

Carers and personalisation: improving outcomes

DH INFORMATION READER BOX	
Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	Social Care / Partnership Working
Document Purpose	Best Practice Guidance
Gateway Reference	15181
Title	Carers and personalisation: improving outcomes
Author	Social Care Policy, DH
Publication Date	25 Nov 2010
Target Audience	PCT CEs, Care Trust CEs, Directors of PH, Local Authority CEs, Directors of Adult SSs, GPs, Directors of Children's SSs
Circulation List	NHS Trust CEs, SHA CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, PCT PEC Chairs, PCT Chairs, NHS Trust Board Chairs, Allied Health Professionals, Emergency Care Leads, Voluntary Organisations/NDPBs
Description	This document explores personalisation in relation to carers. It provides practical examples for achieving better outcomes through greater involvement, choice and control for carers and by adopting whole family approaches.
Cross Ref	Recognised, valued and supported: next steps for the Carers Strategy
Superseded Docs	N/A
Action Required	N/A
Timing	N/A
Contact Details	Elaine Edgar Carers Policy Team Room 116, Wellington House, 133-155 Waterloo Road London SE1 8UG
For Recipient's Use	

Carers and personalisation: improving outcomes

Prepared by:

Bernadette Simpson and Robin Murray-Neill

National Personalisation Advisers

Personalisation Team

Department of Health

Wellington House

133–155 Waterloo Road

London SE1 8UG

For further information, see the Department of Health website www.dh.gov.uk or www.puttingpeoplefirst.org.uk

Contents

Introduction.....	5
1. Carers as expert care partners and whole-family approaches.....	7
2. Early intervention and prevention.....	13
3. Making self-directed support processes work for carers	17
4. Market and provider development.....	28

Introduction

“Historically there has often been too much of a divide between the user and the carer, whereas the physical and emotional well-being of both are inextricably linked.”

Dame Philippa Russell, Chair, Standing Commission on Carers

If we are to meet the challenges of both financial constraint and population change, we must work more effectively, making better use of what we know and what we have. This means harnessing the vast knowledge and expertise of carers themselves, alongside that of those they support, and integrating support arrangements wherever possible, both across statutory, voluntary and community organisations, and within the family or other contexts in which care and support are provided.

*“Opening up public services to challenge is a core component of the Big Society and carers’ knowledge and expertise will be vital in holding local commissioners and care providers to account. Big Society is also about encouraging people from all walks of life to play a more active part in society - developing a society that is more responsive and accessible to the needs of carers should be a key strand.”*¹

This short paper offers signposts for better practice and outcomes. It will be of interest to carers and those they support, and to all others engaged in providing carers’ support, including personalisation/transformation leads in councils. The material can be used to stimulate progress on the achievement of outcomes both for carers and for personalisation more generally, consistent with the *A Vision for Adult Social Care: Capable Communities and Active Citizens*. It includes examples to illustrate how the principles of personalisation have been applied, emphasising the value of finding ways forward that make sense and work best locally.

One of the challenges of personalisation is to enable commissioners, providers, carers and those they support to develop ‘can do’ thinking around care and support that is at once responsive, creative and sustainable. Such a systems-wide transformation, enabling care and support arrangements that are person centred and self-directed, requires that family members and carers, other than in very specific circumstances, have to be regarded as experts and care partners. *Recognised, valued and supported: next steps for the Carers Strategy* (HM Government, 2010) emphasises the importance, in the context of the recent Spending Review, of involving carers in delivering on Quality, Innovation, Productivity and Prevention (QIPP) workstreams such as end of life care and long-term conditions.

The personalisation of services and support promotes choice, control and independence for carers, tailoring solutions around the individual and the family. Important elements of personalisation are active citizenship, the promotion of stronger communities and preventative action. The agenda applies equally to carers and those they support and reflects the interdependence that exists between them.

¹ HM Government *Recognised, valued and supported: next steps for the Carers Strategy* November 2010

“Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible: for example, that advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups, and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can be supported.”²

If we are to achieve this, there is a need to:

- recognise the expertise of, and work in genuine partnership with, carers at all levels of service design and delivery;
- enable carers to design and direct their own support, have access to direct payments and be engaged in the support plan of the person they care for and the assessment where appropriate;
- wherever possible, establish whole family approaches³ that ensure there is integrated support planning that benefits everyone involved;
- fully recognise the differing social and emotional impacts of providing support to another person and that these do not necessarily correlate to the number of hours spent, or the tasks undertaken, in providing care; and
- develop a range of support options and opportunities to match the diverse needs of carers (including those who do not choose to identify themselves as carers) and the outcomes they wish to achieve in their lives.

Many people who provide care do so for a member or members of their family, while others support friends and neighbours. Providing unpaid support to family members or friends is a major contributing activity to the health and welfare of our society. Each caring relationship is unique to those individuals involved, and this needs to be a fundamental consideration in any work with carers and those they support. However, it is possible to identify some key themes in personalising support for carers and some general principles about how to support and sustain the relationship between those involved. Each of the following chapters is based on a key theme and lists key practice statements that councils, NHS organisations and local partners can make use of in addressing local needs and expectations, and in determining what is likely to work well in their locality.

² *Recognised, valued and supported: next steps for the Carers Strategy* (HM Government 2010)

³ In this document ‘whole family approaches’ is used as an umbrella term and is inclusive of those caring arrangements made between people, such as friends or neighbours.

1. Carers as expert care partners and whole-family approaches

“An effective community-based approach is achieved when councils and their partners...actively involve people, carers, families and communities in the design, development, delivery and review of innovative care and support arrangements to maximise choice and independence and utilise the widest range of resources.”⁴

To recognise carers as expert care partners is to value both their role in providing support and the wider knowledge and skills they possess as individuals. Doing so greatly increases the likelihood of more personalised, responsive, and high-quality outcomes for those being supported, and makes carers' valuable and informed contribution available to other carers, service providers and commissioners. To maximise the benefits of these partnerships, training and development opportunities are as important for carers as they are for those employed in the health and social care workforce.

The activity and impact of providing unpaid support is best understood in its context, as a relationship rooted in family, friendship or local community. While there may be specific differences between these contexts, the basic principles apply across them all. For simplicity, we refer to them all here as 'whole-family approaches'.

Too often, carers have experienced a lack of co-ordination between the assessment of need for the person they support and both their own role in meeting that person's needs, and the support they might need in order to maintain that role. At best this is unnecessarily time consuming and wasteful of resources, and at worst it can lead to inaccurate assessments of individual needs for support and mistaken assumptions about the willingness and ability of carers to provide levels of care, which can have a detrimental effect on the health and well-being of all concerned.

“I am making my first steps giving support to people I care deeply about. I see the personalisation of services as a fantastic opportunity. My hope is that this approach will enable me to show my love for my family members in this very practical way for as long as it is needed.” (A family carer)

There is clear evidence of the effectiveness of whole-family approaches in addressing the most complex needs, and of the value of mediation and negotiation between family members when needed. Initiatives such as Family Group Conferencing can address issues such as risk, reliability or incompatible preferences that have frequently prevented whole-family working, and can also demonstrate the positive

⁴ Putting People First Consortium (2010) *Think local, act personal: Next steps for transforming adult social care. A proposed sector-wide commitment to moving forward with personalisation and community-based support*

value of dispute resolution. All families and those involved in caring relationships based on friendship or neighbourliness should have access to these opportunities when required.

“The facilitative skill will be to listen to all interested parties, resolve potential conflicts and arrive at a mutually acceptable plan that has taken the needs of carers into account”⁵

Key practice points:

- Whole-family approaches are the starting point – recognising the interdependence that most of us have with those closest/most important to us.
- Wherever possible and to the greatest extent possible, carers’ expertise is recognised and utilised in assessing, planning and reviewing support to the person they care for, and in determining and meeting their own support needs.
- Where it is not physically possible to work with people as a ‘family’, that interrelationship is still recognised, even where entirely separate assessments/plans etc are conducted.
- In whatever setting or circumstance carers seek help or advice, they are routinely asked what level of support they are both willing and able to provide to the person they care for.
- Carers are an integral part of the design, delivery and evaluation of every aspect of carers’ support and services.

Practice examples: carers as expert care partners

Ealing Carers Connect: working together for independent living

Ealing Carers Connect is a carer-led organisation providing support to carers and formed by a consortium of four organisations in the London Borough of Ealing:

- Ealing Centre for Independent Living
- Ealing Mencap
- Ealing Crossroads
- Alzheimers Concern Ealing

Sian Vasey, Director of Ealing Centre for Independent Living, believes that user-led organisations of disabled people and of carers need to work together. She says:

“carers’ organisations and disabled people’s organisation’s have broadly the same goals – independent living for disabled people. Working together we can pursue our common cause more effectively. Many disabled people are also carers and many carers are also disabled people. Putting people into boxes doesn’t work. Let’s acknowledge that disability is not only experienced by people with impairments it ripples out to a much wider community. Let’s work together to deliver a ‘one stop shop’ for disabled people and their families.”

www.ecil.org/index.asp?pageID=183

⁵ Association of Directors of Adult Social Services (ADASS) (2010) *Making resource allocation work in a financial environment: Good practice for personalised financial resource allocation*

All Together Better

All Together Better is a national course that will identify, train, support and sustain a national network of champions in personalisation, building new alliances that will become powerful and make a real difference. A network of people who think that life could be better for those who need extra support and who want to improve the way things are now – but don't always know where to start.

It is for family carers and people who provide support through social care, health services, education, leisure, and other providers. The tailor-made programme is based on existing family leadership development courses that have a proven track record, including Partners in Policymaking, Sharing Knowledge and Kindred Spirits. It comprises six 2-day residential sessions.

Email: admin@in-control.org.uk

www.in-control.org.uk

Cheshire East Joint Strategic Needs Assessment (JSNA)

In Cheshire East, the findings of local research by the Alzheimer's Society into the views of people with dementia and their families were used to inform the JSNA. The research was funded by the Central and Eastern Cheshire NHS Primary Care Trust.

Under the heading 'Headlines of challenging health and social care findings', the Executive Summary says:

"The top three recommendations from a consultation with people with dementia and their families was to increase public and professional awareness and understanding of dementia, earlier diagnosis and intervention and provision of more information to families about dementia and the services available."

www.cheshireeast.gov.uk/pdf/JSNA%20Executive%20Summary%200910%20Final%2020100423.pdf

Co-production with carers in Nottinghamshire

A co-production team of 10 carers, with a wide range of expertise and experience, worked with two carers assessment workers and two social workers to produce a Carers Assessment and Support Plan process. They addressed key questions, such as 'How do we assess the 'impact of caring'?' and 'How do we assess for meaningful carer outcomes?', and produced proposals for a coherent and effective process that focused on risks to the sustainability of the caring role.

"... what may not be a substantial amount of care to a 25-year-old carer may be otherwise if provided by a seven or 87-year-old carer. Likewise if the caring task is physically demanding, then the question of what is or is not substantial will depend in part on the physical strength of the carer; again, if the carer has recently recovered from a serious mental illness, then even five hours' care may be substantial to him or her. A morning or evening caring task will be substantial to a carer who works nine to five but not necessarily for one who does not – and so on."

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/CarersExpertPartners/?parent=8213&child=8233

Practice examples: whole-family approaches

The two examples which follow are illustrative of Doncaster Council's use of a whole-family approach.

A small amount of funding was provided to pay a tutor to teach basic sign language to a whole family including an aunt in their own home. The aim was to enable the family to better support Megan who has dual sensory loss and complex medical difficulties. Previously only Megan's parents had basic sign language skills which created frustration and relationship difficulties within the family. This small amount of funding has made a significant difference to the family. Communication and relationships have improved with the family carers being better able to support Megan and each other. Megan's confidence and self esteem have been raised as she was involved in the delivery of the training to the family. One family member has gone on to further develop his skills by passing a Level 2 sign language course.

John

John who has a learning disability lives at home with his mum. Unfortunately mum's health is deteriorating and she has recently been diagnosed with dementia. Not only did this mean she could no longer continue to provide all the care and support her son needed, it was apparent she would need care support herself in the near future.

Ordinarily different care agencies would have been used to provide for mother and son's care with workers in the learning disability team accessing a specialist care agency. However as a result of the case going to a risk panel, the idea of using the same agency was explored. During John's assessment it was evident his care needs could be met by a generic rather than specialist agency. Whilst the agency was a little unsure at the beginning, with extra support from the learning disability team the agency found they could meet the needs of both John and his mum. This joined up way of providing care resulted in a better outcome for John and his mum and was more cost effective for the council.

Soldiers, Sailors, Airmen and Families Association (SSAFA) Forces Help Support Group for the Families of Injured Service Personnel (FISP)

The SSAFA Forces Help provides families with the opportunity to meet and talk with others whose relatives have been injured while serving in the Armed Forces. It meets regularly, offering mutual support and allowing families to share experiences, information and advice. Other Service charities have been able to provide short breaks for carers of Service personnel when a need has been identified which cannot be fulfilled through the Local Authority.

www.ssafasupportgroups.org.uk/group/fisp

Family Group Conference service, Essex

Essex Social Care provides a Family Group Conference (FGC) service where they and family members are very concerned about the welfare of a child or adult and an FGC may be the best way of deciding on action. The FGC approach is based on the belief that families can usually find their own solutions to the difficulties they are facing and that children, young people or vulnerable adults have a right to have their families involved in their future planning.

*“I think we got more out of it than the other meetings we have gone to. We managed to talk more about what we wanted to talk about.”*⁶ (a family member)

www.essexcc.gov.uk/vip8/ecc/ECCWebsite/dis/gui.jsp?channelOid=14181&guideOid=15001

Family Action – Rochdale Young Carers

This is a dedicated young carers service working with 80 families a year. This service also has experience of managing personalised budgets for young carers over 16. It is currently delivering a new Family Group Conference service across Rochdale for all young carers up to 21. This service also provides crisis planning and pre-assessment, which encourages communication between family members, and supports them to recognise the role they can take in managing their lives and turning negatives into positive opportunities.

www.family-action.org.uk

The Whole Family Pathway

Developed by The Children’s Society in partnership with the Disabled Parents Network and The Princess Royal Trust for Carers, the Whole Family Pathway is a resource designed to:

- encourage and support the effective implementation of interagency, whole-family assessments and service delivery at local practice levels; and
- promote joint working between adult and children’s services.

“Young carers do not care in isolation from the rest of their family. Although they need support for themselves, their needs should also be considered in the context of their whole family.”

www.youngcarer.com/pdfs/Whole%20Family%20Pathway%2010th.pdf

The Coventry Carers’ Centre: inclusive, whole-family working

“We work with carers from age five upwards, and are therefore able to look holistically at the whole-family situation and help the whole family to deal with the caring situation they find themselves in. We also have no artificial boundaries concerning the condition of the person who is being cared for. Many people have a variety of conditions that are categorised to different work streams in health and social care and which can impact on the support that carers receive, too. We work around the people involved, irrespective of service divisions, in a seamless way.

“We usually work intensively with an individual/couple/family for up to six sessions, during which time we aim to ensure that they are empowered to link into all the services they need to carry on caring, for as long as they choose to do so. This often involves bringing in other agencies from the public, private and third sectors. When required, we are flexible with respect to the number of support sessions. Carers are able to access the wealth of our other services – support groups, carers’ breaks, stress-relieving therapies etc – after the initial intensive work.” (Pauline Dye, Centre Manager)

www.coventrycarers.org.uk

⁶ Mutter, R., Judge, N., Flynn, L. and Hennessey, J. (2002) *Supporting people together: Family Group Conference in mental health services. Research findings and practice development*. Chelmsford: North Essex Partnership NHS Foundation Trust.

Working together to support young carers: a model local memorandum of understanding

Children and young people who care have the same rights as all children and young people, and those providing support and services should be pursuing the same outcomes for them. They should be able to learn, achieve, develop friendships and enjoy positive, healthy childhoods just like other children. Care services should be delivered in ways that sustain families, avoid the need to take on inappropriate caring roles and prevent further inappropriate caring.

The Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) have published a model text for a local joint Memorandum of Understanding between statutory directors for children's services and adult social services. The aim is to offer a firm basis for working together, and working in partnership with health and third sector partners, to support young carers. The document provides for variations to reflect local circumstances.

www.adass.org.uk/images/stories/MOU%20Working%20Together%20to%20support%20young%20carers.pdf

2. Early intervention and prevention

“We place a huge premium on efficient, effective and integrated service delivery alongside partnership working to support the contribution of individuals, their families, carers and the wider community – reducing the need for acute health and care support.”⁷

Caring is a universal activity. Much ‘caring activity’ is simply an integral part of the day-to-day lives of people who do not require any additional support to be able to continue with that activity outside of their own support networks. However, circumstances arise in all our lives which might potentially endanger our ability to continue, in the short or longer term, to provide such support, and it is at that point that people require easily accessible information, advice and signposting. The more widely this is available, the greater the chances that people will be able to find their own solutions to immediate difficulties. As such, universal services are the first line of prevention. Because many people are not aware of carers’ services, one important consideration is the need to communicate information in such a way that people who do not recognise themselves as ‘a carer’ can still access and use it.

A joint paper by ADASS and The Princess Royal Trust for Carers, *Supporting carers – early interventions and better outcomes* (2010)⁸, contains five key messages:

- Early intervention is integral to personalisation.
- Applying early intervention thinking to the support of carers can lead to better value for money and better outcomes.
- There is an evidence base to support the claim that carer support can create savings for adult services.
- Considering carer support in the context of major care pathways such as hospital discharge, falls, dementia and stroke could generate systems-wide efficiencies.
- Systematic information collection from service users and carers would improve both the evidence base and the investment of limited resources in health and social care.

In this context, providers of public services, such as transport, leisure, education, housing and health, and local employers and businesses, need to have a good understanding of the needs of carers so that they can tailor their approach to better meet them.

⁷ Putting People First Consortium (2010) *Think local, act personal: Next steps for transforming adult social care. A proposed sector-wide commitment to moving forward with personalisation and community-based support*

⁸ <http://static.carers.org/files/commissioning-better-outcomes-for-carers-may-10-5079.pdf>

Key practice points:

- Accurate, up-to-date and reliable information and advice is easily available from a broad range of sources to any member of the community who might require it to support them in their caring responsibilities and to help them make informed decisions.
- There is a programme of activity aimed at widening awareness and understanding of carers and improving responsiveness across the whole community, including services such as transport, leisure, education, housing, health, and local employers and businesses.
- There is a range of services and support that is available to all carers, regardless of their eligibility for, or use of other care and support services.

Practice example: providing early support to people experiencing difficulties maintaining their caring role

Kirklees Carers Gateway

Kirklees Carers Gateway sits inside the local authority's Assessment and Support team. It aims to stop carers rising up the tariff of care by early intervention and timely support. This has resulted in increased referrals for carer's assessments (almost a threefold increase) and a range of support being offered, including the use of direct payments. Through outreach in black and minority ethnic (BME) community centres, an increase of 57% in referral for assessment was achieved. 'Looking after Me' courses have been set up specifically designed for BME carers, including being delivered in alternative languages such as Urdu.

"I cannot praise enough the brilliant care and understanding that I have received from Mohammed. I have struggled as a full-time carer for seven years, without any support. Knowing that someone genuine and caring is there at the end of the telephone helps me to carry on." (Mrs S., Kirklees)

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Assessment/?parent=8214&child=8255

Carers Association Southern Staffordshire (CASS)

"CASS is very adaptable as an organisation and believes that if a caring role (no matter how small) is having a detrimental effect on the person who is 'looking after' someone with an illness or disability then they can gain our support... CASS as an organisation does not keep strictly to the 'time' criteria as each individual case is different and the impact caring has on each individual is different."

(Carers Association Southern Staffordshire)

www.carersinformation.org.uk/faq.ihtml

Birmingham: The Good Neighbour Centre, Quarterly Carers Support Evenings

This innovative African Caribbean mental health initiative provides carers with the opportunity to relax, reflect, and receive practical support which includes support to access necessary services and to know their rights as carers. It encourages sharing among Carers.

“We acknowledge that many people are caring for family members, relatives and or friends in one way or another and may not be aware of what support is available to them.”

thegoodneighbourcentre@live.co.uk

Practice examples: promoting carers identification and support in primary care settings

Tameside and Glossop: Joint Carer Champion training

“Carers see general practice as the ‘first port of call’ when they are helping to look after someone. All levels of general practice staff are in a key position to help identify carers, recognise their value and refer them for support.”

Joint Carer Champion training is a unique scheme offering integrated working that is valued by both staff delivering the training and those receiving it. Attendees get added value as professional barriers are broken down and together they share one aim – to support patients who are carers and patients who have carers.

The training is offered to all general practice staff on a rolling programme, and is suitable for all levels of general practice staff, including practice nurses and GPs.

Trainees are given the opportunity to look at current barriers and offered possible solutions, with best practice models being identified which can help them support their carers.

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Carerawarenessstafftraining/?parent=8217&child=8358

The Children’s Society Include Project, Hampshire: GP surgery pack

In response to requests from young carers that notice boards in GP surgeries display up-to-date information about support and resources for young carers and their families, a pack has been circulated to practice managers and GP partners to highlight the support needs of young carers which includes:

- a poster for display in the waiting area, with space for details of the local project/agency offering support to young carers or the nominated person in the practice;
- a poster for use on a staff notice board;
- a ‘quick checklist’ for supporting and signposting young carers;
- a leaflet for healthcare professionals, ‘Supporting young carers and their families’; and
- contact details for further information and training.

“I quite often go in with my mother when she goes to the doctor but they still don’t recognise that fact that I’m a young carer and still don’t pay attention or give time to that matter.” (Young carer)

www.youngcarer.com/showPage.php?file=1118349009.htm

Practice examples: providing information to people outside of health and social care

Employers for Carers

Employers for Carers is a forum for employers to help them retain the 1 in 7 employees in their workforce caring for a family member. It promotes the business benefits of supporting carers and provides advice and support on carer-friendly policy and practice. Employers for Carers can help businesses to remain competitive, with a healthy and productive workforce.

“Good businesses need good people. In the current economic climate, there has never been a more important time to focus on the benefits of retaining skilled workers rather than incurring the costs of recruiting and re-training new staff.”

www.employersforcarers.org/Home

Young carers at school

The Princess Royal Trust for Carers, in partnership with The Children’s Society, has produced Supporting Young Carers, a resource to help schools across the UK to develop a deeper understanding of the issues faced by young carers in order to support this vulnerable group of pupils more effectively.

“Young carers are supported more effectively through collaborative work amongst all staff... so please work hand-in-hand with your colleagues to utilise the ideas and to create and implement your action plans for young carers.”

<http://professionals.carers.org/young-carers/articles/schools-resource-pack,6282,PR.html>

3. Making self-directed support processes work for carers

Research is starting to show that self-directed support and personal budgets can have a positive impact on carers as well as on people using services.^{9 10} Personal budgets can contribute to greater independence for both the carer and the person they support, and enable carers to have a life outside caring.

The following are two short examples of how personal budgets and direct payments can produce positive outcomes for carers:

In Salford, Andrez juggles working full time as a fork lift truck driver with being the main carer for both his parents. Andrez's father has had a stroke and his mother has dementia. Andrez's hobby is to go deep-sea fishing, but owing to his caring responsibilities he hasn't been able to think about doing this of late.

By having a carer's assessment and the opportunity to think about what was important to him, Andrez received a personal budget as a direct payment to fund fishing tackle and expenses for trips.

In Lancashire, Sheila found it difficult to leave her home on a regular basis due to her caring role. She was keen to ensure that she remained the sole carer and that her husband did not go into traditional respite care. The 'Time for Me' fund provided the money for a new sewing machine. Sheila set up her spare bedroom as a workshop and began to develop her sewing skills. Eventually, friends started to ask her to make clothes or undertake repairs. This developed into a small business which is currently flourishing.

This section of the guide focuses on the processes of self-directed support. It identifies good practice in ensuring that these processes are personalised so that they are inclusive of carers and responsive to their needs. Five stages in the process of self-directed support are outlined as follows:

1. First contact
2. Assessment
3. Resource allocation
4. Support planning
5. Review.

⁹ Social Policy Research Unit, University of York (2008) *Evaluation of the Individual Budgets Pilot Programme: Final report*; Social Policy Research Unit, University of York (2009) *The Individual Budgets Pilot Projects: Impact and outcomes for carers*

¹⁰ Carr S & Robbins D (2009) SCIE Research Briefing 20: The implementation of individual budget schemes in adult social care London: SCIE

1. First contact

People come into contact with local councils and health services for a variety of reasons. Often the presenting issue is only a small part of the picture. This first contact provides an ideal opportunity to identify if people have caring responsibilities themselves, or if they have a carer, and to provide further information, advice, signposting or assessment. For local authorities, once the process of undertaking a community care assessment commences there is a duty to consider whether the person has any carers and, if so, to consult them if appropriate.¹¹ In particular, it is important to have processes in place to identify children and young people who are taking on caring responsibilities. Staff need to be ‘carer aware’, and there need to be systems and processes in place which ensure that appropriate questions are asked and that staff are knowledgeable about responding to enquiries for information or further help. There need to be proactive systems that outreach into the community, as well as reactive ones.

Key practice points:

- There is an ongoing programme of carer awareness-raising throughout the council, NHS and partners, which is helping to ensure that the importance and value of carers is recognised at all levels and throughout organisations in the local community. The programme includes senior management, leaders and elected council members as well as people on front-line services.
- There is an active approach to identifying carers and their needs at an early stage.
- Carers’ needs matter and are regarded as ‘everyone’s business’. Investment in carer-specific expertise and leadership helps to ensure this approach.

Practice examples: first contact

The Triangle of Care – Carers included: a guide to best practice in acute mental health care

Developed by The Princess Royal Trust for Carers and the National Mental Health Development Unit with carers of people using acute mental health services, the Triangle of Care describes a therapeutic alliance between the person using acute services, staff members and carers that promotes safety, supports recovery and sustains well-being. It suggests that six key elements are present for carers when a person receives acute care services:

- Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- Staff are ‘carer aware’ and trained in carer engagement strategies.
- Policy and practice protocols about confidentiality and sharing information are in place.
- Defined post(s) responsible for carers are in place.
- A carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway.
- A range of carer support services is available.

¹¹ Department of Health (2004) *The Community Care Assessment Directions 2004*

“Success in achieving change depends upon staff becoming willing ‘champions’ for better partnership working and being able to challenge practice that excludes carers. A more inclusive attitude for carers and families should be promoted, where they are listened to and really heard and consulted more closely.”

<http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html>

The South West London and St George’s Carers, Families and Friends Strategy 2010–13

This strategy was developed by listening very closely to people’s stories. The issue of stigma in mental health came over very strongly as an inhibitor to getting on with one’s own life. This can be overcome by both practical and emotional support: advice on getting back to or keeping work; advice on how to communicate effectively with health professionals to feel more assured about the care being provided; and training staff and holding them to account to Quality Standards that at their heart see carers, families and friends as people in their own right with strengths and entitlements to services and common courtesy.

www.swlstg-tr.nhs.uk/uploads/documents/publications/carers_strategy.pdf

2. Assessment

There are two main aspects to assessment that are important to carers. There is the assessment of the person needing support and there is the assessment of the needs of the person with caring responsibilities. It is important that, while the individuality of the people concerned is respected, the interdependencies of achieving the desired outcomes are also recognised. A whole-family approach (see section 1 of this report) is more likely to achieve effective and sustainable outcomes. Working with carers as partners and taking a collaborative approach enables the contribution of carers to be a positive element in working towards a support plan and not a punitive method of reducing payment. The facilitative skill is to listen to all parties, resolve potential conflicts and arrive at a mutually acceptable plan that takes the needs of carers into account.

It is very important that no assumptions are made about the willingness or ability of carers to continue with support. *“Inappropriate assumptions about how much support carers are willing and able to provide can lead to an underestimation of eligible needs.”*¹²

It is also important that there is an assessment of the carer’s own needs¹³ so that they have an opportunity to look at how caring is affecting them and how they can look after themselves and have a life outside caring, including looking at work, training and leisure opportunities.

¹² Department of Health (2010) *Guidance on eligibility criteria for adult social care 2010*

¹³ Section 1 of the Carers Equal Opportunities Act, 2004, places a duty on social services authorities to inform carers of their right to a carers assessment.

These two assessments should normally take place concurrently so that the carer's assessment can inform the community care assessment (as required by the Carers (Recognition and Services) Act 1995). Bringing the two assessments together as routine has the advantage of ensuring that carers' needs are looked at in all instances and become a matter of concern for all care managers. Referral to a specific carers' organisation or specialism can be appropriate for some carers and, while it may be appropriate for individuals to have private time for discussing their needs, the assessment process should always be co-ordinated. Whole-family approaches are appropriate in many circumstances. The Princess Royal Trust for Carers, in *Putting people first without putting carers second*, makes the following point:

*“Where families wish to, they should have the option of being assessed for eligibility as a whole family, rather than having to negotiate separate assessments and eligibility for each individual.... For most, it would be easier to achieve a package that tackled all of their needs in a coherent way.”*¹⁴

Key practice points:

- Carers are routinely involved in the assessment of the person needing support to provide their expertise and knowledge and their views of what works what does not. Carers are always asked which, if any, aspects of caring they are happy to continue with or not.
- Carers are made aware of the opportunity to have an assessment in their own right, even where the person they care for does not wish to have a community care assessment.
- Carers' assessments put carers in control through self-directed approaches, with access to support or advocacy as required.
- Young carers can benefit from specialist (age appropriate) assessment.
- Approaches to assessment are co-ordinated and information resulting from separate assessments is brought together by care managers to help inform support planning and identify those carers providing high levels of support.
- Systems are in place to ensure that assessment can take place in a timely way.
- Assessments of carers look beyond the caring role to consider the carer's needs for employment, training and a life beyond caring.
- Risks to carers of sustaining their caring role are always considered when making decisions on eligibility for community care services.

¹⁴ The Princess Royal Trust for Carers and Crossroads – Caring for Carers (2009) *Putting people first without putting carers second* <http://professionals.carers.org/health/health-and-wellbeing,808,PP.html>

Practice examples: Assessment

Surrey: developing personal budgets with carers

Surrey County Council has developed its arrangements for personal budgets with the involvement of carers throughout. As a result, the carer's assessment has been embedded in the main Supported Self-Assessment to ensure that these are routinely undertaken. It also reinforces the right of carers to be consulted in the service user's assessment and other statutory obligations (e.g. information provision, eligibility criteria that include risk to carers).

www.carersnet.org.uk/sds/budget.html

Torbay: self-assessment

Torbay Care Trust wants to encourage carers to receive appropriate support as easily as possible. One way is through self-assessment, either on their own or with support. Torbay's self-assessment form includes both an assessment of needs and some information about how to meet these needs. Carers only need to fill in as much as is useful to them. Self-assessment is seen as an ongoing process, not a one-off event.

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Assessment/index.cfm?rateContent=8B048EFECBE64FE76045E0109DE0C2F1&score=4&cid=0&parent=0&child=0

Lincolnshire: trusted assessors

Carers in Lincolnshire said they want easier access to assessment and choice of who assesses them. In response to this, the Council developed a system for training people in the voluntary sector as trusted assessors for carers. This helps to widen access and speed up response times. Each completed assessment is checked by the Council and consistency, quality and outcome are assured through a telephone assessment of carers' experiences and sampling of completed assessments.

The assessment process is outcome focused and was developed with carers, who mapped the questions under seven outcomes that carers identified as being the most important to them.

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Assessment/?parent=8214&child=8494

3. Resource allocation

Resource allocation is about deciding the amount of funding to provide for people. Resource allocation systems (RAS) are the systems that councils use to determine the indicative amount of money for the personal budget.

Once an assessment of a person's needs take place, a council will take into account the availability of support from carers in the process of determining the final resource allocation. However, it must ascertain that the carer is both willing and able to continue to provide this support before adjusting the allocation. There needs to be a well-understood and consistent way of allowing adjustments to the indicative budget.

There are further allocations of resources that can be made to carers in their own right. These can come from health or council funds and are sometimes pooled. In all cases of resource allocation there should be a fair and transparent system.

Key practice points:

- The Supported Self-Assessment Questionnaire asks both what is the extent to which support is available to meet the service user's needs *and* whether the providers of this support are willing and able to continue doing so.
- There is a question and adjuster relating to each personal care question/domain. This allows greater flexibility to relate support to individual domains of need, enables the views of the carer/s to be more accurately understood, and enables the collection of useful information that can be used at a later date.
- The local mechanism for adjusting the resource allocation takes into account the availability of support, and the willingness and ability of carers to continue to provide this support.
- Adjustments to the resource allocation based on the carer's willingness and ability to provide support are not applied until after a carer's assessment, and the process ensures that resource allocation systems cannot be signed off until a carer's assessment is available.
- No reductions are made to resource allocation on the basis of support provided by carers aged under 16 and careful consideration is given to the level of involvement of carers aged 16-18 in order to protect their rights as young people.
- There is a transparent and equitable system for allocating resources for support required by carers in their own right, to enable them to maintain their caring role. The system is proportionate and does not involve overly time-consuming or bureaucratic processes.
- There is maximum choice and control in the use of resources for carers. Specific resources for carers are allocated as personal budgets where appropriate and wherever possible carers have the option to receive direct payments.

More detailed information on resource allocation systems can be found at:

www.puttingpeoplefirst.org.uk/Topics/Browse/Finance/Resourceallocationsystems/

Practice examples: resource allocation

London Borough of Richmond's assessment process

Richmond's new assessment process has more emphasis on the carer. It incorporates the following:

- Identifying and understanding the contribution of carers to meeting a service user's needs, along with how much care they are able to and willing to commit to providing on an ongoing basis.
- Understanding the carer's contribution and how that is calculated towards the support the service user requires as part of their RAS.
- Understanding the amount of support and/or resource a carer needs to ensure that they are able to maintain their caring role.

Carers are involved in the assessment of the person they care for along with all relevant parties. The carer's assessment ensures that the need of the carer is also taken into consideration, and the identification of young carers is included in this assessment. Carers are also included in the development of support planning for the service user. There is a carer's RAS for allocating specific resources to ensure support to carers to balance their role with pursuing a life of their own. Breaks for carers are included within the service user's RAS.

<http://www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Assessment/?parent=8214&child=8493>

Surrey Supported Self Assessment and Resource Allocation System

In Surrey, the Supported Self Assessment and Resource Allocation System captures information about the support that the carer needs to continue to care on an ongoing basis. The main RAS looks at substituting for support from the carer (paying for the carer to have some time away from caring). The personal budget for the service user will therefore often include a specific amount to help carers support the service user (sharing the care to sustain the caring situation). However, it does not provide (give points) for things that promote the carer's social inclusion or make financial allocations to address carers' one off needs. Resources for this can be allocated separately through a carer's personal budget. There is also discretion to transfer all or part of a Community Care Service to the carer as a 'Carers Service' where this is not being used for intimate personal care. The guidance emphasises that, where a full Supported Self Assessment is being undertaken, assessors should discuss with the family the use of any element within the main RAS identified for a carer's needs.

www.carersnet.org.uk/sds/pb.pdf

4. Support planning

Once people know how much money they have (resource allocation), a support plan needs to be developed that describes how they want to spend it. The local council will need to agree that the support plan meets the eligible needs and is in line with achieving the agreed outcomes (or personal goals) that the person wants to achieve. The growing number of people who are using their own money (as self-funders) may have particular difficulty in identifying reliable sources of information and advice. They may find support planning particularly useful when making decisions about the most appropriate and affordable local options for care and support for their relative. Support plans can be made for the person

receiving support and for the person providing it. Support plans are more likely to work well when they are co-ordinated and when a whole-family approach is taken. There are interdependencies between a carer and the person they support, so it is important to make sure that arrangements and plans do not have unintended consequences. Often small changes can make a plan produce better outcomes for everyone following discussion and negotiation with those concerned. Pragmatic solutions are often more effective and a more efficient use of resources than prescriptive approaches.

Key practice points:

- Support planning takes into account the needs of both the person needing support and the carer so that there is an integrated approach that makes best use of resources and delivers effective outcomes for everyone involved.
- Where appropriate, services and support needed to sustain the caring role are included as part of the personal budget of the person requiring support.
- Support planning for carers includes problem solving, information and advice. These are available to carers regardless of eligible needs.
- No assumptions are made about the willingness or ability of carers to take on responsibilities of managing the money, employing staff, procuring support or services etc, and there is a range of good support options available to assist with this.
- Carers are given information and advice on the range of good support options available to assist them and have a choice as to the level of responsibility they wish to exercise.

Practice examples: support planning

Hounslow: effective outcomes through taking a whole family approach to using a personal budget. Mr Aslam was involved in a serious road traffic accident that resulted in a brain injury. He has been left physically disabled and unable to communicate. He is completely reliant on others for all his care needs. His wife does all his care for him as she does not want anyone else to do his personal care; she has tried paid care workers in the past but did not like them. Now with a personal budget the council is supporting Mrs Aslam in her caring role as well as meeting his outcomes. The support plan was agreed as part of a best interest decision. As well as specific activities to meet Mr Aslam's outcomes, the support plan was written with a whole family approach and included:

- private English lessons in the family home for Mrs Aslam to enable her to communicate with other agencies on behalf of the family;
- a taxi to take their 3 young children to school and back, as Mrs Aslam finds it difficult to do this and care for her husband;
- saving for a family holiday instead of Mr Aslam going to respite whilst the rest of the family go away.

Crossroads Care, Oxfordshire

This brokerage service provides a holistic, whole-family approach, supporting individuals and their carers to use their personal budgets to maintain their family life by recognising that each has their own needs for support.

“You have given my son’s life back. Since his brain injury he was sat at home; now he goes to the gym, for long walks, swimming and is enjoying life to the full. Your personal assistants are wonderful – I have a break when he is out for eight hours at a time to do what I want to do.”

“Mrs L phoned – she had a wonderful break and her husband had a fantastic time going to music therapy, something she was too tired to do. She had her hair done... never known anything like this service before.”

www.oxfordshirecrossroads.org.uk

Carers Gloucestershire: volunteers

Carers Gloucestershire has proved a cost-effective and accessible mechanism to support carers. Carers Gloucestershire has been able to attract other funding and has a volunteer workforce to support its delivery. This helps to give added value to the investment from the public sector and includes their Advice and Advocacy Service, which provides help such as:

- working alongside the carer to find the best possible solution;
- exploring all possibilities;
- writing letters or making phone calls on the carer’s behalf; and
- attending meetings with the carer and speaking on their behalf if they so wish.

www.carersgloucestershire.org.uk

Carers FIRST, Kent

Kent has adopted a carer-led model of support for carers. Carers FIRST is an independent, charitable organisation supporting and helping carers with funding support from Kent Social Services and other sources. Carers FIRST aims to give comprehensive help to all carers, through access to information and resources, discussion, advocacy, one-to-one support, and groups where they can meet other carers in similar situations. It also provides young carers with support groups and activities, as well as a befriending service for carers and older people.

<http://www.carersfirst.org.uk/?page=home>

5. Reviews

An outcome-focused review is part of the self-directed support process. It is a way of carrying out reviews that puts the main focus on the results being achieved for the person being cared for and their family. The purpose of an outcome-focused review is to:

- review progress in using a personal budget to achieve the outcomes set out in the person's support plan;
- share learning about what has been tried and has worked or not worked;
- identify next steps to achieve these goals;
- update the support plan;
- make clear if the person's support needs, or the carer's willingness and ability to provide previously agreed support, have changed; and
- help the council to check if the person is still eligible for social care.¹⁵

It is important that reviews focus on both the person in need of support and the person providing it. Responding to a carer's needs may require a change in the support plan of the person who receives care, for example:

- additional support if a carer is not able to continue with a previous or assumed level of caring; or
- other changes to accommodate a carer's needs where the individual's support plan impacted adversely on the carer, and the changes can be made in line with the individual's wishes.

Carers with their own personal budget should have specific reviews of how well agreed outcomes are being met. Information from reviews can help to inform commissioning plans and improve provision.

The situation of carers and those they support may change dramatically between one review and another. In some cases major transitions may happen between reviews – for example, a young disabled person who leaves education and moves to adult services or a person whose long-term condition changes significantly – and outcomes about independent living may need to be adjusted in the context of end of life care.

Key practice points:

- There are systems in place to review carers' needs and respond to changes, and to react to emergency situations.
- Carers' needs are routinely reviewed alongside the needs of the person they support, or more frequently if required, using an outcome-focused approach.
- Carers' needs are an important part of the review stage of the person they support.
- There are systems to assess demand and gaps in provision for carers. Information on the choices, spending patterns and outcomes of carers with personal budgets is collected to inform commissioning and improve provision.

¹⁵ Bennett, T., Cattermole, M. and Sanderson, H. (2009) *Outcome-focused reviews: A practical guide*. London: Department of Health www.supportplanning.org/Support_Planning_Downloads/OutcomeFocusedReviews2.pdf

Practice example: reviews

Islington Carers Centre (ICC)

ICC has recently started a transition project for young adult carers aged 16–25, which is sponsored privately. This project aims to introduce young carers to adult services by providing information and activities in a way that is age appropriate. This user-led group is part facilitated by a paid worker. Services include access to the ICC internet café, information and advice on hand, mentoring, a legal advice service (in planning), social trips, peer group support, training opportunities, and access to grants and hardship funds.

www.islingtoncarerscentre.org

4. Market and provider development

Giving people more choice and control through personalisation means that councils, with their partners, need to move away from traditional block contracts, increasing the number of personal budgets and the use of direct payments to manage all or part of them, and supporting the growth of a market in the services that people want. In response to this, the market and providers need to ensure that a range of quality, personalised support is available.

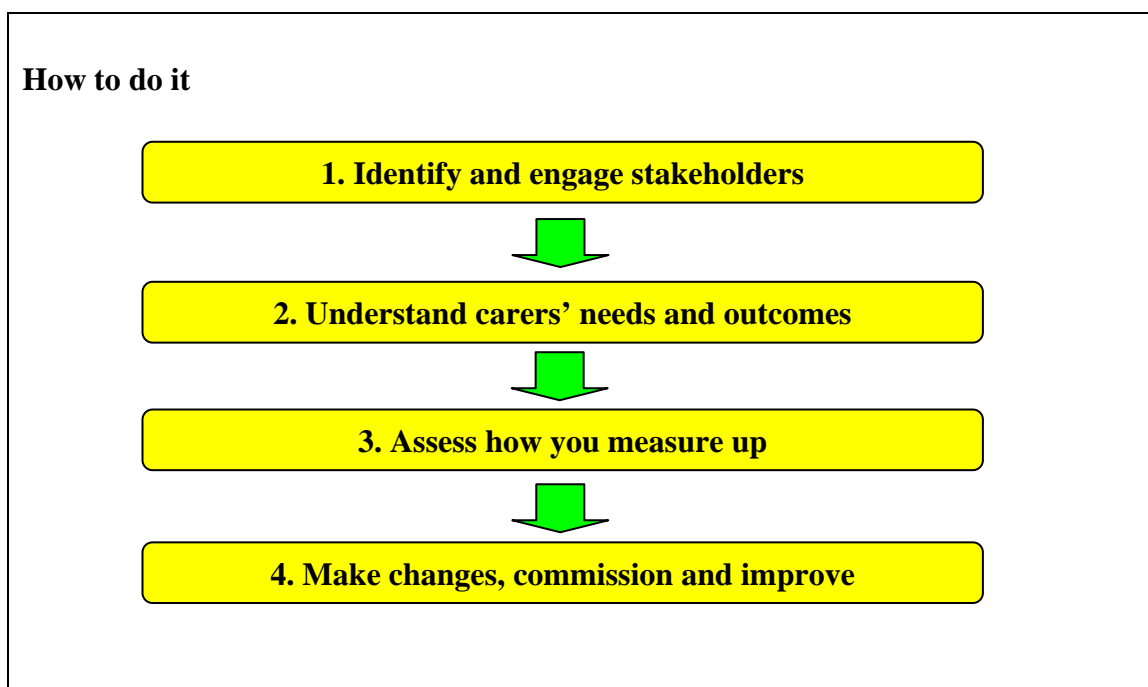
The new partnership agreement *Think local, act personal: Next steps for transforming adult social care* identifies the critical role of market and provider development in ensuring that a range of quality, personalised support is available. It states that councils should:

Facilitate a broad range of choice in the local care and support market, including housing options, and personalise the way in which care and support services are delivered wherever people live.

In 2010, ADASS and The Princess Royal Trust for Carers published *Commissioning better outcomes for carers – and knowing if you have*. This paper encourages commissioners, and consequently providers, to focus on the following question:

How will you, carers and people more generally know if you have improved outcomes for people who give and receive care and support?

This paper offers a simple model to help local commissioners, working in partnership, to respond to this:



Carers' leads and personalisation leads have a joint interest in promoting these ways of working. The information gained in this way, if collected consistently and systematically, can help councils to identify local needs and make better use of resources.

Key practice points:¹⁶

- There is strong engagement of carers in setting the direction for local commissioning and service development and in holding the commissioning authority to account. Information on carers is included within Joint Strategic Needs Assessments.
- The development of a sound, co-produced evidence base about the needs of carers, the choices they would like to make in meeting those needs and how effectively they are achieving their desired outcomes. Gaps in market provision are identified and communicated to suppliers and local people.
- There are constructive relationships with providers about carers' needs, based on a shared view of the outcomes to be achieved; a common understanding of any constraints and an equitable distribution of risk; and making targeted support available to suppliers to help them to adapt and respond, while developing a local infrastructure that supports carers to have choice and control.
- There is a well-publicised range of person-centred support for carers in the local community from many different providers, enabling carers to have maximum choice and control about how agreed outcomes are met.

Practice examples: market and provider development

Adults Supporting Adults (ASA) Lincolnshire At Home Day Service for people with dementia

This service, established with Carers' Grant funding, provides support from 10am to 3pm, delivered in the provider's home and the local community. The ASA matching process ensures that provider and client(s) are compatible, with one provider supporting up to three people at a time, depending on people's needs. Some people use the service to maintain skills such as cooking, gardening, or simply eating together and using cutlery. Isolated older people welcome the manageable social experience in a consistent, familiar setting.

The service also provides a break for family carers. One family member used the time to change her mother-in-law's bed – if her bed was changed while she was at home, she thought it was being stripped in readiness for her to leave. Family carers and providers use a communication book to share information about any issues and to share the clients' activities during the week, which assists conversation when the client returns home.

The service is offered to clients with mild to moderate dementia, but clients often build up a rapport with the provider, which means that support can continue as their dementia progresses, in one case for eight years. All providers receive training in moving and handling, basic first aid and dementia awareness,

¹⁶ For more information see Department of Health (2010) *Practical approaches to market and provider development*

which is Alzheimer's Society and Skills for Care approved. All providers, who are self-employed, are Criminal Records Bureau checked, as are any family members who will be involved in support. Providers are insured and their homes are health and safety checked. They receive monthly supervision and are re-approved every two years through the panel process.

www.naaps.org.uk/en/small-community-services/

Book Your Own Breaks, Hertfordshire

Book Your Own Breaks is a partnership between Hertfordshire County Council, Slivers of Time, Crossroads Care Hertfordshire and Carers in Hertfordshire. The project enables carers to book care workers on line at anytime, and to get the particular support worker they want at the time and location of their choosing without having to deal directly with payment and administration.

As the site effectively shows carers their available budget and actual cost of the care, they are able to monitor and track their own expenditure against allocated budget with minimal paperwork required. Following a successful first six months, it is also being piloted in children's services for parent carers, and being taken up by other councils.

"This booking puts me back in control of my life and is a huge support" (carer)

"I'm not very computer literate; however the system is easy to follow" (carer's support worker)

www.bookyourownbreaks.com/

Carer Relief Service, East Riding

East Riding's Carer Relief Service includes three services, all of which support carers in East Riding. These are the Carers Emergency Cover, Carer Relief Sitting Service and Flexible Breaks Service. Bringing together these three services under one management structure provides greater efficiency and effectiveness. The Carer Relief Service is tailored to the individual circumstances and needs of the carer. It offers more choice, independence and control with the aim of improving well-being.

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Opportunities/?parent=8215&child=8331

Carers' emergency card schemes

Carers UK conducted a snapshot survey of local authorities and found only about 30 such schemes out of 150 local authorities in England. Skilled workers assist the carer to draw up their emergency plans. The plans are held by the scheme, which provides a 24-hour response service. Carers carry a card with the scheme's telephone number and a unique PIN to avoid any personal details appearing on the card. If an emergency arises, the carer or someone with them calls the scheme, which can then arrange replacement care based on the plan.

An example of a carers emergency card scheme is North East Lincolnshire's Carers Emergency Alert Card scheme, which also shows how additional benefits can be linked to the card.

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/Opportunities/?parent=8215&child=8330

Acknowledgements

This document was written with help and advice from members of the Department of Health Carers and Personalisation reference group:

John Bangs – Commissioning Manager (carers) Surrey County Council

Nasa Begum – Principal Advisor Adult Social Care Social Care Institute for Excellence

Gordon Conochie – Joint Policy & Parliamentary Officer, The Princess Royal Trust for Carers & Crossroads Care

Viv Cooper – National (Complex Needs) Families Lead (Office of the National Director for Learning Disabilities)

Helen Dorr – All Together Better graduate

Elaine Edgar – Head of Policy, Carers Team Department of Health

Lynne Elwell – National Co-ordinator Family Leadership, in Control

Moira Fraser – Director of Policy, The Princess Royal Trust for Carers & Crossroads Care

Michael Hake – ADASS Carers Policy Network

Carolyn Heaney - Deputy Regional Director Yorkshire & Humber, Social Care & Local Partnerships
Department of Health

Emily Holzhausen – Director of Policy and Public Affairs Carers UK

Vicki Raphael – National Valuing Families Forum

Dame Philippa Russell – Chair, Standing Commission on Carers

Kate Sibthorp – Partners in Policymaking, in Control

Cally Ward – National Families Lead (Office of the National Director for Learning Disabilities)

Contributions, advice and information also came from many other people including carers and people working with carers.

There has not been space to include all the examples in this document so more can be found at:

www.puttingpeoplefirst.org.uk/Topics/Browse/Carers/