, which create dependency rather than promote independence and impede the enjoyment of full citizenship.

2. About the study

- 2.1 A literature review provided the context for the research, an understanding of existing evidence and policy development to date.
- 2.2 12 carers of people with dementia were interviewed to provide an in-depth appreciation of their experience of using a direct payment.
- 2.3 Interviews were carried out with social work staff in 10 Scottish local authorities who had an understanding of both strategic and operational issues in relation to the provision of direct payments for people with dementia.
- 2.4 A freedom of information questionnaire was sent to all Scottish local authorities to find out their direct payment rate/s and the circumstances in which these would be paid to recipients. As personalisation is associated with early intervention and prevention, the questionnaire also asked for the authority's current operational eligibility criteria for community care services.

3. Study findings

- 3.1 There is a move towards greater personalisation in the majority of local authorities participating in the research, although policy development was at an early stage and direct payments remained the main approach to individualised funding.
- 3.2 Scottish local authorities have a wide range of different direct payment rates and use different criteria to determine what level is paid to each recipient.
- 3.3 Although direct payments were promoted by the local authorities taking part in the research, uptake by people with dementia and their carers was low. More than half of the 12 case study participants found out about direct payments through informal means, such as family and friends.
- 3.4 National statistics show that the number of direct payment recipients for a person with dementia can be no greater than 600 across Scotland; however, the actual number is likely to be much smaller as the national figures will include other care groups. If actual take-up across Scotland mirrors that of the 10 local authorities participating in the research then there would be approximately 300 direct payments for people with dementia.
- 3.5 There are many parallels between the benefits of direct payments as highlighted by the social work interviews and the experience of the 12 case study participants including:
 - flexibility, choice, control and consistency over when support is provided and by whom
 - providing appropriate responses to the particular needs of people with dementia
 - helping to keep the person with dementia at home in the advanced stages of the illness.
- 3.6 The study has highlighted a number of barriers that limit the wide scale implementation of direct payments for people with dementia and their carers including:
 - the need to have someone willing to take on the responsibilities and requirements that go along with holding a direct payment
 - eligibility thresholds often result in people with dementia qualifying for support only when their condition has deteriorated, limiting the opportunity to arrange support in a planned way
 - the time taken to set-up a direct payment can be prohibitive, given that dementia is a degenerative condition with care needs increasing over time.

4. Personalisation models

- 4.1 There is a wide range of approaches to providing the service user and their family choice and control over the support they receive. They can enable people with dementia and their carers, unwilling or unable to take on the management of a direct payment, the opportunity to personalise their support. They also offer practical examples and shared experience for Scottish local authorities in their development of personalisation.
- 4.2 Alzheimer Scotland is committed to promoting the personalisation of services for people with dementia and working to make sure its own services are fully flexible and operating in a way which gives control to service users and their carers and families.

5. Conclusion and recommendations

- 5.1 This study has identified a number of improvements to policy and practice that might increase the up-take of direct payments by people with dementia and their carers:
- **Increase potential recipients' awareness** through publicity and impartial information, so that people with dementia and their carers are aware of what is involved in taking on a direct payment ahead of an assessment of their needs.
 - **Improve understanding within social work departments** towards direct payments and their potential benefit for people with dementia.
 - **Streamline systems, with reduced bureaucracy and a quicker process** of putting a direct payment in place.
 - **Improve support and information and make reporting requirements more straightforward** for the direct payment recipient.
 - **Work with local authorities to ensure parity in the operation of direct payments**, so that recipients in different areas have equal flexibility and choice over how and when they spend their direct payment, providing it is meeting their assessed needs.
 - **Adapt legislation to allow an appropriate person to take on managing the direct payment** on behalf of a person with dementia, when the person lacks capacity and there is no one with power of attorney or guardianship.
 - **Introduce a straightforward process for health money to be included in direct payments** in recognition that the needs of people with dementia do not fit neatly into social work or health board defined parameters.

5.2 There is a need for transformational change in order to scale-up personalisation so that the majority of people with dementia and their carers can have genuine control over their support:

- **Local authorities should use an outcomes based approach** when assessing the support needs of people with dementia. The focus should be on the impact or end result of support and/or services on the person with dementia and their carers life. People with dementia and their carers should also be supported to take an active role in assessing their own need for support.
- **Social work resources should be structured so as to facilitate individualised funding**, with a fair and equitable budget to allow support to be designed around the person with dementia and their family, and a variety of options for managing the social care money to suit individual circumstances.
- **Health boards and local authorities should ensure the provision of good early stage support and a preventative approach** to supporting people with dementia and their carers.
- **The Scottish Government should establish a change fund** to enable the development of post diagnostic support planning, with a flexible budget to help people to maintain their natural supports from an early stage and an indicative budget for future care planning to follow the person as their needs progress.
- **Local authorities should develop a preventative and planned approach** to funding support for people with dementia and their carers throughout the journey of the illness, taking a long term view on the cost of care. There should be a focus on value for money and the best outcome with the removal of restrictive cost ceilings and an unlocking of resources to facilitate the creation of a range of options open to families as the needs of the person with dementia progress.

Case study 1

Personalised respite

Lisa cares for her elderly mother May, who has vascular dementia; they live in a remote rural part of Scotland. As May did not want to go into the local respite unit, Lisa asked their social worker for an alternative. The social worker suggested using a direct payment to arrange their own support.



Holiday cottage

“The social work department were open-minded, flexible and supportive” Lisa

Lisa’s sister lives in England, a journey May was unable to undertake. The direct payment was used to rent a holiday cottage a short drive from Lisa’s home, with her sister and brother-in-law travelling to the cottage to care for May. This allowed Lisa and her husband to spend time alone in their home for the first time since moving in six years ago; they could relax in the knowledge May was being cared for by family.

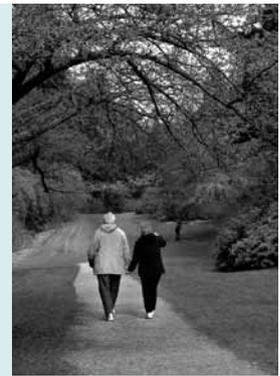
Good outcome for all

Whilst the direct payment provided personalised respite for the family, it also provided good value for money for the local authority as there were no care costs involved in providing the respite. The direct payment was used to pay for the holiday cottage, May’s expenses, such as meals out, and her daughter’s travel expenses from England.

Case study 2

Employing a personal assistant for personal care

Al cares for his wife Marion who has dementia; they live in a city centre. Marion has been assessed as needing 1 hour and 45 minutes of personal care per day. Having previously received support from private sector agencies, arranged by the social work department, Al now uses a direct payment to employ a personal assistant for Marion.



Making the change to direct payments

Al was unhappy with the inconsistency of carers and the standard of service provided by the first private sector agency he experienced. He asked the social work department to use a different agency, a request which took three months to implement.

'Carers would regularly cut visits short and blatantly cut corners. The agency regularly sent different care workers, which meant spending time showing them where things were and what was required.' Al

Whilst the new agency was good for the first few weeks, they soon resorted to the same bad practices as the first agency. Al made complaints about the service but felt they had no impact, as he felt that the care workers knew they had the backing of the system.

Al found out about direct payments by chance at a welfare rights talk given at an Alzheimer Scotland carer support group. Once he applied for a direct payment things moved fast, with the support of his social worker and all other staff members involved in the process.

They initially received a direct payment at the lowest hourly rate; however, Al felt they needed a carer with an awareness of Marion's illness. He asked his social worker for a higher rate, so that he could employ someone with better understanding of dementia. This was approved by the social work department once they received a supportive letter from Marion's consultant.

Teething problems

Al initially found it difficult to find an appropriate person to employ; he wanted someone who would be working for them only so they were not "slotting you in" with other clients. He feels the nature of dementia makes flexibility essential, and having someone who is not fully booked for the day means they can provide the extra help they may need at any time. Al's daughter helped with the advertising and selection of a personal assistant, and they found their current carer after a few attempts. Al feels it is important to build a good relationship with the carer so they start to feel like one of the family.

Flexibility

Their personal assistant has accompanied them on a trip to London to visit family. Although Al could only pay the normal daily hours, their carer appreciated the opportunity to explore London. When staying in their daughter's holiday home in Spain, Al used the direct payment to pay a local person to help with Marion's personal care.

1. Introduction and policy context

Summary

- Whilst there is a broad commitment to the principle of personalisation, policy development is at an embryonic stage.
- There are many models of personalisation; however, direct payments have been the main approach in Scotland to date.
- The number of people with dementia will double within the next 25 years; the existing system of social care is unable to cope with current demand.
- This report examines how direct payments are working for people with dementia and their carers.
- It also considers the potential of other approaches to personalisation for people with dementia and their carers.

In the last few years, the principle of personalisation has rapidly become a prominent feature of social policy discussions. However, it is not widely practised; very few people with dementia and their carers in Scotland have genuine control over the support they receive.

Personalisation provides choice and control to the social care user, with services that orientate around their lives; it can be considered a right of citizenship. Personalisation is not just about what services can do, but about ensuring that services work with the natural support provided by people's friends and family and with wider community resources.

Direct payments have been the main approach to personalisation in Scotland. Alzheimer Scotland has undertaken an in-depth study into how direct payments are working in practice for people with dementia and their carers. This report sets out the results of the study. It also looks at alternative approaches to the personalisation of adult social care within the UK.

1.1 Dementia

Dementia is a global term used to describe a range of brain diseases characterised by a progressive decline in intellectual and other mental functions. Whilst Alzheimer's disease and vascular disease represent the most common causes, there are a number of other less common forms of dementia¹.

There are currently 71,000 people with dementia in Scotland, around 2,300 of whom are under the age of 65². Dementia is the second highest³ contributor to years lived with a disability in people aged over 60³.

Dementia is a key health issue facing the nation over the coming decades. As our population ages, the number of people with dementia in Scotland is set to double over the next 25 years.

1.1.1 Support needs of people with dementia and their carers

As dementia is a degenerative condition, people's care and support needs will increase as the illness progresses. In the early stages of the illness people will require support to maintain skills, confidence and independence and to maintain their connections with friends and community. Gradually over a period of years, people's ability to manage day-to-day activities without help

¹ Dementia contributes 11.9% of all years lived with a disability for those aged over 60 years for chronic non-communicable illness.

decreases; ultimately most functions of the brain will be affected and people with dementia will eventually need constant supervision and help with all aspects of personal care and activities of daily living.

The complex, unpredictable and progressive nature of the condition means dementia has a profound impact on both people with dementia and those who care for them. Most support for people with dementia is provided by informal carers, typically a family member. Family carers need support in order to maintain the caring relationship and their own health and well-being.

1.2 Current system of adult social care

The trend in adult social care provision has been away from meeting relatively low-level need towards more intensive care needs. There is a widespread lack of post diagnostic and early stage support for people with dementia. Public resources are aimed at those with the highest level of need, but even amongst this group, services are only being used by a relatively small proportion of people with apparently similar levels of need⁴.

There are proportionately fewer resources in social care funding for older people compared to other groups⁵; there is also a propensity towards personal care, as opposed to social support, and an expectation that older people lead more restricted lives than younger adults.

The current system is largely based on the care management model, where the professional assesses need, determines entitlement and puts in place support. Those with an assessed need are often fitted to pre-purchased services, with support rarely commissioned for an individual⁶. Services struggle to respond flexibly enough to individual needs. Research in 2008 by Alzheimer Scotland found that whilst existing services have been shown to provide appropriate support for many people with dementia, there was a lack of flexibility and people with dementia were not qualifying for support until their condition had deteriorated⁷.

1.2.1 Pressure for change

The *Changing Lives*⁸ report highlighted the unsustainability of the current social care system and the need to change in response to increased demand, greater complexity of needs and rising expectations of those who require support. The problems it identified included those using services having little say over how they are delivered and often having to accept what is available rather than what is needed.

Dementia is predominately an illness of old age. Scotland faces increased future demand for social care as the population ages; the number of people aged 75 and over will continue to grow, with an increase of 84% over 25 years⁹. The response to current demand by many local authorities has been to restrict those qualifying for support through tightening eligibility criteria¹⁰.

Growing dissatisfaction has been expressed, particularly by working age disabled people, about the inflexibility and unreliability of directly-provided social care services, which create dependency rather than promote independence and impede the enjoyment of full citizenship¹¹. In addition, services often do not provide the flexibility to complement and work around the support provided by family and friends. Expectation levels amongst older people are also set to increase, with the baby-boomer generation likely to be more demanding social care users, objecting to age discrimination and insisting on greater choice and quality¹².

1.3 Personalisation

Personalisation represents an over-arching principle which is based on choice and control for the individual adult social care user. However, it is not just about what social care services can do; natural supports and wider community resources are central. Personalisation can also be considered as a point of principle that citizens have a right to dignity and to control over their support, and should expect services to orientate themselves around their lives, rather than the other way round¹³. Personalisation can help people be supported to live the lives they want to live - from being passive recipients of services they become involved in shaping their support.

Whilst the term personalisation may be relatively recent, the ideas behind it have evolved over a number of decades and are reflective of the goals and values which underpin the social work profession. Personalisation has its origins in the independent living movement, which led to the creation of the first means of individualising funds within the social care system (Independent Living Fund) and subsequent development of direct payments¹⁴.

In Scotland the policy approach to making adult social care more responsive to the individual has been to support increased take-up of direct payments whilst developing the recommendations of the *Changing Lives* report, which considered increasing the personalisation of services to be *both an unavoidable and desirable direction of travel*¹⁵.

Terminology of personalisation

There are many terms surrounding personalisation, with confusion over what they refer to. This report will adopt the following definitions:

Personalisation - the umbrella term that describes an individual having choice and control over the shape of their support along with a greater emphasis on prevention and early intervention.

Self-directed support - Scottish Government term that describes the ways in which people can have an informed choice about the way support is provided to them and greater control over how their care needs are met, and by whom. It involves a range of options, including direct payments and individual budgets, which may or may not involve the transfer of money to the individual.

Direct payments - money in lieu of services organised by a social work department, which allows a person with an assessed need the opportunity to arrange their own personalised care. Direct payments can also incorporate additional funding sources including health board monies and Independent Living Fund payments. They have been available to adults of working age since 1997 and were extended to those aged 65 and over in 2000.

Individual budget - a way by which people play a more central role in assessing their needs, with the provision of an indicative budget that details the amount of money allocated to support them, which may combine several funding sources. An individual budget provides people unwilling or unable to take on a direct payment greater control over the money being spent on their behalf.

Personal budget - a term used to describe individual budgets that are made up of funds from local authorities alone; largely social care funding but potentially including housing support monies.

1.3.1 Potential and challenges

Whilst the values of personalisation have been in existence for some time, the practice is not tried and tested; a number of concerns surround its implementation. Personalisation does not provide a ready-made answer to the problems that currently exist with adult social care, and brings its own set of challenges. The greatest challenge may be funding new approaches alongside maintaining existing services for reducing numbers of service users¹⁶.

The approach raises questions about the tension between flexibility and accountability. Whilst the current system is criticised as being risk-averse, giving choice and control to service users raises concerns about culpability and how the role of regulatory bodies should adapt. There are also concerns about equity and how it can be made to work for all client groups regardless of location. In rural areas local variations affect the capacity to tailor support and to sustain developments¹⁷. Smaller packages of care and a less developed experience of individualised funding present particular issues for making personalisation work equitably for older people. Older people have also been shown to face particular barriers in accessing direct payments, including a protectionist culture within care management¹⁸.

Personalisation represents a shift from a medical model to a social model of support, with the professional working alongside the person; it should deliver support that is suited to individual needs and circumstances. It advocates prevention and early intervention, which may reduce the need for more costly support in response to crisis, providing long term benefits for both the individual and the system¹⁹. It also makes use of and sustains community and natural supports, reducing the burden of expectation on local authority social work departments.

Personalisation may enable the needs of people with dementia to be addressed more appropriately; the needs of people with dementia fluctuate as well as increase over time, and personalised support provides greater flexibility for changing and intensifying needs. Self-directed support may be used, for example, to purchase support from someone who is known and trusted to support the person with dementia in their own home or a familiar setting, or from a specialist provider.

1.3.2 Policy developments

England

In England the personalisation of adult social care is being driven by the Department of Health, who expect local authorities to make significant progress towards introducing personal budgets by 2011. *Putting people first*²⁰, a concordat between central government, local government and the social care sector, provides a statement of intent and sets the direction of adult social care. Personalisation is also a key concept for the future of the NHS in England, with individual health budgets to be piloted in England for users of NHS health services²¹.

Thirteen local authorities completed a three year individual budget pilot project (2005 to 2007) and around one fifth of authorities have now mainstreamed personal budgets in England²². However, the target of 30% of people who have community-based social care packages having a personal budget by 2010/2011 is unlikely to be achieved by most local authorities²³. In 2009 there were 92,878 people receiving personal budgets and of these 38,000 were older people; however, the proportion within individual local authorities varied widely from 1% to 31%²⁴.

Evidence from the evaluation of the individual budget pilots in England suggested that older people often approach services at a time of crisis when they feel vulnerable or unwell, when decision making and support planning will be stressful²⁵. It was considered important to work with people in the short term to stabilise the situation and build confidence before planning longer term support. It was also important that personal budgets for older people were in the context of a whole system change including access to good information, advice, advocacy and enablement services²⁶.

Older people's support plans have been shown to reflect a high level of need for personal care rather than social activity; in addition individual budgets smaller than those for other groups restricted the scope for innovation²⁷. People with dementia are considered the last care group the personalisation agenda is working for, with, unlike other care groups, assumptions being made about their abilities²⁸.

Scotland

There is a commitment to personalisation at a national government level in Scotland²⁹, and the Association of Directors of Social Work has also stated its support for personalisation³⁰. Direct payments have been the main approach to personalisation in Scotland. Whilst the *Changing lives*³¹ report advocated the personalisation of social care as both *an unavoidable and desirable direction of travel*, policy development varies between local authorities and is largely under-developed³².

At the time of writing this report, a Scottish Government consultation is underway on a 10-year strategy to develop personalisation in health and social care in Scotland³³. The strategy refers to self-directed support in its wider sense^b, and unlike English Government policy, it does not advocate the implementation of a single approach. The purpose of the strategy is not to provide detailed guidance for local authorities to implement; however, it is intended to begin a cultural shift to drive broader choice and control for people using health and social care, with or without taking direct control of the money in the form of a direct payment.

1.4 Direct payments

1.4.1 Background

Direct payments have their origins in the disability movement in England, whose activism led the way for policy implementation³⁴. Whilst enabling legislation was implemented in 1996, those aged 65 and over only became eligible for direct payments in 2000. The largest group of recipients has consistently been those with a physical disability, with mental health service users having the greatest difficulty accessing a direct payment³⁵.

Experience of implementing individualised funding of any kind is less developed for older people than younger disabled adults. The low uptake of direct payments by older people was the driving force behind the introduction of a mandatory duty to offer payments to all eligible clients from 2003³⁶.

The timing of policy developments and data on the growth of direct payments illustrate that national government policy has some impact on uptake. However, regional variations in the number of direct payment recipients highlight the influence of local political and policy factors³⁷.

^b A range of options that enable the individual to have informed choice about the way support is provided to them, including direct payments and individualised funding.

1.4.2 Current context

Despite the requirement to offer a direct payment to everyone with an assessed need for adult social care^c, the number of people receiving a direct payment is very low relative to the number of people receiving support. There were 3,017 direct payment recipients in Scotland in 2008/2009, almost half of whom had a physical disability³⁸. This should be considered in the context of 68,334 home care clients in 2009³⁹, which is only one of a range of supports direct payments can be used to purchase.

National statistics on the number of people receiving a direct payment do not allow for the number of people with dementia receiving payments to be identified. Given the different recording practices of local authorities, people with dementia are likely to be contained within a number of different categories that will also include individuals from a number of other care groups; these are *mental health*, *unknown client group* and *others*. These three classifications represent a total of 626^d direct payment recipients.

Whilst the Social Work Inspection Agency inspection reports⁴⁰ of local authority social work departments praised five authorities for their performance in relation to direct payments, they were critical of almost two thirds of authorities. Criticisms were mainly in relation to lack of promotion and information. Further issues included the time taken to put a direct payment in place, overly bureaucratic systems, failure to inform potential recipients and resistance from staff.

1.5 Outline of report

This report describes the study by Alzheimer Scotland into the current operation of direct payments for people with dementia and their carers; it also outlines other approaches to personalising adult social care.

Chapter two outlines the purpose of the study and the research methods adopted.

Chapter three presents the study findings.

Chapter four provides an understanding of different approaches to personalisation and their application.

Chapter five outlines recommendations for action to address the issues identified by the study.

Throughout, the direct payment experiences of the 12 people with dementia and their carers interviewed for the research are presented as case studies.

^c A person must be capable of managing a direct payment, with or without assistance; in addition, before receiving a payment they must give consent. However, someone with appropriate power of attorney or guardianship can provide consent on the person's behalf and take on the direct payment. People subject to certain mental health or criminal legislation are excluded from receiving a direct payment.

^d These statistics are divided into age groups; this number includes people aged 35 and over.

Case study 3

Self-employed personal assistants to provide sensitive discreet support



Susan cares for her elderly mother Elizabeth, who has dementia. They live in an accessible rural area. Elizabeth is physically active and independent, and doesn't accept that she needs to be cared for. However, her confusion and disorientation mean someone must be on hand to ensure her wellbeing both within and outwith their home. Susan was keen to ensure care was provided in a way that preserved her mother's dignity and self respect.

Susan runs her own business from home, but must carry out a number of tasks outwith the home. As the local authority day centre did not suit their requirements, the social worker told Susan about direct payments. Susan has power of attorney for her mother, so she is able to manage the payments on Elizabeth's behalf.

Familiarity and flexibility

Elizabeth receives a direct payment of 16 hours per week, which is used to purchase the services of two self-employed personal assistants. These carers are also separately employed by Susan to help with her business and carry out household tasks, an arrangement that preceded the direct payment.

"People must be both known and trusted, as you are leaving them in your home to care for a vulnerable person" Susan

Direct payments provided a very effective method of providing assistance that meets the needs of both Susan and Elizabeth. It has enabled care to be provided in a discreet way by people who are known to Elizabeth; it also provides the flexibility necessary to have care at times to suit Susan's business schedule.

Case study 4

Employing personal assistants as part of mixed care arrangements



Bill has been caring for his wife Anne, who has advanced Alzheimer's disease, for 16 years; they live in an urban area.

Bill cares for his wife with the support of two personal assistants, employed with a direct payment, and home care workers provided directly by the social work department.

Bill has been in receipt of direct payments for eight years, and whilst he believes they are a good system on balance, his experience is that they can be 'fraught with difficulties'.

Difficulties along the way

Bill initially used the direct payment to purchase support through a private sector agency. However, Bill found the standard of care workers provided varied enormously - he was forced to tell the agency that some of the carers could not return to his home.

Bill found it difficult to find suitable people to employ as personal assistants; he has also experienced staff problems along the way. One personal assistant failed to return to work or make contact after Bill highlighted a problem with the care she was providing.

Current support

One of their personal assistants has been with Bill and Anne for four years; and whilst the other has only been with them for a short while, she is settling in well to providing for Anne's needs. They also have consistency with the home care workers provided by the social work department.

Relationships and flexibility

The personal assistants have developed a strong relationship with Anne and have a good understanding of her needs and preferences.

"By holding Anne's hand I will know if she is relaxed, upset or in pain" Personal Assistant

The care provided by the personal assistants allows Bill to go out and maintain his interests and community activity, and the direct payment means support can be arranged at times to suit his needs. Anne also attends a social work department day centre twice a week along with one of her personal assistants, who provides for her personal care needs at the centre.

2. About the study

Summary

The study looked at how direct payments are working for people with dementia and carers in Scotland and at other ways of personalising services. It used four methods:

- A literature review
- Interviews with 12 carers using direct payments on behalf of someone with dementia
- Interviews with 10 social work staff involved with direct payments
- Freedom of information questionnaire to all Scottish local authorities about direct payment rates and eligibility criteria for social care services.

2.1 Introduction

Direct payments are the main approach to personalisation in Scotland. The study sought to identify how they are working in practice for people with dementia and their carers in Scotland. It also sought to highlight alternative approaches to personalisation of support.

This chapter outlines the research methods adopted, their purpose and difficulties encountered.

2.2 Literature review

A literature review was undertaken to set the framework for the research. The review focused on set questions in order to provide an understanding of policy development and current context surrounding personalisation and direct payments.

As personalisation is a developing policy area, internet searches and recent publications, such as journal articles and specialist magazine news stories, provided an insight into alternative approaches to the personalisation of support.

2.3 Interviews with direct payment recipients

A case study approach was adopted to provide examples of how people with dementia and their carers are using a direct payment to personalise the support they receive, whilst identifying the benefits and any problematic issues in practice. The acknowledged low number of people with dementia using a direct payment in Scotland made recruiting participants for the research potentially difficult. There was also concern that the nature of the illness and associated stresses meant that, when users were identified, participating in the research could understandably be considered an unnecessary burden. Despite these issues the target of 10 case studies was exceeded, with 12 research participants being identified.

Recruitment of research participants was sought via the distribution of an information sheet through Alzheimer Scotland networks^e and via the independent self-directed support organisations that support recipients of direct payments throughout Scotland. Twenty local authority social work departments were also contacted with a request to identify direct payment recipients. The authorities contacted represented a mix of urban and rural locations; however, no case studies were identified through local authorities.

^e Alzheimer Scotland distribution networks included its newsletter and website

The information sheet provided an outline of the research project, the purpose of participation, an assurance of anonymity, an explanation of how the information would be used and the researcher's contact details. Interview participants essentially self-selected their participation in the study.

Face-to-face^f or telephone^g semi-structured interviews were used to provide an in-depth appreciation of participants' experience of direct payments. A total of 12 case study interviews were carried out. The interview schedule sought to identify the reason for using a direct payment, how they found out about it, the process of putting payments in place, mental capacity issues, how it is working in practice, benefits and any difficulties. These interviews were carried out between May and November 2009 on an anonymous confidential basis.

The 12 case study stories are interspersed throughout the report, with analysis of the findings presented in chapter three. They are presented on an anonymised basis, names have been changed and the accompanying photos are posed by models.

2.4 Interviews with social work staff

A target was set to carry out interviews in one third of Scottish local authorities with a member of staff involved in the operation of direct payments. The purpose of the interview was to seek their views and experience on the policy's operation for people with dementia and their carers, identifying benefits and any barriers. Interviewees were also asked about the development of other forms of personalisation in their local authority.

Twenty local authorities were initially contacted in May 2009 to seek ethical approval for a member of staff to participate in the research. These authorities represented a cross-section of urban and rural locations; they also had a mix of high, medium and low numbers of direct payment packages in place, according to the Scottish Government's national statistics. This approach did not provide a sufficient number of participating authorities. The remaining 12 authorities were then contacted in August 2009 and asked to participate in the study.

Face-to-face^h or telephoneⁱ semi-structured interviews were carried out with a member of social work staff in 10 local authorities. The interviews were with managers or specialist members of staff who had an understanding of both strategic and operational issues in relation to the provision of direct payments. These interviews were carried out between July and October 2009 on an anonymous basis. The participating local authorities are listed in appendix one.

Findings from the interviews are presented in chapter three.

2.5 Freedom of information questionnaire to all Scottish local authorities

A freedom of information questionnaire was sent to all Scottish local authorities. The purpose of the questionnaire was to find out their direct payment hourly rate or rates and the circumstances in which these would be paid to recipients. As personalisation is associated with early intervention and prevention, the questionnaire also asked for the authority's current operational eligibility criteria for community care services. This was to establish the threshold at which people with dementia and their carers became eligible for support.

^f Ten face-to-face case study interviews

^g Two telephone case study interviews

^h Eight face-to-face interviews

ⁱ Two telephone interviews

Responses were received from 28 of Scotland's 32 local authorities. Whilst authorities provided details about their direct payment rates, many authorities were unable to provide their current eligibility criteria as these were under review as a result of the implementation of the Scottish Government's national eligibility guidance. Analysis of responses is presented in chapter three.

Case study 5

Overnight care at home

Susan cares for her husband George, who has Pick's disease, a type of dementia characterised by slow deterioration of social skills and changes in personality. The couple moved from London to a remote rural part of Scotland in 2001 and have become established in a supportive local community. Whilst George is retired, Susan continues to work part time.



Their social worker told Susan about direct payments, after she expressed a desire to have a break away from home for a week.

Break from caring

They receive an annual direct payment to pay for a carer to stay overnight with George so that Susan can have time away from home. Susan contributes £17.45 per night's care. Carers, employed on a needs basis, are people known to Susan; they also work for the social work department as carers. The couple have also used a voluntary sector agency to provide overnight care; however, their rate was significantly higher than the directly employed carers.

Alternative use

The direct payment has provided an opportunity for Susan to have a break away from home, staying in a holiday cottage and also spending time with family on a city break. However, Susan has found it difficult to plan time away as George does not always like or understand her being away from home. It also requires her to take time off work.

Susan would like to use the direct payment in other ways to get a break, a change their social worker has said should be possible.

Case study 6

Employing a personal assistant to remain at home

John cares for his elderly father Bill, who was diagnosed with Alzheimer's disease in 2004; they live in a city and received a direct payment for a year prior to Bill moving into a care home. The direct payment, initially for 14 hours per week increasing to 22 hours, was used to employ a personal assistant to complement the care provided by Bill's family.



Extra support for family carers

Prior to receiving the direct payment, Bill was supported by his family to live in his own flat near to his son. They were told about direct payments by a friend, after the social work department had been unable to offer any support that met Bill's needs.

Friendship and flexible support

They found Ron, an experienced personal assistant, through a friend. He lived within walking distance of Bill's flat and was very flexible; he would drop-in for short periods, which meant 22 hours provided a lot of coverage in a week.

Ron and Bill proved a good match for each other, with their relationship adding to Bill's quality of life. Ron continues to visit Bill as a friend now that he lives in a care home.

Best possible outcome

The family felt fortunate to have had Ron as a carer; direct payments had provided them with this opportunity. Ron's flexibility provided great value for money for the local authority.

'We could not have achieved such an intensive high quality service by any other means' John

After Bill suffered a fall and was admitted to hospital, deterioration in his illness meant he could not return home. However, the direct payment had been an essential part of keeping Bill at home for an additional year.

3. Study findings

Summary

- There is a move towards greater personalisation in the majority of local authorities participating in the research, although policy development was at an early stage and direct payments remain the main type of individualised funding in each of the authorities.
- Scottish local authorities have a wide range of different direct payment rates and use different criteria to determine what level is paid to each recipient.
- All local authorities which took part in the research said they promoted direct payments; however, uptake by people with dementia and their carers was low. More than half of the 12 case study participants found out about direct payments through informal means, such as family and friends.
- National statistics show that the number of direct payment recipients for a person with dementia can be no greater than 600^j across Scotland; however, the actual number is likely to be much smaller as the national figures will include other care groups. If actual take-up across Scotland mirrors that of the 10 local authorities participating in the research then there would be approximately 300 direct payments for people with dementia.
- There are many parallels between the benefits of direct payments as highlighted by the social work interviews and the experience of the 12 case study participants, with the main benefit being the flexibility provided.
- Significant barriers exist to the wide scale implementation of direct payments for people with dementia.

3.1 Introduction

This chapter provides the findings from the interviews with 10 social work staff, in 10 local authorities, involved in the operation of direct payments and of a freedom of information request to all Scottish local authorities^k. It also brings together the experiences of the 12 carers interviewed to provide the case studies of people with dementia and their carers who were using or had used direct payments^l.

The research found many benefits to direct payments for people with dementia and their carers; overall it was working well for the 12 case study participants. However, there were several limitations that meant direct payments were not seen by social work staff as universally appropriate for people with dementia.

^j These statistics are divided by age groups; this figure represents the total for mental health, unknown client group and others (aged 35 and over).

^k Responses were received from 28 out of 32 Scottish local authorities.

^l Whilst the case studies provide an insight into the factors that may influence peoples' experience, it is acknowledged that no general conclusions can be drawn from these findings.

3.2 Models of personalisation

Social work staff were asked about any alternative approaches to personalisation their local authority had put into practice or might be considering implementing. Direct payments were the main type of individualised funding in each of the local authorities participating in the research study. However, there were moves in six of the 10 local authorities towards other types of personalisation. In two cases there were projects already in place:

- In one local authority there was an individual budget project which was gradually being increased to greater numbers of people, which included people with dementia.
- In another local authority, a home care tendering pilot was one year into implementation, with the results expected to inform wider practice and future procurement. Contracts were tendered on the basis of the service recipient at the centre, with people having choice over who their paid carers were and when they came into their home.

In four local authorities possible changes were at an early discussion stage; in three cases this was looking at the possibility of individual budgets, whilst the other was discussing self-directed support in its wider sense, but as this was at an early stage it was not yet clear what shape any policy changes might take.

3.3 What are the direct payment rates?

Each Scottish local authority^m was sent a Freedom of Information request asking for:

- Their direct payment rate/s per hour.
- If they had more than one payment level, the circumstances in which each would be paid.
- What would happen if the recipient wished to purchase support from a more expensive provider.

The majority of local authorities had more than one direct payment level. There was wide variation in these levels, with the lowest payment rate ranging from £6.58 to £12.07 and the higher rates from £11.42 to £22.50. There was also some variation between the seven authorities that had a single flat rate, ranging from £10.20 to £11.42.

There was no direct correlation between the levels of direct payments and the numbers of paymentsⁿ in place in each local authority, suggesting that the level of payment is not the only factor influencing uptake.

A breakdown of local authority direct payment rate/s and their rationales for the level paid are outlined in appendix three.

^m Responses were received from 28 out of the 32 Scottish local authorities.

ⁿ Rate per 10,000 population according to the Scottish Government national statistics

3.3.1 Payment of different rates

The 21 local authorities which had more than one payment rate used a variety of factors to determine the level they paid to each recipient:

- Seven authorities based this on the assessed need and type of support required.
- Seven based their payment level on whether the recipient would use it to employ a personal assistant or purchase the service of an agency, with the agency payment level being higher in each instance. In a further two authorities this was a determining factor alongside the recipient's geographical location within the authority^o.
- Two authorities had multiple rates dependent on type of support and whether a personal assistant or an agency was to be used.
- Two authorities determined the rate paid according to the client group the person was assigned to e.g. older people, learning disability.
- One authority paid the hourly rate it would have cost them to provide or purchase the support directly.

3.3.2 Higher support costs

Local authorities also had a variety of approaches if the recipient wished to purchase support from an agency with a higher hourly rate than their set rates:

- 13 local authorities might pay a higher rate; many qualified this by adding that the circumstances would be a factor, for example if this was the only agency that could meet the person's needs.
- Eight authorities would allow the person to purchase fewer hours.
- 16 authorities would allow the person to top-up the direct payment level^p.

3.4 Factors influencing up-take of direct payments

Existing research evidence highlights the importance of effective leadership, staff knowledge and positive attitude, good quality information provision for potential recipients and ongoing support for those using a direct payment⁴¹.

^o Those living in rural locations would receive a higher direct payment to reflect the additional cost of purchasing support.

^p These were not mutually exclusive policies, with some local authorities taking more than one approach when the recipient wished to purchase support from a more expensive provider.

3.4.1 Publicity

“Very few people come to us and specifically say they are interested in direct payments”
Social work staff member

All 10 social work staff said their local authority undertook some level of publicity in order to inform the general public about direct payments. This mainly took the form of written information in social work offices, public libraries and on the local authority website. Five local authorities also carried out targeted outreach events, such as talks at carer group meetings, whilst a further three authorities supported the work of independent organisations in their promotion of direct payments.

Some of those interviewed considered promotion to the general public unnecessary, as it was only relevant to those with an assessed need for adult social care, whilst some were concerned that wider promotion might create unrealistic expectations given limitations on availability.

“There is more we could be doing in relation to advertising direct payments, but there is concern you are raising expectations because if you do not have the funding then people will have to remain in the nursing home where they are, get home care services or day care until funding becomes available” Social work staff member

3.4.2 Knowledge of direct payments

The majority of social work interviewees believed awareness of direct payments was good amongst social work staff members. However, one felt knowledge should be better, whilst a further two felt awareness was better in some teams than others; for example that those who worked with the traditional user groups, such as physical disabilities, knew more than those who worked with older people.

“My impression is that staff think it [direct payments] is a mine field and steer away”
Social work staff member

All authorities had measures in place to support staff in delivering direct payments, through some combination of a central point of reference, training and/or ongoing support. Guidance was general and not specific to different care groups. Some interviewees highlighted the issue of staff not having the opportunity to put the knowledge into practice often, so they would therefore not be confident in using direct payments.

“If you are not putting it into practice then you lose the knowledge, plus things change so you are not keeping up-to-date” Social work staff member

3.4.3 Being offered a direct payment

Half of the 10 social work staff interviewed believed everyone would be told about direct payments, whilst half said they could not be certain this was happening. Two suggested that it would be dependent on whether it was felt relevant to the person's circumstances.

"My guess is that this does not always happen, given the number of direct payment packages in relation to the number of people on our books" Social work staff member

Alzheimer Scotland's 2008 survey⁴² of 160 carers of people with dementia found 12 were using a direct payment out of only 25 who had been informed about them by their social work department.

Most interviewees said that direct payments would be discussed once assessed needs had been established. Two said people would be informed about it before the assessment, at a pre-assessment meeting in one case and by their reception team in the other.

Finding out about direct payments - 12 case studies

In five cases the recipient found out about direct payments from their social worker; in most cases this was in response to expressing an interest in something different or in having an alternative to what the social work department could provide directly.

The remaining seven found out about direct payments informally; in most cases this was from a friend or family member.

3.4.4 How direct payments are presented to potential recipients

Social work staff were asked how they felt direct payments were presented to those with an assessed need for social care. Three of the 10 felt it would be presented as a positive option, and five believed that it would be presented realistically, highlighting the benefits whilst pointing out the requirements and responsibilities.

The remaining two felt that it would depend on the circumstances; in one case this related to the particular views of the social worker involved, with practitioners having differing views influenced both positively and negatively by their past experience.

"I have come across family carers who have been told "don't think about direct payments" by their social worker" Social work staff member

The other respondent felt it was dependent on the client and other circumstances. In this person's experience a lot of direct payment recipients were people who had not found services to suit them, and being given a direct payment had then worked well as they felt in control. This person also said that in other cases financial constraints had a bearing.

"If someone was assessed as requiring support during the day, the social worker would be keeping in mind financial constraints and might not think they could offer a direct payment if there was a vacancy at a pre-purchased service" Social work staff member

3.4.5 Support for potential and ongoing recipients

All local authorities had arrangements to provide information and practical support to potential and ongoing recipients of direct payments. Support included initial advice and information for those thinking about taking on a direct payment, support with employing a personal assistant, help with the practicalities of setting up a direct payment and ongoing support for managing the payment. This varied in relation to who provided the service; around half (four) had a combination of in-house and independent support, whereas the remaining had either in-house (three) or independent (three) support providers.

Process of putting direct payments in place - 12 case studies

The majority of carers interviewed said the process of putting payments in place had been straightforward, the key factor being the input of a supportive social worker.

"We received valuable support throughout the process from our social worker" Family carer

However, four of the case study participants experienced difficulties. In each of these cases there was a delay in the direct payment being put in place as a result of the time taken by the social work department to process the claim. The time taken from initial application ran from several months to over a year.

"It took nine months from our initial enquiry; three months to be allocated a social worker and six months to receive the first payment" Family carer

In two instances the process was elongated primarily as a result of reluctance by the professional involved to provide a direct payment in the particular circumstances.

"I was initially told direct payments were for younger people with disabilities" Family carer

In a further case, whilst the process of putting the payment in place had been smooth, there had been a delay in the local authority providing information on administrative reporting. This meant the carer did not get off to the right start with everything in place.

"Mental exhaustion made it difficult to chase things up" Family carer

3.5 People with dementia and direct payments

All 10 local authority staff interviewed believed direct payments were relevant for people with dementia; most qualified this by saying it was dependent on having someone to manage the payment[†]. These responses are consistent with existing research evidence⁴³ and the 12 case studies.

"We have had quite a few people with dementia getting direct payments; most have been extremely effective" Social work staff member

[†] A person must be capable of managing a direct payment, with or without assistance; in addition, before receiving a payment they must give consent. However, those with appropriate power of attorney or guardianship can provide consent on the person's behalf and take on the direct payment.

3.5.1 Number of people with dementia using direct payments

Of the local authorities participating in the research eight were able to provide an indication of the number of people with dementia receiving direct payments in their local authority. Three authorities had under five recipients, a further three had between five and 10, with the remaining two having 15 and 20 recipients respectively. If actual take-up across Scotland mirrors that of the 10 local authorities participating in the research then there would be approximately 300 direct payments for people with dementia.

3.5.2 Type of support being purchased

National statistics do not differentiate between the types of support being purchased by different age or client group. Overall, payments are used for personal care (57%), social/recreational activities (31%), domestic tasks (29%) and respite (14%). Direct payment recipients use their payments more often to employ personal assistants (44%) than purchase services from a service provider (26%)^s.

In the local authorities participating in the research, people with dementia and their carers were using their payment for respite, replacement for day care and home support. They were also being used to enable people to remain at home, supported by a large input from family carers.

Reason for choosing direct payment - 12 case studies

In nine cases the reason for deciding to take on a direct payment was to personalise support so that it was responsive to the individual needs and circumstances of the family. Linked to this six recipients expressed a reluctance to accept directly-provided services, as these either did not suit their requirements or they were concerned about their quality or reliability.

Direct payments were being used as part of a package of care by six of the case study participants in addition to support provided directly by social work or privately purchased support.

3.5.3 Benefits of direct payments for people with dementia

All of the local authority interviewees believed direct payments had benefits for people with dementia and their carers. **Flexibility** was highlighted as the main benefit and this was referred to by everyone interviewed in relation to:

- support suited to the personal circumstances of the family
- better responses to fluctuating, as well as increasing, needs of people with dementia
- complementary support to what was already provided by family carers.

“With the best will in the world we are providing people with dementia living in the community with support packages that can only provide care four times a day, with possibly an overnight if they require toileting. But there is still a vulnerable time whereby there is no cover and as people progress they need a lot of supervision and I think direct payments is the route to go down in terms of ensuring the person is safe” Social work staff member

“If we are providing services it is very difficult to get the flexibility that people with dementia really need” Social work staff member

“Flexibility and choice is a big thing, we have our travelling salesman box of services - day care, home care and respite - sometimes they are very relevant, but sometimes they do not fit” Social work staff member

Additional benefits highlighted by social work staff were:

- **Choice and control** over how support is provided and the form it takes.

“The person organising support has a hands on role in who is doing what and when” Social work staff member

- **Consistency** in the timing of support and also who is providing it.
- Enabling family carers to respond to **crisis situations**.

“Should a crisis situation arise there is money sitting in an account to use to cover it without having to call half a dozen people to get permission” Social work staff member

- Using direct payments provided **familiarity**: it allows the opportunity to employ someone who is known to the person with dementia, and it can also keep the person in familiar surroundings with recognisable things around them.

“Whilst we still remembered bits of things all of us would want to be at home” Social work staff member

⁵ Does not add-up to 100% due to missing data

- It can **keep people at home** who would otherwise be in long term care by complementing the support provided by family carers; people have continued to have a good quality of life at home.

"I have a client who would not be in the community without it, the direct payment provides the flexibility to work support around the daughter's work" Social work staff member

- It can provide **enabling** support rather than task-focused care.

Benefits of using direct payments - 12 case studies

All 12 case study participants experienced some benefits from using direct payments. Ten highlighted benefits that related to **flexibility, choice** and **control**:

- Enabling the main carer to continue working
- Allowing choice over which agency to use or staff to employ
- Doing things that were not available as a directly provided service
- Working around existing support provided by family carers and/or directly-provided or arranged services
- Enabling recipients to choose the timing of support, either at regular times or varied according to the needs of the family carer/s.
- Allowing support to be provided by people known to the person with dementia.
- Enabling the main carer to leave the home and continue to pursue their own interests.

Three of the case study participants felt the direct payment was adding to the **quality of life** for the person with dementia; it was supporting the person socially, providing trips outwith the home and providing the friendship of the employed carer.

In three cases it had enabled the person with dementia to **continue to be cared for at home** during the advanced stages of the illness; in another case it had enabled the person to remain at home for an additional year before moving into a care home.

3.5.4 Barriers for people with dementia according to social work staff

Social work staff were asked if they believed any difficulties existed that would preclude a person with dementia getting a direct payment. All 10 felt there were potential barriers. Whilst some of these related directly to people with dementia, many were wider structural issues that applied to all care groups.

Capacity and someone to manage the direct payment

Given the progressive nature of dementia there must be an appropriate person to manage the direct payment as the illness progresses. Many of those interviewed acknowledged the issue of people not being able to get a direct payment unless the person with dementia has capacity to consent or the family carer has appropriate legal powers in place.

“I was trying to think would a person with dementia on their own have a direct payment, obviously there is the support agency but you would need an agency that really understood dementia” Social work staff member

“You need to be a particularly strong person to take it on” Social work staff member

In each of the case studies the direct payment was managed by the main carer, either the spouse or son or daughter. In most cases the family carer had power of attorney for the person with dementia; in one instance the spouse had guardianship.

Responsibilities and requirements

“The difficulty we have in older peoples’ services is getting people to actively consider it as an option” Social work staff member

Some highlighted the responsibility and requirements that go along with having a direct payment being daunting for a person to take on, particularly as an employer. People can feel direct payments are a good idea but choose not to take them up because the requirements are too much.

“It’s a heavy responsibility and stressful; the person who takes it on personalises the responsibility and there can be a lot of stress and anxiety” Social work staff member

In the majority of the case studies, the management of the payment, administration and level of reporting requirements was unproblematic. However, some commented that they believed it would be difficult for those who do not have relevant experience[†]. One recipient felt it was overly bureaucratic given the level of payment they received, whilst another found the administration and reporting was a burden on top of everything else going on in their life.

[†] Many of those managing the payment had business or administrative experience.

Staff and potential recipient attitude

“Unless you get the hearts and minds of the social workers on board it is more complicated to put in place” Social work staff member

Positive staff attitude towards direct payments has been shown in previous research to be an important factor⁴⁴. Some of those interviewed felt the way direct payments were viewed by social work and then presented to people was a potential barrier. The perception of potential recipients as of what it means to have a direct payment was also considered a factor, which some interviewees linked to lack of information.

“How it is sold by social work is an operational issue we need to resolve as local authorities”
Social work staff member

Lack of awareness and promotion

Lack of advertising and promotion was considered by some as a barrier. People are not being told about direct payments until they are being assessed and are then asking for a service. If there was more widely available information people might be prepared before the assessment stage to find out more about it.

More than half of the case studies found out about direct payments by informal means through family or friends.

Financial constraints and existing services

“We have people waiting for home care packages at the moment because we do not have the services available and the budget - people requesting a direct payment would be no different unless their needs were critical” Social work staff member

Budgetary limitations and cost ceilings were considered a significant barrier. In addition money can be tied-up in pre-purchased services and there would be a desire to use this first.

“Budgets are a significant barrier; we have to shut something to free-up money”
Social work staff member

“If someone requires 24 hour care that is outwith our cost limitations”
Social work staff member

Level of need and eligibility thresholds

Some social work respondents highlighted that by the time people with dementia qualify for support, given that they have to meet eligibility criteria by having critical or substantial need, the dementia will be more advanced and there is less opportunity to know the person's own wishes. The family carers will also have been caring for a number of years and may be reluctant to take on the responsibility that goes along with a direct payment.

“With people with dementia the care has been ongoing for years; by the time people are coming to us they are looking for social care and health to take on responsibility”
Social work staff member

Eligibility criteria and threshold for services

Alzheimer Scotland requested a copy of the current operational eligibility criteria and priority thresholds at which services became available from each Scottish local authority. Many local authorities were reviewing their policy in accordance with the recent Scottish Government's national eligibility criteria for personal and nursing care for older people⁴⁵. The 13 authorities who did respond had four priority levels and restricted services to the top two priority levels (substantial or critical need); some authorities would provide support to those assessed at the third level if resources allowed. Those in the lowest priority group typically received only advice and information. This is consistent with the practices of the majority of Scottish local authorities as identified in 2008⁴⁶.

Whilst the new national eligibility criteria acknowledge the need to take a preventative approach and that local authorities *will want to consider whether the provision of services or other interventions might help prevent or reduce the risk of an individual's needs becoming more intensive*, it also recognises its implementation presents a challenge to personalisation, early intervention and prevention⁴⁷. The criteria are based on four levels of need and risk factors, similar to the eligibility criteria currently in operation in Scottish local authorities, thus indicating the likely continuation of current practice.

Time taken to set-up a direct payment

The length of time taken to set up a direct payment was thought prohibitive by social work staff, as people have an immediate need for support.

"It is a time consuming process, from telling people to negotiating and setting up; taking on staff is a lengthy process and ongoing" Social work staff member

Limitations on choice

A number of interviewees spoke of having limited choice of supplier of services from whom they could purchase services; monopolies existed in some areas, and there were difficulties in finding people to employ in rural areas.

Difficulties experienced - 12 case studies

Three recipients had experienced no difficulties with their direct payment. Whilst the remainder experienced some problems, in most cases this related to one or two temporary problems.

Difficulties with staff or with agency carers - Three recipients experienced problems with staffing issues. In two instances personal assistants failed to return to work, leaving the family carer with an extended period of uncertainty and unable to make future plans until proper employment law procedures had been followed; this was almost a year in one case. Another family carer felt their position to be unclear because the paid carers were employed by a private sector agency, which they felt restricted their ability to determine how care was delivered.

Lack of information and support - Two recipients experienced significant problems as a result of lack of information and support. They had to be resourceful in finding things out for themselves; in both cases receiving a direct payment required a great deal of persistence and determination.

Level of direct payment insufficient - Two recipients experienced problems with the level of payment; in one instance the hourly rate was significantly lower than the charges made by their agency of choice. In the other case the carer successfully requested a higher rate so that a more experienced paid carer could be provided for the person with dementia.

Two experienced more fundamental difficulties:

Flexibility restricted by social work department - One recipient experienced a significant lack of flexibility from the social work department who tried to be very prescriptive in how the payment should be used. The family carer had to stand their ground in order to arrange personal care in a three hour block each morning, instead of in three one hour blocks throughout the day as the social work department would have provided it directly. The social work department were also rigid about what activities could be carried out during the personal care time, for example objecting to the time being used to take the person with dementia to the GP surgery, as they considered this a cost that should be met by the NHS.

Delays in increasing care package resulted in care home being the only option - For one carer, significant delays in processing the application for an additional direct payment meant that by the time the first payment was received the person with dementia's needs had increased. The social work department offered no explanation to justify this delay, and the family carer experienced a lack of communication between the three staff members involved in the process of setting up the direct payment. Had the process of putting direct payments in place been smoother, the family carer believes that it might have provided an alternative to the person with dementia moving into a care home.

3.5.5 What changes would help

Existing research evidence recommends improved information and support for potential recipients, support for frontline social work staff, consistent practices and procedures that focus on flexible care rather than detailed audit of expenditure and clear policy guidance from central government⁴⁸.

Local authority staff participating in the research made a number of recommendations to improve practice. These related to both structural issues (legislation, funding and guidance) and local authority operational issues.

Structural changes suggested

A **middle ground** between the recipient of a direct payment having capacity and the necessity for someone to have power of attorney/guardianship.

Consistency with the Independent Living Fund in rules on employing close relatives⁴⁹.

Reviewing how money is given to **health boards** so that it can be freed up to be given as a direct payment.

Bridging funding as resources are currently tied up in existing and pre-purchased services.

More **realistic guidance** to potential recipients - existing guidance was felt to create an unrealistic expectation.

Operational changes suggested

Outcomes focus, stopping looking at support in terms of hours and focussing instead on what support should be achieving for the individual.

Reducing bureaucracy and making the system more straightforward so that it is not overly complicated for the recipient and ensuring there is support for the recipient.

More funding and increasing cost ceilings put on care packages so that there is more money to keep people at home and maintain their care in the community.

Taking a **long term view** on the cost of care and value for money; for example giving couples extra respite may delay the need for long term care providing a better outcome for the family and the local authority.

“£3,000 per year for respite to enable a person to remain at home can be a good use of money and outcome for the family” Social work staff member

⁴⁹ Independent Living Fund allows for the employment of a close relative providing they do not live in the same house, whereas a close relative can only be employed using a direct payment in exceptional circumstances as determined by the local authority.

Centralisation of self-directed support within the social work department, instead of responsibility lying with care management; one point of contact to advise recipients throughout the process, with hands-on support that could bow out once the arrangements were established.

Work to increase **awareness and understanding** of direct payments within social work departments and to potential recipients.

“Direct payments have been around for a long time and we have used them for a long time, but it still feels like something new” Social work staff member

“I think it is about local authorities taking more control over how they promote it to people - it has been part of the assessment and review process for many years but I do not think in older people services it has dramatically increased the number of people getting it - we are obviously not doing something right” Social work staff member

What would have helped - 12 case studies

Many of the recipients of direct payments interviewed for the case studies suggested things that would have improved their experience:

Better, more timely information so that people are made aware of their rights, know who to contact and are aware of the different stages involved in getting a direct payment.

More support with carrying out the reporting requirements of the direct payment.

Greater flexibility that allows the recipient full control over the timing of when and how money is spent, providing it meets the care and support needs of the person with dementia and their family carers.

A system that was quicker to respond so that, as the needs of the person with dementia intensify, the direct payment can be increased quickly to allow support to be stepped up, enabling the person to continue to live at home.

3.6 Findings summary

The study has shown that whilst there is a general move towards personalisation, policy development is at an early stage and direct payments remain the main approach to giving choice and control over support. It has been demonstrated that direct payments are providing a number of benefits for people with dementia and their carers including:

- Flexibility, choice, control and consistency over when support is provided and by whom.
- Providing appropriate responses to the particular needs of people with dementia, such as providing enabling care aimed at maintaining skills and allowing people who are known to the person with dementia to be employed as personal assistants.
- Helping to keep the person with dementia at home in the advanced stages of the illness.

Whilst direct payments are working well for some, the numbers benefiting are very small relative to those receiving support. The study highlighted a number of barriers that limit their efficacy for people with dementia and their carers including:

- The need to have someone willing to take on the responsibilities and requirements that go along with holding a direct payment. This is often the main carer who is already providing the majority of support.
- Eligibility thresholds often result in people with dementia qualifying for support only when their condition has deteriorated, thus limiting the opportunity to arrange support in a planned way and have the person's views taken into account.
- The time taken to set up a direct payment can be prohibitive as, unlike many other care groups where the person's condition may be largely stable, dementia is a degenerative condition with care needs increasing over time.

Case study 7

Private sector agency providing personal care and respite at home



Evelyn cares for her husband David, who has vascular dementia and a heart condition. They live in a remote rural location.

Having seen a neighbour's experience of local authority home care, Evelyn decided she wanted to have control over when and how their support was provided and was told about direct payments by her son, who runs a care agency in England.

Their direct payment was initially for two afternoon breaks for Evelyn per week, increasing soon after to include three hours' personal care per day after David had a period in hospital.

Restricted choice

Whilst they use the direct payment to purchase support through a private sector care agency, Evelyn's preference would be to purchase the services of self-employed personal assistants. However, her local authority informed her that this would not be possible⁹.

Given this restricted choice, Evelyn decided to use an agency because she did not want the responsibility and requirements that go along with being an employer. Evelyn chose the agency on the basis of their inspection report; however, the service provided has not matched-up to the report. She now considers the inspection reports to be 'rhetoric', with no effective check on the actual service the agency is providing.

Experience of agency carers

Evelyn thought carefully before making a complaint when they experienced problems with the carers the agency initially provided, as she was concerned the agency might stop their service. However, she did complain, and they now have the same two regular carers providing the service and are happy with the standard of care provided. However, Evelyn feels their way of working creates dependency.

"Carers put David's slippers on for him, whereas I would encourage him to do this for himself" Evelyn

Evelyn feels using an agency makes her position unclear and makes her unable to challenge the way in which carers work as they are not employed by her; she would feel better able to determine how support was delivered if she was using self-employed personal assistants.

⁹ Scottish Government self directed support guidance allows for services to be purchased from self employed personal assistants, however, a personal assistant cannot be asked to be self-employed to enable the individual receiving direct payments to avoid taking on employer's responsibility.

Case study 8

Personal assistant and private sector agency

Angela and her mother Catherine, who had advanced Alzheimer's disease, lived a short distance from each other in a small town. Catherine remained in her own home throughout the journey of her illness - made possible by the dedication of her daughter and the support they received through direct payments.



Financial struggle and difficulty getting right balance

Angela's friend told her about direct payments; prior to receiving them Angela found it difficult to get the balance of care right. Catherine received a couple of hours' support here and there, which was being paid for from both her own and her daughter's resources. They had been paying for care in this way for a couple of years, but could not have sustained it financially.

They received a direct payment for around seven years; it was used to employ a personal assistant and purchase care through a private sector agency to support the care provided by Angela and her partner.

Familiarity and good quality of life

Once they received the direct payment they continued to use the same agency they were already using to purchase care privately; Angela had a good relationship with the agency, and the agency could ensure the carer provided was familiar to Catherine. They also employed a personal assistant, who was someone who had previously provided care for Catherine when employed by the agency; Angela therefore knew she would be a good carer for her mother.

The direct payment enabled Angela to continue working; it also gave Catherine a good quality of life with trips out of the house every day including pub lunches and trips to the hairdresser. All Catherine's care needs were provided for by one carer at a time.

Trials of managing care staff

Angela experienced some difficulties along the way. The personal assistant and the agency carer had disagreements on both a professional and personal level. Angela tackled these problems head-on, reminding the carers that Catherine's care was paramount.

A previous personal assistant went on long-term sick leave and the agency had to be used for almost a year to provide care. Angela sought advice from two employment lawyers over this period but they could not offer a remedy; after ten months Angela had to write to the personal assistant to inform her she was being dismissed because she refused to make contact with Angela.

4. Personalisation models

4.1 Introduction

Personalisation is about meeting the needs of individuals in ways that work best for them. The vast majority of support for people with dementia is provided by family and friends; personalisation therefore offers the opportunity to fit services around these existing supports in people's lives.

The previous chapter demonstrated that whilst direct payments work well for some families they are not suitable for everyone. The most significant barriers include the requirements and responsibilities that go along with holding a direct payment and the financial constraints placed on their use by the existing service-led structure of most social care.

This chapter considers alternative approaches other than direct payments that enable individuals, their family and supports, to shape the support they receive.

4.2 Individual and personal budgets

An individual or personal budget is the amount of money that will fund a person's care and support, following on from a social work assessment of their needs. It provides an indicative overall budget that the person, together with their representatives and social work support, can use to develop a support plan.

Individual budgets can combine resources from a wide range of funding streams^v, reflecting the needs of many different client groups. They can provide an overall budget for a range of services, which the person may choose to receive as cash or services or a mix of both. The individual budget pilots in England had limited success bringing together all possible funding sources⁴⁹; the Department of Health has since changed its focus to the implementation of personal budgets for all those eligible for social care. Personal budgets are mainly derived from social care resources, but can also include housing support monies.

Early experience of individual budgets for older people⁵⁰

In response to older people often approaching social work at times of crisis, some of the individual budget pilot local authorities in England initially provided services, introducing individual budgets once the situation had stabilised and support planning was more appropriate.

The most profound impact of individual budgets for older people was for those on the brink of residential care, where equivalent resources were providing a tailored service which maintained care at home. However, for those with lesser needs, even small care packages were being adapted to better reflect an older person's needs and wishes.

^v Individual budgets can include social care resources, Independent Living Fund, housing support, disabled facilities grant, integrated community equipment services and Access to Work monies.

There are different ways in which the budget can be held, including by the person themselves or their representative as a direct payment, by their chosen service provider, with an independent broker service^w, as an individual service fund or by the local authority. Through knowing how much money is available and what must be achieved, the person and their family can plan support around their individual needs and circumstances.

4.2.1 In Control individual budget model

In Control is an independent organisation that works with a number of local authorities in Scotland and England to implement their system of self-directed support⁵¹. The In Control approach is based on people knowing how much money is available to them and having control over how the money is spent.

In Control provide practical tools to transform the current prevailing care management model of assessment and care planning, towards a system that involves the person participating in assessing their needs and shaping the paid support around their individual circumstances and natural supports⁵².

In Control advocate the use of a Resource Allocation System, a supported self-assessment questionnaire that allows people to know early in the process how much money is available from the local authority to fund their support. Their approach is also driven by an outcomes focus - looking at the impact or end result of support and/or services on a person's life.

North Lanarkshire In Control demonstration project^x

North Lanarkshire Council launched their In Control demonstration project in April 2008; this involved 16 people, together with their families, taking control of an individual budget. The purpose of the project was to demonstrate whether the traditional way of working could be improved by establishing *a more person-centred and flexible approach - one based on greater partnership and transparency between the Council, its social work staff, people and their families*⁵³. Those participating in the project could spend their individual budget on anything providing it helped to meet the outcomes identified in their support plan.

Rosemary is the full time carer for her elderly mother who has dementia. The responsibility of being the sole carer was a strain for Rosemary before receiving an individual budget through her local authority. Their individual budget now provides Rosemary with a break of twelve hours a week, whilst her mother is cared for in their own home. They also use their budget to take short trips and holidays together.

"Holidays make my mother come alive. Her dementia never seems so bad and she has things to talk about and tell other people. Being in receipt of In Control money has given us a life again." Rosemary

^w A broker will assist the individual/personal budget recipient to implement their support plan and can also manage the budget on their behalf.

^x Information on the North Lanarkshire demonstration project is from the review of the project outlined in the publication *Way ahead: our early experience in North Lanarkshire of demonstrating the impact of the In Control approach*.

4.2.2 Individual service fund

When a person would like to use their individual or personal budget to purchase support from a particular service provider they can use an individual service fund (ISF). The ISF is held by the service provider on the person's behalf, with the person having control over how the money is spent and the service provider being accountable to them. A support plan details the specific support required by the individual, together with when and how they want it to be delivered. This model has been used particularly in the field of learning disability, where individuals may have substantial packages of support and also be able to choose the staff who will work with them.

This approach can be used for one individual's support budget or a block contract^y, which a service provider receives on the understanding they are committing to using that money in an individual way and not as part of a general pooled budget⁵⁴. An agreement or contract describes how the service provider will support the individual, what the responsibilities are on either side and how the agreement can be ended.

The ISF approach is quite different from the more traditional way of commissioning services where a provider is commissioned either to provide a block number of hours across a number of service users or a number of hours is "spot purchased" for a single service user. In both these cases, the service user is allocated hours of service and, although this is done in discussion with the person using the service and/or their carer, there is no scope to spend the money on anything other than these hours of support and no control rests with the person.

Example of an individual service fund^{z 55}

Margaret, who has reduced mobility, is 64 and lives with her husband; her husband is unable to care for his wife or maintain the house due to his own health problems. Margaret has an individual service fund which she has used to keep the same carers and agencies involved in her care as before.

However, using an ISF meant that she could determine how they support her in the things she particularly needed and wanted help with. This included accompanying Margaret to do her own shopping, instead of having it done for her. It has helped Margaret to get her independence back and regain her social life.

The ISF model does restrict the ability of the service user to use an alternative service provider. There is also the possibility of a conflict of interest, with the provider organisation both holding the fund and also supporting the service user to choose a package of support. This approach may give the service user less direct control and the service provider may view the local authority as the customer⁵⁶.

^y Block contract monies represent a budget to deliver support to a number of people

^z This example comes from the Department of Health publication *Putting people first: personal budgets for older people*

4.3 Alternative approaches to managing a direct payment

4.3.1 User controlled trust

A user controlled trust enables a group of people prepared to act on a person's behalf to take on managing a direct payment and organising their care. This provides an alternative approach when the person requiring support does not have mental capacity to manage a direct payment. The trust members sign a deed, creating legal duties and responsibilities. Whilst the person receiving the direct payment cannot be one of the trustees, they can be involved in the planning and have their wishes taken into account. The trust should ensure the individual remains the focal point of any decision making regarding their care⁵⁷.

It is important the trustees are committed to the person for whom the trust is made and have a good knowledge of their needs. A trust can be drawn from family members and wider contacts. Trustees who know the direct payment recipient can ensure an understanding of the person when they have diminishing capacity, whilst having trustees drawn from a wider basis than family members can help provide safeguards to the direct payment recipient, and could help to take pressure off the direct carer.

4.3.2 Direct payment card

A Chip and Pin card is being used in some areas as a means of people receiving their direct payment. This provides an alternative approach to the direct payment being paid into a bank account, which means recipients do not need to open a bank account exclusively for the management of the direct payment.

The local authority credit the direct payment amount onto the card, enabling the recipient to then use it to pay for services face to face, over the internet or on the telephone. It can also be used to pay personal assistants' salaries through a variety of approaches including telephone banking and payroll services.

This approach can allow the direct payment recipient choice and control without having to manage a bank account. It can also reduce the administrative requirements, as the local authority is able to see how the recipient has used the direct payment through the card statement.

The Kent Card⁵⁸ is used by Kent County Council as their preferred method of making direct payments. The Card is a Chip and Pin Visa which allows direct payments to be made to the recipient, within a predetermined limit. It has been in operation for three years with around 1,000 in circulation. *The Edinburgh Card*⁵⁹ has more recently been adopted by The City of Edinburgh Council.

4.4 Alzheimer Scotland

Alzheimer Scotland is committed to promoting the personalisation of services for people with dementia and working to make sure its own services are fully flexible and operating in a way which gives control to service users and their carers and families.

The following provide some examples of our work in personalising support and our aim of ensuring that no-one has to go through dementia on their own.

4.4.1 Dementia Advisor Network

In autumn 2009 Alzheimer Scotland launched its Dementia Advisor Network with 19 dementia advisors in 18 local authorities, with the aim of having an advisor in every local authority and ultimately every town in Scotland. With two exceptions, the Dementia Advisors are fully funded by Alzheimer Scotland's own fundraised resources and form part of the organisation's contribution to improving support for people with dementia and their families and carers.

Dementia advisors provide light-touch contact with people with dementia, family members and carers, as a point of contact throughout the illness from diagnosis to end-of-life. Their role is to empower people with dementia and their carers by assisting them to access the information they need, promoting independence, self-help, well-being, choice and control.

The dementia advisors also have a wider development role in increasing the awareness of dementia and helping communities to become more dementia-friendly.

4.4.2 Post diagnostic support pilot

Alzheimer Scotland's post diagnostic pilot project, *Facing Dementia Together*, is based in East Renfrewshire and Renfrewshire and works in partnership with local authorities and the health board. Funded by the Scottish Government for two years, the project's aim is to extend the level of self-directed support for the care and support of people with dementia, and to empower people with dementia to feel able to take control and make their own choices.

Project staff work with people in the early stage of the illness, involving their families and carers as appropriate, to support them to:

- Understand and come to terms with living with dementia
- Benefit from peer support from other people with dementia
- Put in place legal arrangements to maximise their control over future decisions made on their behalf
- Plan ahead for their future needs, discussing options for future care and setting out their wishes using advanced person-centred planning tools to creatively design services and fit them to their natural supports including support from family, friends and community.

Project staff also work with local authority and health board staff to develop approaches and systems, raise awareness and assist in the cultural shift towards personalisation of services for people with dementia.

Alzheimer Scotland Facing Dementia Together Case Study

Ann enjoyed an active social life until recently. She was a professional artist, keen gardener and bee keeper. She loved being outdoors and hill walking. She was also an active member of the church.

Ann became disconnected from her social life in the two years prior to her diagnosis of Alzheimer's disease. This was largely due to her mobility deteriorating to the extent she could no longer go out unaccompanied. Additionally, many of her friends had passed away or their health had deteriorated such that they were unable to leave their homes. At the point of referral to the post diagnostic team Ann was depressed, isolated and considering long term care.

Ann's awareness of the changes in her abilities, and of the changing dynamics in her established relationships with others at church and at the artist group she was a member of had a negative impact on her sense of self and self esteem. Due to these factors she was not interested in re-establishing these links. Project staff helped Anne to develop coping strategies for her short term memory loss. This impacted positively on her mood and on her sense of isolation. They also worked with Ann to establish new community links, based on her long term interests allowing her to redevelop skills and form new relationships, impacting positively on her self-esteem.

Ann is now a member of a community art group. Recently project staff arranged a person centred planning meeting with Ann, her daughter and her community psychiatric nurse, to help ensure that she and her daughter are able to take control of decisions about her future care. They discussed self-directed support as a personalised option.

The project is being evaluated by the Dementia Services Development Centre at the University of Stirling.

At time of writing the pilot has been going for less than a year. Project staff have worked with a number of people with dementia at levels ranging from simple information provision to a person-centred planning meeting, with the person with dementia, family members and key professionals looking at dreams and fears for the future to enable the person and family to take control of decisions about future care.

The experience of the pilot to date has identified a number of issues impacting on the ability of people with dementia to plan their own future care:

- Diagnosis often does not come early enough, and people may have already lost connections within their communities such as their local church or bridge club, and/or have given up some or all of their hobbies and interests. This can mean that it is no longer a case of helping them to maintain their natural supports but to regain them or develop new ones.
- Local authorities are working to national eligibility criteria for personal care services and are under financial constraints. This means they have difficulty in providing resources for preventative supports to people early on in their illness before they would be assessed as needing personal care.

- There are no agreed resource allocation systems, which makes it difficult to predict how much individual budget a person would get at the point where they need services, in order to plan with confidence.
- It takes time for people to go through the process of coming to terms with their condition and accepting it, and reach a point where they may (or may not) want to look at what the future is likely to hold for them and make plans. The process has to move at the pace which suits each individual.

4.4.3 Self-Directed Support Pilot

Funded by the Scottish Government, Alzheimer Scotland is delivering a two year pilot in North, East and South Ayrshire demonstrating best practice in supporting people with moderate to severe dementia facing the prospect of long stay care, and their families, to design creative personalised solutions using self-directed support as an alternative to institutionalised care.

The project aims to demonstrate that self-directed support is a practical, cost-effective approach to providing more personalised services which better support both the person with dementia and their family.

Self-Directed Support Pilot Case Study

Ellie is in her late 70s, has three children and five grandchildren whom she adores; she is a keen artist and fanatical shopper.

In August 2009 Ellie was admitted to hospital following a fall. Ellie remained in hospital for 6 weeks, after which her family were advised she should go into a care home as she required constant care 24 hours a day.

Ellie was referred to Alzheimer Scotland's Self-directed Support Pilot Project and has now been back living in her own home for the past few months. Her family, with the support of the Project, received a direct payment and devised a flexible package of care to meet Ellie's needs. They now employ two personal assistants using the direct payment monies; this enables the family to manage their other commitments, without being overwhelmed. Ellie remains connected to her friends, family and community and enjoys her continued independence in her own home....and the occasional shopping trip!

Ellie's package of care costs over £100 per week **less** than the standard charge for a nursing home.

This pilot project has also been going for less than a year but has already established a number of self-directed support packages which are enabling people with dementia to stay in their own home.

Project staff work directly with individuals and carers and families to assist them to explore options for the care of the person with dementia, maximising natural supports and using purchased services or employing personal assistants. They also work with social work staff to assist them to develop their practice.

Pilot staff have identified a number of issues which affect the ability of people with dementia to take up self-directed support:

- Families are often not given information about this option and some professional **staff are unclear** about direct payments and internal systems.
- Assessments are **based on hours of service provision not the outcomes** to be achieved, which stifles creativity and options.
- Processing of direct payment applications is **too slow** in some authorities for people nearing long term care, taking up to 6 months to get the packages up and running. **Long timescales have a bigger impact upon people with dementia than others who have more stable impairments.**
- Assessment and care planning continue to be led by the professional rather than people with dementia and carers, reducing the **choice and control**.
- **Limited resources, existing block funded contracts and lack of flexibility with budget streams restrict choices** - for example one authority can give a direct payment instead of home care hours but all day care and respite money is committed to buildings-based services.

Case study 9

Private sector care agency support to remain an active part of community

Bill cares for his wife Rita, who was diagnosed with early onset Alzheimer's disease a number of years ago; they live in a small town. Bill had refused the local authority home care service, as he was concerned carers would arrive at irregular times, interfering with their own routine. A private sector agency had provided short-term temporary care for Rita to allow Bill to attend a series of information sessions for his own healthcare needs and he had been happy with the care they provided.

Bill is now using a direct payment to pay the private sector agency to care for Rita whilst he attends church meetings, which allows him to remain an active part of his faith community.

Financial struggle

There is an £8.77 shortfall per hour between the agency weekend cost and direct payment standard rate, which Bill must pay. Their social worker had suggested using an alternative agency; however, Bill does not want to change as he has confidence in the care being provided for Rita.

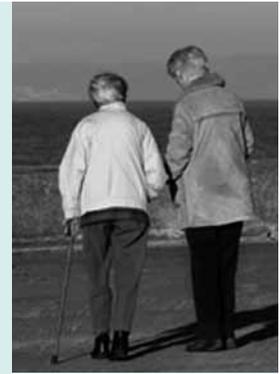
Unfortunately this is not a support Bill can rely on having in the medium to longer term. It is a financial struggle to supplement the agency payments; Bill recently had to cut back the number of hours of care from six to four per week, primarily for financial reasons.



Case study 10

Husband providing personal care

Michael cares for his wife Mary, who has vascular dementia; they are both aged over 70 and live in a small town. They receive a direct payment to pay for Michael to provide personal care for his wife. Michael is registered self-employed, with Mary purchasing care services from him. The direct payment contract is between Mary and the local authority, and Michael signed it as Mary's guardian.



Exceptional circumstances

Michael initially found out about direct payments when reading a leaflet on free personal care in 2002; he realised that he was carrying out the majority of the tasks outlined in the leaflet for his wife. On qualifying for the state pension Michael's entitlement to carer's allowance ceased; the injustice he felt at this regulation gave him the impetus to seek a direct payment.

Michael applied for a direct payment when the amendment to legislation, brought about by the Adult Support and Protection (Scotland) Act 2007, allowed local authorities to determine whether exceptional circumstances exist which would justify using a direct payment to employ a close relative in a particular case.

The application for a direct payment was initially refused. Michael sought advice through his MSP and then complained to the local authority about the decision. A senior officer from the social work department visited them at home to re-assess their case, spending a number of hours observing the care Michael provided for Mary. The senior officer accepted exceptional circumstances existed which permitted employing a close relative. However, there were still a number of obstacles to overcome including Michael obtaining guardianship for Mary.

Persistence

Michael believes the process of getting a direct payment could have been much smoother had he received timely appropriate information along the way. Mary granted Michael continuing power of attorney (financial matters) at an early stage in her illness - had their solicitor informed them about welfare power of attorney at this stage, Michael would not have had to seek guardianship.

"Getting a direct payment required a great deal of persistence, determination and resourcefulness" Michael

However, once he came into contact with the senior officer she provided key information which smoothed the process.

5. Conclusion

The study has shown that direct payments are working well for some people with dementia; with the flexibility and control they provide being the greatest benefit. The case studies demonstrate that direct payments are enabling people with dementia to remain at home during the advanced stages of the illness, adding to quality of life for both carers and the person with dementia, providing cost effective care and responding sensitively to the specific needs of families and the person with dementia.

However, despite direct payments having been in existence for over two decades, with older people being eligible for 10 years, and a requirement to offer them to everyone with an assessed need for support, the number of people using them remains very low overall and the number of users with dementia is lower still. At present, direct payments are the main mechanism allowing people with dementia and carers to take control of the support they receive. The study has highlighted a number of improvements to policy and practice that might increase uptake of direct payments by people with dementia and their carers.

5.1 Recommendations - direct payments

In order to improve the uptake and effectiveness of direct payments by people with dementia local authorities should:

- **Increase potential recipients' awareness** through publicity and impartial information, so that people with dementia and their carers are aware of what is involved in taking on a direct payment, ahead of an assessment of their needs. The research has demonstrated people with dementia and their carers currently often find out about direct payments by chance through informal means.
- **Improve understanding within social work departments towards direct payments and their potential benefit** for people with dementia and their carers. Research evidence demonstrates a protectionist culture towards older people and people with dementia and an expectation that they will lead more restricted lives than younger care groups, and this study has shown that the way direct payments are presented to potential recipients can be shaped by professionals' own views.
- **Streamline systems, with reduced bureaucracy and a quicker process** of putting a direct payment in place. Unlike many other care groups, where delays in providing a direct payment are therefore especially problematic. Symptoms may be largely stable, dementia is a progressive illness with needs increasing over time. There is a need for timely intervention in response to changing and increasing care needs.
- **Improve support and information and make reporting requirements more straightforward** for the direct payment recipient. The individual budget pilots in England demonstrated the personal challenges and transitions older people may face, such as suddenly taking on a new role as a carer⁶⁰. They found that individualised funding for older people required a "whole system" approach, including access to good information, advice and advocacy and services that support older people with planning and arranging services.

- **The Scottish Government should work with local authorities to ensure parity in the operation of direct payments**, so that recipients in different areas have equal flexibility and choice over how and when they spend their direct payment, providing it is meeting their assessed needs. The data on local authorities' various direct payment rates and criteria and the different experiences in the case studies demonstrates the differing levels of flexibility between local authorities, including the ability to purchase the services of self-employed personal assistants the scope to afford agency rates and the timescale in which the direct payment had to be spent.
- **Adapt legislation to allow an appropriate person such as carer to take on managing the direct payment on behalf of a person with dementia, when the person lacks capacity and there is no one with power of attorney or guardianship.** This is in keeping with the English example of a *suitable person*^{ab} being able to take on the direct payment on the person's behalf⁶¹. The appropriate person should have a duty to ensure that the principles of the Adults with Incapacity Act are adhered to.
- **Introduce a straightforward process for health money to be included in direct payments** in recognition that the needs of people with dementia do not fit neatly into social work or health board defined parameters.

5.2 Recommendations - developing personalisation

Direct payments operate in the margin alongside the dominant care management system of adult social care and are only one of a number of ways of personalising peoples' services. There is a need for transformational change in order to scale-up personalisation so that the majority of people with dementia and their carers can have genuine control over their support. It is also essential that structural issues, which limit the opportunity to develop individualised funding, are addressed:

- **Local authorities should use an outcomes-based approach** when assessing the support needs of people with dementia. The focus should be on the impact or end result of support and/or services on the lives of the person with dementia and their carer. People with dementia and their carers should also be supported to take an active role in assessing their own needs for support.
- **Social work resources should be structured so as to facilitate individualised funding**, with a fair and equitable budget to allow support to be designed around the person with dementia and their family, and a variety of options for managing the social care money to suit individual circumstances.
- **Health boards and local authorities should ensure the provision of good early stage support and a preventative approach** to supporting people with dementia and their carers.

^{ab} Usually the suitable person will be a family member or friend who may previously have been involved in the care of the person eligible for services. Whatever the relationship of the proposed suitable person to the person requiring care the local authority must ensure that the best interests of the person lacking capacity are prioritised above all other considerations.

- **The Scottish Government should establish a change fund** to enable the development of post diagnostic support planning, with a flexible budget to help people to maintain their natural supports from an early stage and an indicative budget for future care planning to follow the person as their needs progress.
- **Local authorities should develop a preventative and planned approach** to funding support for people with dementia and their carers throughout the journey of the illness, taking a long term view on the cost of care. There should be a focus on value for money and the best outcome, with the removal of restrictive cost ceilings and an unlocking of resources to facilitate the creation of a range of options open to families as the needs of the person with dementia progress.

It is essential that the Scottish Government's forthcoming *Self-directed Support Strategy*, in conjunction with the *National Dementia Strategy*, provide a clear message on the direction of travel towards greater personalisation of health and social care so that the majority of people with dementia and their carers have genuine choice and control.

Case study 11

Direct payment contributing to a larger package of care



Katherine, living in England, organises the care of her mother Jean, who has vascular dementia and lives in a small town in Scotland. Jean suffered a serious life-threatening illness and spent a number of months in hospital. Full-time live-in care was put in place to enable her to return home which was paid for from personal resources.

After the care package had been set up a friend suggested they might be entitled to a direct payment towards the cost of Jean's care. The hospital social worker had previously informed them there was no need for social work involvement if they were arranging private care.

Direct payments make a valuable contribution

They used a private sector agency to provide self-employed personal assistants and Jean now receives a direct payment of £9,000 per year towards the cost of her care, with the bulk of the costs continuing to be met from personal resources. A personal assistant lives with Jean for a period of three to four weeks, with Katherine travelling to her mother's home to manage the change-over of carers. This allows Katherine to ensure each new carer understands how care is to be provided; ensuring Jean's quality of life and routine is paramount. Katherine's travel expenses are included in the cost of the care package.

In addition to the direct payment the social work department provides a local care agency to give the live-in carer an afternoon off each week.

Good quality of life

Since returning home from hospital Jean has made significant progress in her physical health and wellbeing. She enjoys a good quality of life in her own home, which Katherine believes could not be achieved in a residential environment.

Katherine found that during Jean's time in hospital health and social care did not work together to plan future care; nursing staff were of the opinion residential care was the only option whereas social work did not take an interest until Jean was considered medically fit to leave hospital. The family did not receive any support in their bid to have their mother return home - had the receipt of direct payments been a critical factor in enabling Jean to leave hospital she might not have been able to return home.

Case study 12

Social support from a voluntary sector support worker



Margaret cared for her elderly father Ian, with the help of community supports, for eight years before he moved into a care home. Ian, a very active man, lived in his own home in a city a short drive away from his daughter.

Ian had been receiving social support from a designated male support worker provided by a voluntary sector organisation when a friend told her about direct payments.

Direct payment as support needs increased

As Ian's support needs increased, Margaret applied for a direct payment to increase the time the support worker spent with Ian from six to 16 hours per week.

By the time Margaret received the first direct payment she had two outstanding monthly invoices from the voluntary sector organisation, who had informed her they would be unable to continue providing the service indefinitely without payment. At this stage Margaret was feeling forced into considering her father moving into a care home, as the level of care being provided was no longer sufficient to support Ian at home.

Playing catch-up

Margaret did not want her father to go into a care home; had the system not been so difficult and slow, she would have felt able to pursue increased support, still using a direct payment so that she could use the same organisation, which she trusted.

"My father's deterioration and patterns of behaviour could have been managed had care been increased as it was needed" Margaret

Having successfully managed her father's care in the community for many years, Margaret was left feeling let down by a slow bureaucratic system which meant they were always playing catch-up with Ian's support needs. Ian is now living in a care home.

6. Appendices

Appendix 1 - List of participating local authorities

Social work staff were interviewed in the following local authorities:

Aberdeenshire Council

Clackmannanshire Council

Dundee City Council

East Ayrshire Council

East Dunbartonshire Council

Fife Council

Moray Council

North Ayrshire Council

North Lanarkshire Council

South Lanarkshire Council

Appendix 2 - Case study details

Gender	Female
Age	70s
Relationship to main carer	Mother (daughter)
Location	Small accessible town
Finding out about self-directed support	Friend
Way payments used	Employing a personal assistant and using a private sector agency
Difficulties	Setting-up the direct payment Finding out information about self directed support Staffing issues - personal assistant on long term sick leave
Benefits	Enabled person with dementia to be cared for at home throughout the illness Supported the family carers, enabling main carer to continue working All care and support provided for by one carer at a time

Gender	Female
Age	70s
Relationship to main carer	Mother (daughter)
Location	Remote rural
Finding out about self-directed support	Social work department
Way payments used	Rent holiday cottage for other family members to care for mother and allow main carer respite in her own home
Difficulties	None
Benefits	Enabled main carer time in her own home in knowledge mother was being cared for by family Value for money for local authority

Gender	Female
Age	70s
Relationship to main carer	Wife
Location	Small accessible town
Finding out about self-directed support	Free personal care leaflet
Way payments used	Husband providing personal care (exceptional circumstances)
Difficulties	Time delay as a result of lack of timely information Application initially refused
Benefits	Husband was providing personal care

Gender	Female
Age	64 years
Relationship to main carer	Wife
Location	Urban area
Finding out about self-directed support	Social work department
Way payments used	Purchase support from a private sector agency to care for person with dementia when husband goes out
Difficulties	Direct payment level significantly lower than the agency hourly rate, resulted in the family carer reducing the number of hours care is provided by the agency Main carer has found reporting requirement to be overly bureaucratic
Benefits	Enabled the main carer to continue being an active member of their faith community

Gender	Female
Age	70s
Relationship to main carer	Mother (daughter)
Location	Small accessible town
Finding out about self-directed support	Friend
Way payments used	Contribute to the cost of full time care to be provided by live-in personal assistants supplied by a private sector care agency
Difficulties	Long time delay in payments being put into place Failure of hospital social worker to inform family about possible entitlement to self-directed support
Benefits	Enabled person with dementia to return home and be cared for, when residential care was being suggested by social worker

Gender	Female
Age	70s
Relationship to main carer	Mother (daughter)
Location	Accessible rural area
Finding out about self-directed support	Social work department
Way payments used	Purchase the support from self-employed personal assistants to provide social support and care for the person with dementia in the home and on outings
Difficulties	None
Benefits	Enabled the people who are known to the person with dementia to be used as personal assistants Provided flexibility to enable the main carer to continue working

Gender	Male
Age	70s
Relationship to main carer	Father (daughter)
Location	Urban area
Finding out about self-directed support	Friend
Way payments used	Support worker provided through voluntary sector agency
Difficulties	Time delay in application being processed resulted in outstanding invoices from service provider. It also meant support could not be increased quickly enough to delay person with dementia moving into a care home
Benefits	Social support for person with dementia to carry out activities outwith the home

Gender	Male
Age	60s
Relationship to main carer	Husband
Location	Remote rural
Finding out about self-directed support	Social work department
Way payments used	Employ carers on a needs basis to sleep-over with person with dementia, to enable family carer time away from the home
Difficulties	Managing the administrative requirements of the direct payment is an added burden for the main carer
Benefits	Enabled the family carer time away from the home to have a holiday and visit with family

Gender	Male
Age	80s
Relationship to main carer	Father (son)
Location	Urban
Finding out about self-directed support	Friend
Way payments used	Employ a personal assistant to provided support for person with dementia in their own home
Difficulties	None
Benefits	Enabled the person with dementia to live at home for an additional year Friendship formed with personal assistant, adding to the quality of life

Gender	Female
Age	60s
Relationship to main carer	Wife
Location	City centre
Finding out about self-directed support	Welfare rights talk given at a voluntary sector carer support group
Way payments used	Employ a personal assistant
Difficulties	Finding appropriate person to employ as a personal assistant
Benefits	Flexibility to arrange personal care to suit their needs Personal assistant provides consistency and developed understanding of care needs

Gender	Female
Age	70s
Relationship to main carer	Husband
Location	Urban
Finding out about self-directed support	Social work department
Way payments used	Employ personal assistants
Difficulties	Problems with the quality of care staff provided by the private sector care agency Finding suitable people to employ as personal assistants One personal assistant failed to return to work or make contact with the main carer
Benefits	Personal assistants have formed a good understanding of the person with dementia's needs Provides flexibility to enable the family carer to go out with the home to carry out their own commitments and interests Enabled the person with dementia to continue being cared for in their own home during the advanced stages of the illness

Gender	Male
Age	70s
Relationship to main carer	Husband
Location	Remote rural
Finding out about self-directed support	Son
Way payments used	Purchase the support of a private sector care agency to provide personal care and respite for main carer
Difficulties	Local authority would not allow family carer their preference, to purchase the services of self-employed personal assistants The requirement to spend direct payment within each quarter year means the main carer cannot save the respite hours to suit her needs better Service provided by the private sector agency service not matched-up to their Care Commission inspection report. There were problems initially with the carers provided by the agency
Benefits	Provides flexibility to enable personal care hours to be arranged in one three hour block in the morning, instead of three one hour blocks of personal care throughout the day which they would receive through the local authority directly provided service Allows the family carer time to pursue their own interests two afternoons per week

Appendix 3 - Local authorities direct payment rates

Local authorities	Direct payment rate/s	Rationale for rate paid
Aberdeen City	No response	No response
Aberdeenshire	No response	No response
Angus	Multiple	Type of support required
Argyll & Bute	Single	Not applicable
Clackmannanshire	Single	Not applicable
Dumfries & Galloway	Multiple	Dependent on the care group e.g. older people, mental health, physical disability
Dundee City	No response	No response
East Ayrshire	Single	Not applicable
East Dunbartonshire	Multiple	Type of support required and whether employing a personal assistant or using an agency.
East Lothian	Multiple	Whether employing a personal assistant or using an agency. Also a rate for specialist support, which is negotiated at point of assessment.
East Renfrewshire	Not provided	Whether employing a personal assistant or using an agency.
Edinburgh, City of	Multiple	Whether employing a personal assistant or using an agency.
Eilean Siar (Western Isles)	Single	Not applicable
Falkirk	Two, with an additional enhanced rate	Whether employing a personal assistant or using an agency. Scope for higher rate for specialist needs.
Fife	Standard and enhanced rate	Enhanced rate for those assessed with complex needs.
Glasgow City	Standard and enhanced rate	Enhanced rate for those assessed with complex needs.
Highland	Operate policy of equivalence; pay the amount it would cost to directly provide or purchase the service.	Based on assessment of need and support required.
Inverclyde	Three	Type of support required
Midlothian	Two	Whether employing a personal assistant or purchasing from an agency.
Moray	Standard and enhanced rate	Enhanced rate paid in exceptional circumstances for complex needs.
North Ayrshire	Three	Whether employing a personal assistant or purchasing from agency. Enhanced rate for employing personal assistant with appropriate skills for those who require additional support.
North Lanarkshire	Three	Level of support recipient requires to manage their direct payment and arranging support, type of support required and level of fluctuation in the person's care needs.
Orkney	Three	Type of support required.

Perth & Kinross	Three	Personal assistant rate; two agency rates, level paid dependent on distance between them and recipient.
Renfrewshire	Single	Not applicable
Scottish Borders	No response	No response
Shetland Islands	Two	Type of support required
South Ayrshire	Single	Not applicable
South Lanarkshire	Multiple	Type of support required and whether employing a personal assistant or purchasing from an agency.
Stirling	Multiple	Whether employing a personal assistant or purchasing from an agency. Different rates for those living in urban and rural localities.
West Dunbartonshire	Multiple	Type of support required; and whether employing a personal assistant or purchasing from an agency.
West Lothian	Three	Standard rate for core care needs, enhanced and exceptional rate for those with complex needs or who require a specific intervention.

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Let's get personal

- personalisation and dementia

The principle of personalisation has become a prominent feature of social policy discussions. This report is the outcome of an in-depth study into how direct payments are working in practice for people with dementia and their carers in Scotland.

The study included interviews with family carers and social work professionals and data collection from local authorities. It reveals how effective personalised approaches to organising support can be, with 12 case-studies of people using direct payments, currently the main form of personalisation available in Scotland. It also shows that the numbers of people using this approach are low - very few people with dementia and their carers in Scotland have genuine control over the support they receive. The research identifies crucial barriers that limit the wider implementation of personalisation for people with dementia and their carers.

The report sets out key recommendations to empower people with dementia and their carers to personalise the care and support they receive so that it is meaningful to their lives.

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