Putting People First without putting carers second
Can greater choice and control be offered both to people requiring care and at the same time, to those relatives or friends who care for them?

Personalisation is now the driving agenda for adult social care and *Putting People First* recognises that increasing numbers of ordinary people will be called upon to contribute to care delivered in people’s own homes. Of the UK’s six million carers, 1.3 million are already caring, unpaid, for over 50 hours a week. Carers have always wanted better outcomes for the people they care for. However, with many carers suffering poverty, ill health and isolation due to unsustainably heavy caring roles, they also want and deserve better outcomes for themselves.

This Report has been produced by The Princess Royal Trust for Carers and Crossroads Caring for Carers, with support from the Local Government Association, NHS Confederation, The Improvement and Development Agency and the Association of Directors of Adult Social Services (ADASS). It examines the challenges local councils and health trusts face in making personalisation a reality for carers alongside those they care for. It also highlights a range of solutions that are already in place to meet those challenges, often involving inspirational partnerships between Third Sector carers’ services and innovative commissioners within councils and the NHS.

Some of the “high impact” ventures covered in this document:

- Supporting carers to manage personal budgets in the North East.
- Home-based mutual interest groups in Redbridge that also give carers breaks.
- Online self-assessment processes for carers in Kent.
- Supporting carers in employment across the North of England.
- GP-based carers support services in West Sussex.
- A Care Passport produced by hospitals and the carers service in East Sussex.
- Partnerships with housing associations, libraries, Fire Services and Drug and Alcohol Teams (DAATs).
- Recognising that service users from Black and Minority Ethnic (BME) Communities may not be benefiting from services making the additional impact of the caring responsibility higher for BME Carers.

Discussion points for commissioners:

- How can we deliver the *Putting People First* commitment of providing a universal, joined-up information and advice service to all individuals and carers?
- How can we ensure the development of independence of both the cared-for and the carer?
- How can we ensure that information regarding carer entitlements reaches the most isolated?
- What must adult services have to do to meet the *Putting People First* commitment that ‘no parent has to rely on care provided by their children’?
- What kinds of support and breaks do carers want?
- How can we ensure there is a range of providers to meet the needs of all communities?
- How can we ensure that carers retain their choices, including the choice to reduce caring or maybe stop altogether?
- How can commissioners support the Third Sector to sustain effective identification and inclusion, and early intervention services?
- How can we help more carers take up Direct Payments and personal budgets, whilst still giving them the choice to receive a more traditional service?

Our messages for the review of adult care and support:

- We must explore how personalisation can be applied to whole families and communities, as well as to individuals, thus establishing new partnerships between the person receiving care, carers and professionals.
- We must investigate how the personalisation agenda has impact on the interfaces between services, and, in particular, what it means for the NHS.
- We must develop an understanding of how to personalise information provision, alongside the well developed models of personalising support services.

The Princess Royal Trust for Carers
Crossroads Caring for Carers

We are grateful for the support and advice of:

Association of Directors of Adult Social Services
Carers UK
The Department of Health
The Local Government Association
The National Black Carers and Carers Workers Network
The NHS Confederation

The Princess Royal Trust for Carers and Crossroads Caring for Carers would like to thank the Department of Health for their support in developing this document.

This document should be read alongside the discussion points for commissioners produced by Association of Directors of Adult Social Services (ADASS) with support from all the partners above, *Putting People First and supporting carers some key messages for local leaderships* available as a download from www.adass.org.uk/images/stories/PPF%20local%20services.pdf and www.carers.org/professionals
The Princess Royal Trust for Carers and Crossroads Caring for Carers

The Princess Royal Trust for Carers – What do we do?
The Princess Royal Trust for Carers’ mission is to make a positive difference to the lives of carers. The Trust is the largest provider of comprehensive carers support services in the UK. Through a unique network of 144 independently managed carers’ centres, 85 young carers services and interactive Websites, the Trust currently provides quality information, advice and support services to almost 364,000 carers, including over 20,000 young carers.

Each of our carers’ centres are independent charities that deliver a wide range of local support services to meet the needs of carers in their own communities. All carers’ centres provide, either by telephone, drop-in or outreach surgeries: information and advice about all issues affecting carers, including benefits and carer assessment procedures; emotional support with staff, trained volunteers and other carers; and community consultation to ensure that carers have a strong influence on local policy, planning procedures and outcomes.

The Princess Royal Trust for Carers and our network of carers’ centres work together so that carers’ voices are linked to regional and national decision making bodies. The Trust uses research and data held by the network on carers to make the case for carers’ services and instigate change. We use our considerable experience and the expertise and knowledge of the network to pilot new more flexible ways of delivering services, actively demonstrating how these can be used in different parts of the country.

As well as working in partnership with the network of carers’ centres and providing a range of flexible services at a local level, the Trust works in partnership with UK-wide statutory and voluntary organisations, such as the Royal College of General Practitioners, to achieve its aims.

Crossroads Caring for Carers – What do we do?
Crossroads Caring for Carers has two main roles - the first is to support the network of Crossroads schemes so that they are able to develop and deliver services to carers and their families. This support includes advice and guidance on service issues, policies and procedures, insurance, training and quality assurance. Our second area of work is to make links with other organisations and the government in order to strengthen support for carers. We aim to broker national partnerships that result in more service delivery at a local level and to contribute to the development of legislation and policy that might impact on Crossroads schemes and on carers.

Crossroads Caring for Carers has 120 member schemes throughout England and Wales providing over 4.6 million care hours every year to more than 35,000 carers and 35,000 people they care for. Every scheme provides practical support where and when it is most needed - usually in the home. A trained Carer Support Worker will take over from the carer to give them “time to be themselves”. We talk to the carers about how often they would like us to visit, how long the visit should be and at what time they would like our support provided. They then have “time” to use as they wish – to see friends, keep appointments, study, read or even just to sleep. Many of our schemes provide additional services including young carers’ projects, holiday play schemes for disabled children and care for people who are terminally ill.

A Crossroads service is about giving time - improving the lives of carers by giving them time to be themselves and have a break from their caring responsibilities. Our aim is to provide a reliable service, tailored to meet the individual needs of each carer and the person they are caring for. We have schemes in most parts of England and Wales, which provide a range of services to meet local needs.

“Putting People First without putting carers second”
Case Studies

01.
An older couple in the North West have an adult daughter (47) who has Downs Syndrome. This family have had very little help from social services since their daughter was born, but have recently needed a care worker for her due to her father’s blindness and the mother developing Transient Ischemic Attacks or TIAs, (commonly known as mini-strokes) which can require emergency hospital admissions. An agency was supplying a care worker, but this was often a different worker each day, leaving both daughter and mother anxious. A Direct Payment allows the family to employ a worker and the daughter is now very settled and not at all anxious, which in turn means that the parents are much less worried. The Carers’ Centre is now attempting to obtain Direct Payments for the father in order that the mother can get more rest and access carers’ support services.

02.
S, who uses services in the East of England, attended five days at the Community Resource Centre doing a variety of activities, 70% of which was on site. S was approached about having Direct Payments and told about the control and the freedom that he would have to do what he liked. By the time the family were told about the proposal, S was so enthusiastic about it that his family felt obliged to agree.

Now that the new system is in place and an assistant employed to help support S with activities, it transpires that the resource allocation cannot pay for five days a week. This means that S’s mother, Mrs. B has had to reduce her hours at work to be with him on a Friday. The family also has to stand in if the Support Worker is off sick, on holiday and so forth. They feel that there is no back up.

The family agree that S is now having wider experiences and a more active life, but the impact on them as family carers has not been considered. They are disappointed that their choices were not taken into account. Direct Payments were meant to encourage independence. They expected a reduction in responsibility rather than an increase.
What is personalisation?

Personalisation, as set out in the government’s concordat, Putting People First, develops the concept that offering choice, control and independence to everyone who uses services is one of the best ways of ensuring the individuals’ changing needs and wishes are met. Services should be designed and offered to respond to people’s needs rather than people having to fit in with a standard service offering. People will only be able to make choices if they are well informed, so, crucially, Putting People First advocates a “universal offer” of advice and information for carers as well as for those requiring care, whether or not they are likely to be eligible for state-funded support.

Where possible, people, their families and communities will be helped to be self-supporting. This will mean helping people to become experts about their health condition. It will also require support for communities to include and value those with long-term conditions. People can take control of their health more effectively before they reach crisis, so Putting People First contains a strong message about offering support at the earliest possible stage.

In practice, personalisation can mean:

- currently excluded groups and communities being reached and involved in developing an area’s services;
- a family getting more help and guidance to understand every stage of the care system and find their way through the “care pathway”;
- a focus on achieving personal goals, sometimes through offering services not traditionally seen as “social care”, or through pooling budgets from a number of different sources such as social care, housing, welfare and perhaps in the future, the NHS;
- having the choice to receive a cash “Direct Payment” or control of a social care budget instead of receiving the social care service that money would traditionally have been used to fund;
- receiving intensive help to regain independence after a stay in hospital, followed by low-level support to stay independent and living at home.

Whilst personalisation offers more flexibility to individuals, local government reform is giving local councils and health trusts more flexibility as well. Local areas are being encouraged to focus on local need identified through risk assessments that give ordinary people a voice. Agencies are asked to think beyond their traditional client group and look to the impact on the whole community. The divisions between council departments, and between councils and health trusts, are being broken down, with budgets no longer ring-fenced by central government. To this end, the NHS is piloting personal budget approaches.

These two sets of reforms could mean a complete change in our understanding of what social care is and how it’s delivered. However, this is being implemented in the context of tightening budgets, and concerns about the way that current eligibility criteria excludes increasing numbers from accessing council-provided social care. So these reforms bring both risks and opportunities that don’t just affect people who need support, but also their families and communities.

Who are carers?

Carers provide ongoing unpaid care for a relative or friend who cannot manage on their own due to disability, serious illness, old age or substance misuse.

- There are almost six million carers in the UK – one in ten people.
- 2 million people move in and out of caring each year.
- 1.2 million care for over 50 hours a week.
- 42% are men, 58% women. 175,000 are children.

There are particularly high incidences of caring in some black and minority ethnic communities, but lower access to support. For instance, almost twice as many Pakistani women are carers when compared to the national average.

Unpaid carers already provide more care and support than the NHS. Over the next three decades, the number of carers will increase by around 80% or 3.4 million carers. In this way, we will rely increasingly on ordinary people to deliver the ambitious reforms set out in Putting People First.

Carers welcome greater choice and control

Carers are a significant and diverse group who care because they want the best for the person they are helping to support, and welcome services that offer their relative, partner or friend a more tailored, flexible and responsive service. Whilst carers want their relatives to be able to achieve their independent living goals, some of the policy development around independent living risks overlooking people, such as many older people with dementia, whose goal is to live with dignity in a family unit. Independent living need not always mean living alone.

Where a person’s goal is to live independently of family care, that goal should be the focus of support services. There will be occasions when the wishes or needs of different family members appear to be in conflict and, in those cases, children and vulnerable adults must be supported to have their voices heard and their rights protected. Skilled and flexible practitioners demonstrate every day that the care and support system can encompass all kinds of personal and family circumstances. We should not aim towards a system that works only for the young disabled person who wishes to live in their own home or only for the elderly person with dementia who wished to be cared for by their family, but towards a system that works for both these kinds of choices. In both cases, the choices of the person needing care should be supported and realistic solutions put in place, without assumptions being made about either what is best for them or what care their families can and are willing to provide.

It is encouraging that Putting People First recognises that supporting carers is at the heart of delivering personalisation, or indeed any affordable system of social care.
“In the context of changing family structures, caring responsibilities will impact on an increasing number of citizens. Examples include an eighty-year-old woman having to cope with her husband’s dementia, a young mother pursuing a career and bringing up a family while looking after her elderly parent, a business executive working overseas whose widowed mother is hospitalised overnight following a stroke and older parents seeking for the right support to ensure their adult son with a learning disability can live independently.”

A key goal in *Putting People First* is for “family members and carers to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life. Programmes to be supported which enable carers to develop their skills and confidence.”

The Prime Minister’s New Deal for Carers, with a ten-year carers’ strategy launched in June 2008, contains a range of positive spending commitments and pilots, aimed at finding out how to improve support for carers. Its aspiration is to recognise carers both as expert care partners and as individuals in their own right who aspire to work, education and leisure. However, much of its success will depend on local areas recognising the importance of the New Deal in delivering the wider agenda of modern, personalised and sustainable adult care and support services.

With any bold new reform, energy and commitment is needed to push forward change. This must be balanced with the flexibility and thoughtfulness required to avoid “throwing the baby out with the bathwater”. The following chapters aim to offer inspiration to sceptics and food for thought for zealots. Through this balance, it is hoped that every area of England can follow the lead of the carers’ services and commissioners that are already demonstrating how to put people first, without putting carers second.
No reform of adult care and support will be judged a success by the people it affects if it cannot deliver health and peace of mind. We know that large numbers of carers currently suffer ill-health and damaged well-being through caring:

- More than 80% say caring has damaged their health.
- Three out of four are worse off as a result of caring.
- In Leicestershire, 3% of carers reported that they had lost their homes as a direct result of caring.
- If reflected nationally, this would equate to 177,000 carers.
- More than half have given up work to care.
- On average, carers retire eight years early, missing out on years of income and pension contributions.
- Half also pay for equipment/care for their relative due to inadequate disability benefits.
- 14% of carers have had an assessment which led to a change in support or services.
- 28% of young carers have problems in secondary school.
- 12.5% of young Pakistani and Bangladeshi men combine work and caring (compared to 5% young white men). Twice as many Pakistani women as the national average are carers. Families in these communities are significantly more likely to be on low incomes than white households.

Carers have had to fight over many years to gain some recognition as “partners in care”, and too often they are still left with all of the responsibility but none of the support or recognition. Those carers’ rights that exist (to assessment, involvement and support in some circumstances) are triggered by certain stages of the current community care system, such as a person with heavy, full-time and often very physical caring roles. The starting point for achieving these basic goals will complement the provision of the national helpline for carers.

At present, carers often find that their carers’ assessment identifies their needs but not the basic services they require to stay safe and well when taking on heavy, full-time and often very physical caring roles. Back injury is common amongst carers who are lifting relatives unsafely. Carers without the right support to back them up report constant anxiety about what will happen if their health fails. The initiatives in this chapter demonstrate how services can recognise, share and help manage some of the risks faced by carers day after day. The model supports the development of a core information offer from every agency signed up to the Hertfordshire Carers strategy. This can trigger the signposting of a carer by any agency to Hertfordshire for information, support and/or referral to an appropriate local service. The core information process will complement the provision of the national helpline for carers.

Similarly, Sunderland local authority’s agreement with The Princess Royal Trust Sunderland Carers’ Centre has a range of targets for reaching particular groups and communities. One of the outcomes specified by the contract is “Making a positive contribution: Carers have influenced service provision and policies which affect the people they care for and themselves as carers.” The Centre offers schemes, targeted at the most deprived communities and easily overlooked groups, to develop carers’ confidence. There are partnerships focused on helping carers access formal and informal education and employment opportunities. There is a focus on helping carers to develop a collective voice to influence local services and decisions.

For more information please contact: Sue Reeve at Carers in Herts on Sue.Reeve@carersinherts.org.uk or Ailsa Martin at The Princess Royal Trust Sunderland Carers’ Centre on ailsa@sunderlandcarers.co.uk

Safe handling project in Birmingham

Research carried out by the Carers Support Initiative ‘Your Health, Who Cares?’ report of June 2001, found that over 50% of carers suffered back pain. Birmingham Crossroads provides carers with training in first aid and safer lifting and handling in carers’ own homes or group training sessions. Outreach work identifies where safe handling equipment in the home is not being used and facilitates a tailored training session for the carer. Home-based training is useful for carers who cannot attend groups, or who work. The service maintains an efficient referral pathway to occupational therapy teams in the area and facilitates safe and effective discharge from hospital through training carers.

Carers receive free training through an open referral system. The service is also sold to individuals in receipt of Direct Payments so that their personal assistants can be trained. A steering group includes representatives from funders, occupational therapists and carers. The service has produced a training video. The service is staffed by a full-time manager and seven part-time trainers.

For more information please contact: Barbara Rudge on barbarawbcrossroads@yahoo.co.uk
Carers emergency planning and respite in Sefton

Sefton Council commissions The Princess Royal Trust for Carers Sefton Carers Centre to provide the Carers Emergency Respite Team (CERT). The service provides home-based respite support to carers in crisis or emergency situations for a period of up to 48 hours. During the 48-hour period the team can provide a series of ‘pop in’ calls or, if necessary, will arrange a total move in to support the person being cared for. An important feature of the service is the advanced care planning which is carried out when a carer registers with the service, so that everyone in the team is clear about the individual’s needs and support that would be required in an emergency. The care plan includes an exit strategy, which considers how support will continue to be provided beyond the 48-hour period if this is required. Typically, the exit strategy will include the carer’s network of support, and if this is limited, the service links in with the local authority social services department.

For more information please contact: Liz Williams on help@carers.sefton.gov.uk
Choice and control for carers and the people they care for

The research briefing published by Social Care Institute for Excellence (SCIE) entitled Choice, control and individual budgets: emerging themes notes that: “Carers have been poorly represented among recipients of direct payments.” One carers’ centre manager commented that carers “can only get Direct Payments when the cared-for meets ‘substantial’ eligibility criteria. Often by this time both the carer and cared-for are exhausted and the responsibility can feel like too much of a burden.” The evaluation of the Individual Budgets pilots’ impacts on carers is due early 2009 and emerging evidence suggests that there is work to be done to ensure that these approaches are consistently family- and carer-friendly.

Where carers have accessed Direct Payments, many have found that receiving a budget “in lieu of a carer’s break or service has allowed them welcome flexibility. Carers can even pool their budgets to commission a new service that has previously not existed. The case studies in this chapter outline new approaches to helping carers take control of their assessments and interact with personal budgets systems. It is likely, and welcome, that increasing amounts of carer support will be commissioned directly by the individual carer, using their personal budget allocation or their own money. Crossroads Caring for Carers has produced a briefing on using personal budget approaches to funding carers breaks services. To support this, The National Black Carers and Carers Workers Network has found some evidence that Direct Payments can help people from black and minority ethnic communities access more appropriate support.”

However, carers’ entitlements to support (and therefore the budget they could expect to be allotted) remain extremely low, and so such approaches are not the only way of funding carers’ support. Furthermore, carers can receive nothing if they remain hidden from services. The case studies in this Report demonstrate innovative partnership in order to reach carers who would otherwise care in isolation. This is especially the case amongst some black and minority ethnic communities where awareness and uptake of information and support is particularly low.

It is essential to continue to use “core funding” to finance services that successfully identify carers and offer them information and advice. Many carers value the informality of small third sector carers’ organisations that help them to understand their information and support needs and find a comfortable and useful way into “the system”. This kind of personalised information service remains essential alongside local “single gateways” for information and the new National Help and Advice phone and Web service. Information and advice services should not be compromised by rigid information-sharing requirements that might not be palatable to some groups and communities. Experience shows that rates of carer recognition rise dramatically when there is a core funded specialist carers’ service. The Harrogate, Craven and Airedale Carers Resource, member of The Princess Royal Trust for Carers network of carers’ centres is typical of successful carers’ centres in leveraging eight times its core funding budget in additional funding for its work, as well as uncovering over £1m a year in unclaimed benefits for individual carers.

Supporting carer involvement in personalised approaches in Brighton and Hove

The Princess Royal Trust for Carers network member Brighton and Hove Carers Centre has been funded by the Learning Disabilities Development Fund to provide a part-time Support Worker to:

- inform carers about the opportunities available for people with Learning Disabilities via Direct Payments, Individualised Budgets, Person-Centred Planning and Health Action Plans and support their involvement in individualised support planning and service provision, working with the Person-Centred Approaches Sub Group;
- inform and support carers in their right to a Carers’ Needs Assessment and enable them to access respite, activities, legal, financial and emotional support, including self-care activities currently offered via the Expert Carers Looking after Me Course;
- undertake focused work to ensure that older carers of people with Learning Disabilities have made plans for the future of the cared-for;
- advocate on behalf of carers if services are not being delivered as planned and give them a voice in consultation events for example, Carers Forums, Carers Sub Group and relevant Partnership board sub groups.

For more information please contact: Sheila Killick, Adult Carers’ Team Manager at The Carers Centre for Brighton and Hove on 01273 234045. Or see www.thecarerscentre.org

Supporting carers in the North East to achieve a personalised respite service

Crossroads North East England Development Project will receive the equivalent of £15,000 in cash and consultancy support to pilot and demonstrate a new service for carers and the people they care for. Called ‘Dedicated Care’, the service supports carers in identifying and accessing the services they need and want, and recruits the staff of their choice to deliver it. Crossroads remains the employer, responsible for training, maintaining professional standards, payroll and supervision. Carers and their families have control and flexibility built into their service package so that they get the services they want, when they want them, provided by the person of their choice. The service will be funded by payments from carers’ individual budgets or from self-funders’ own money. The first pilots will start in April 2009 and a scheme will be rolled out across areas of the North East which are not currently covered. Learning from the scheme will be shared nationally.

For more information please contact: Alan Mackay on alan.mackay@crossroads.org.uk
Self-assessment processes for carers in Kent
Carers First in Tonbridge is working with Kent Council to pilot an evaluation of an online self-assessment which, it is hoped, will lead to improved access to statutory and voluntary services, feeding into the Council’s strategy to deliver more initial needs assessments for users and carers online. See: www.kent.gov.uk/SocialCare/adults-and-older-people/self-assessment/declaration-carers.htm

For more information please contact: Ron Alexander on ron.alexander@carersfirst.org.uk

Giving South Asian carers a voice in Tameside
Tameside Borough Council has a number of services aimed at meeting the needs of its local black and minority ethnic communities. Since 2001, carers from the local South Asian Community have been offered a tailored course about being a carer which is run by the Adult Services Racial Equality and Diversity team. The course covers the availability of care, respite, transport and language support services over twenty weekly sessions. A recognised Open College Network certificate is awarded on successful completion. The ongoing dialogue with carers through the support groups and the course has led to greater uptake of mainstream services such as telecare and the development of specific services such as day care for Asian women with learning disabilities.

See: www.tameside.gov.uk/carers/blackethnic#t1
See also the We Care Too Reports from The National Black Carers and Carers Workers Network: http://afiyatrust.org.uk
Putting People First

The new focus within social care on individuals can sometimes lead to those same individuals being talked about as if they exist in a vacuum. “Independence” can sometimes be conflated with living alone. But the first place we are either socially included or excluded is within our families and communities.

Where once it was difficult for a disabled person to assert their individuality, now the challenge for many is to be recognised as parents, partners and family members. With services for adults and for children being managed entirely separately from each other, there is a greater need than ever to be able to assess the needs of whole families. In our work with carers we see the results of fragmented services: carers of sick relatives who cannot get support when their own health deteriorates under the burden of caring; parents who may find that neither adult nor child is being managed entirely separately from each other, so that their needs in a coherent way. Some black and minority ethnic communities can be subject to assumptions by services that ‘they look after their own’.

For every family, there is a sustainable level of caring which ultimately leads to ill-health and higher costs to the economy all round.

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 some families, when the potential for caring relationships and mutual support is taken into account, the need for support will be found to be lower than it would have been through separate assessments of its individual members. Other families will be found to have higher levels of need, due to the interaction of a range of challenges. For most, it would be easier to achieve a package that tackled all of their needs in a coherent way. Some black and minority ethnic communities can be subject to assumptions by services that ‘they look after their own’.

There is a need to have a greater understanding of diverse and complex nature of families in the 21st Century and to provide services that are culturally aware.

In some areas, carers are exploring approaches aimed at putting families in charge of coordinating a number of different caring inputs. Approaches such as Circles of Support and the online support coordination method developed by Plan UK (http://hyze.org) have been developed primarily by the parents of disabled children. There is a need to pilot these approaches with the carers of older people, people with mental health problems and people with substance misuse problems.

The services in this chapter have refused compromises or trade-offs, aiming for maximum independence and choice for everyone their services come into contact with.

The caring café for dementia carers in Richmond upon Thames

Richmond Crossroads, with support from Alzheimer’s Society, Big Lottery and others, provides carers and people affected by dementia with the opportunity to socialise in a friendly and welcoming environment, supported by a skilled staff team. The café is open every Saturday from 11am to 4pm in the centre of Richmond on premises given free by Richmond Age Concern. It provides respite, support, social opportunities and activities to tackle isolation. Transport is provided when needed.

Up to ten people with dementia can use the café whilst their carer goes into town for up to two hours, but most carers wish to remain with the person they care for. Workers, including a part-time coordinator, four café support workers, receptionist, Dementia Advice Worker and volunteers, provide support through dementia care and personal care.

For more information please contact: Eleanor Willett at Richmond Crossroads on richmonduponthamess@crossroads.org.uk

Bridging the adults/children services divide in Winchester and Buckinghamshire

In response to parents requesting support with their parenting, the Winchester Young Carers Project is experimenting with developing the Triple P (Positive Parent Programme) through Hampshire County Council. This training enables the worker to support parents in their parenting role. It often helps with their parenting of disabled children which can have positive impacts on the whole family dynamic.

The Project is also developing mediation sessions between the young carers and their parents. Often tensions build up in the family due to issues stemming from long-term illness or disability. The aim of the mediation sessions is for the young carer and their parent(s) to talk in a controlled environment about feelings and issues that they find challenging so that they can be understood and can understand each other.

Carers Bucks’ Strengthening Families Course has piloted a similar approach. Each week the course has focused on a different topic, with children and parents working in parallel groups that feed back to each other at the end of the session. The course was designed to give parents and children different methods for talking, without shouting or arguing, and to improve empathy and coping mechanisms for times of stress. Transport and a creche for younger children were also provided.

For more information please contact: Winchester Young Carers on office@wycp.org.uk or Carers Bucks on 01296 392711.

“Putting People First without putting carers second”

Dignity and respect for the whole family

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In response to parents requesting support with their parenting, the Winchester Young Carers Project is experimenting with developing the Triple P (Positive Parent Programme) through Hampshire County Council. This training enables the worker to support parents in their parenting role. It often helps with their parenting of disabled children which can have positive impacts on the whole family dynamic.

The Project is also developing mediation sessions between the young carers and their parents. Often tensions build up in the family due to issues stemming from long-term illness or disability. The aim of the mediation sessions is for the young carer and their parent(s) to talk in a controlled environment about feelings and issues that they find challenging so that they can be understood and can understand each other.

Carers Bucks’ Strengthening Families Course has piloted a similar approach. Each week the course has focused on a different topic, with children and parents working in parallel groups that feed back to each other at the end of the session. The course was designed to give parents and children different methods for talking, without shouting or arguing, and to improve empathy and coping mechanisms for times of stress. Transport and a creche for younger children were also provided.

For more information please contact: Winchester Young Carers on office@wycp.org.uk or Carers Bucks on 01296 392711.
HomeShare personalised respite in Redbridge

Redbridge Crossroads engages “Homesharers” - highly trained care staff who use their own homes to host a group of people requiring care - as an alternative to traditional day care provision. Each ‘visitor’ is matched with a compatible group of two or three peers for a weekly five-hour session. With travelling, this equates to a seven-hour respite break for their carer.

The project focuses on matching compatible people and so, as well as receiving care, the groups of visitors can also socialise. Groups include a war veterans group, a stroke group, groups based on music, poetry and crafts, and groups for younger people with dementia who are likely to be more physically active. Homesharers receive extra support from volunteers for these groups to give a one:one support ratio.

Whilst caring can lead to stress and poor health, many carers find leaving the person they care for an additional anxiety, so the provision of personalised care provides piece of mind as well as a break. A small, consistent, tailored group setting is more beneficial for those with memory loss. The unit cost for this scheme is £99.05 per day, compared with the local Day Care rate of £120 per day.

For more information please contact: Eluned Santos on Eluned@redbridgecrossroads.com

Homecare for people unable to access mainstream services in Broxtowe

Broxtowe Crossroads has set up a specialist homecare project to support carers and people with dementia who are unable to access mainstream services such as day centres, often due to their challenging behaviour. The staff team receives extra training in dementia, communication and challenging behaviours and is dedicated to working with those who are particularly difficult to engage. The project aims to maximise and maintain the daily living skills of people with dementia, whilst providing their carers with a break alongside advice and support in dealing with challenging behaviour.

For more information please contact Mel Wheeler at Broxtowe Crossroads on office.broxtowecrossroads@btconnect.com
Current regulations aim to help people with support needs to use their Direct Payment or Individual Budget to pay almost anyone they choose, except their family carer, to provide care for them. It appears that some local authorities are taking an increasingly flexible view of this. Carers have expressed strong views both for and against being paid through Direct Payments. Whilst maintaining a system where someone can pay anyone they wish to help them, except the person who does the bulk of the support, seems indefensible, making it easy to pay family carers has the potential to bring a million people into the health and social care workforce. Employing a spouse or child raises problems if disputes arise and European studies show that carers might be socialised into inappropriate caring roles rather than pursuing a caring/career balance if they were paid for their care.

This highlights a tension in the need for resolution within current social care policy. On the one hand, personalisation gives recipients of care a free choice in who supports them. On the other, the “professionalisation” of social care seeks to ensure everyone working in the field is police checked, registered and qualified. Essentially, family carers, whether paid or unpaid, are unlikely to access living incomes or opportunities for career progression.

We believe that the ideal situation for most carers of working age is to be able to balance caring and paid employment. To make this a reality requires flexibility and imagination from all the support services in touch with the family as well as employers. One carer’s centre reports that a carer whose son purchases support and residential accommodation via Direct Payments has to provide his son’s transport on two days of each week when the son goes to services without his support worker, and also covers if the support worker is off sick. Situations like this suggest that the risks associated with new forms of care packages are not always shared fairly between families and the State. Balancing work and caring is a particular issue for some under-supported groups and communities. For instance, 12.5% of young Pakistani and Bangladeshi men combine work and caring, compared to 5% of young white men.

The services described in this chapter help achieve the delicate balance between work and care. Such services are well-established in their local areas but nationally, still remain the exception. From these examples, we must recognise the huge potential for the economy, stipulating the need for in-depth research into the potential long-term cost benefits of keeping working age carers in touch with the world of employment, even when their caring role stretches over many years.

**Supporting carers in employment in the North.**

The Carers Resource at Harrogate, Craven and Airedale, network member of The Princess Royal Trust for Carers, runs the Changing Lives project. It offers fun and motivating courses from computer skills and interview techniques to confidence building and works with local employers to offer carers guaranteed interview schemes. Whilst the project has been replicated elsewhere, its staff stress that its success lies in an approach built on an understanding of the local employment situation, through relationships with regional development agencies and local employers.

For more information please contact Ailsa Martin at 01423 500555 or at director@carersresource.org

**Juggling Work and Care**

The Carers Resource at Harrogate, Craven and Airedale reports that a carer whose son purchases support can go a long way to retaining a valuable circle of support between carers, their employers and the cared-for. This helps carers to effectively combine caring and paid employment without reaching crisis point. The project will inform employers of the issues of caring and how a little understanding, flexibility and support can go a long way to retaining a valuable workforce. East Cheshire Crossroads will also deliver practical support including services such as overnight sits, lunchtime calls and a helpline during working hours.

For more information please contact: Kate Wilkinson at kwilkinson@eccrossroads.org.uk

**Crossroads schemes helping carers to manage work and care**

The scheme is funded on a ‘payment by results’ basis. It has supported more than 700 carers in its lifetime, with over 100 learners currently taking courses. The project has helped 25 carers into full-, part-time or voluntary work and has provided skills coaching and Next Step services to 250 carers. Referrers include JobCentre Plus and community mental health teams. Changing Lives also now works with those receiving care.

For more information please contact Anne Smyth on 01423 500555 or at director@carersresource.org

**PIE (People into Employment)**

PIE (People into Employment) is a long established partnership between Sunderland Carers Centre, the PCT, hospital trust, adult services, a local physical disability alliance and a local not-for-profit training organisation. It works with employers to improve awareness, policy and practice and to promote the Carers in Employment Charter. It enables carers to prepare for and remain in paid employment.

PIE provides small amounts of training, including City and Guilds Learning for Living, but its main focus is to help carers identity training needs and access existing local support and training. It covers interview skills and confidence building and works with local employers to offer carers guaranteed interview schemes. Whilst the project has been replicated elsewhere, its staff stress that its success lies in an approach built on an understanding of the local employment situation, through relationships with regional development agencies and local employers.

For more information please contact Ailsa Martin at ailsa@sunderlandcarers.co.uk

**East Cheshire Crossroads**

East Cheshire Crossroads took its proposal for SeCuE - Supporting Carers in Employment – to the RSA Dragon’s Den event and won a £10,000 package of support and consultancy. SeCuE aims to create a circle of support between carers, their employers and the cared-for. This helps carers to effectively combine caring and paid employment without reaching crisis point. The project will inform employers of the issues of caring and how a little understanding, flexibility and support can go a long way to retaining a valuable workforce. East Cheshire Crossroads will also deliver practical support including services such as overnight sits, lunchtime calls and a helpline during working hours.

For more information please contact: Kate Wilkinson at kwilkinson@eccrossroads.org.uk

The Report is at:

www.crossroads.org.uk/_downloads/_associationnews/ACE_Action_for_Carers_%20in_Employment.pdf

“The project offers fun and motivating courses and aims to build confidence and find new training and employment opportunities.”
Support for carers has traditionally been seen as the role of council social services where most of the legal duties reside. However, increasing numbers of local health trusts are recognising the business case and health gains of supporting carers and are forming partnerships which capitalise on the health service’s reach into families. In some areas, huge numbers of carers have been identified and put in touch with support for very little cost.

The table below, from The Carers’ Resource in Harrogate (TCR), Craven and Airedale (one of The Princess Royal Trust for Carers network members in North Yorkshire), illustrates the huge difference in numbers of carers accessing specialist support, between carers registered at GP practices working with the Carers Resource, and those registered at practices who are not:

In 2002, Torbay Council commissioned Manchester PSSRU to evaluate the use of Carers Support Workers or Officers (CSO) in GP Surgeries. General Health Questionnaires (GHQ) were used with 88 randomly selected carers. There was a highly significant reduction in distress amongst the carers during the time they received the service from the Carers Support Workers. Despite over half of carers saying that they were in good health, overall GHQ scores at referral/ commencement were high. In fact, in terms of a traditionally used cut-off score on the GHQ-12 (1/2) to identify cases of psychiatric disorder in primary care, 94% of the carers could be identified as having psychiatric disorders at Time 1. After receipt of the Carers Support Workers, the proportion of carers who could be identified as symptomatic cases reduced by 21%. In particular, the proportion of carers experiencing problems with concentration and sleeplessness reduced substantially. The majority found the Carers Support Worker to be ’very helpful’. In addition, the majority of carers perceived the service as making a difference to their situation whilst over half felt that the Carers Support Workers ’very much’ made a difference and 31% said that they made ’a little’ difference.

For more information please contact: James Drummond at Torbay Care Trust on Jamesdrummond@nhs.net

Access to free NHS funded Continuing Care has been opened up to some people with long-term medical conditions who in the past have received their support from social services. Some people, therefore, particularly those with fluctuating conditions, risk moving to and from two different care systems: a personalised social care system that gives them control of their care budget but charges them for the privilege; and a health care system that, while free for all, does not currently allow people to take control of their care package in the same way. However, a judge recently accepted a family’s argument that there was no legal bar to their PCT making substantial payments to an independent user trust in lieu of NHS continuing healthcare provision. The principles of choice, control and family-friendly approaches must be extended into NHS care.

GP based carers support in West Sussex
The Carers Development Worker (Primary and Community Care) project at The Princess Royal Trust Worthing & District Carers Liaison Service has had dramatic effects on the numbers of carers identified by GP practices. Some practices have consistently increased their numbers of registered and supported carers since 2004. One full-time equivalent Carers Development Worker based at the service works with 37 GP practices. The project:

- identifies a link person in each GP practice;
- completes an annual Monitoring Tool;
- uses an action plan for task completion;
- provides Carer Awareness Training and information/support for all GP staff;
- promotes healthy living practices at carers events;
- ensures that GPs work to the GMS contract (Management Indicator 9).

For more information please contact the service via www.carerswsx.org.uk

Networking Primary Care Carers Champions in Cheshire and Greenwich
As part of its Carers Strategy, Western Cheshire PCT has asked each GP Practice to identify a Carer Link from their staff to act as the main support point for carers; keep practice information up to date; link with other services; and meet with each other with PCT support. A group including carers and carers’ organisations steers the project.

For more information please contact: Tom Livingstone at Chester Crossroads on chester@crossroads.org.uk

Greenwich Carers Centre, a member of The Princess Royal Trust for Carers network, has developed a carers’ support protocol for local GPs which the PCT promoted to all their surgeries. The protocol includes leaflets and information posters. The Centre is now developing a Carers Champion Egroup for local primary care partners. Each surgery will nominate a Carers Champion who will receive regular updates from the Centre, share good practice and represent the surgery at carer forums organised by the Local Council and the Carers’ Centre throughout the year.

For more information please contact: Sue Mitchell, CEO on sue.mitchell@greenwichcarerscentre.org

Hospital based resources for carers in East Sussex
The Princess Royal Trust for Carers network member Care for the Carers and East Sussex hospitals NHS Trust have produced a range of resources for supporting carers. This includes a good practice guide for hospital staff covering topics such as: information sharing; a Carers Information Leaflet; and a Care Passport which allows carers to help the cared-for person express their care needs and let staff know they can share information with the carer.

For more information and relevant contact details see www.carers.org/local/south-east/eastbourne/
Putting People First without putting carers second

PCT and council partnerships in Sandwell
The Princess Royal Trust Sandwell Carers Centre has pioneered several effective partnerships with the PCT and the Council. A Carers Champion, who is a GP, sits on the Professional Executive Committee of the PCT. The Centre works with GP practices to ensure that adequate carers’ information is in place. The carers who attend a carer group set up by one practice all set their own agenda. As a result of this input, the practice has a daily “carer’s appointment”, accessible in an emergency for carers who want to see a doctor. The Centre is now developing Gold, Silver and Bronze carer support and involvement awards for practices.

For more information please contact: cares.sandwell@btinternet.com

Macmillan Crossroads Cancer and Palliative Care Project in Huntingdonshire
Macmillan Crossroads and Palliative Care Project is a partnership to support carers and people affected by cancer through their journey. A Steering Group of carers, health and social care providers and commissioners, as well as representatives from Macmillan Cancer Support and Crossroads, oversees the service.

This new specialist service aims to:
• improve the quality of life of both carer and person with care needs;
• reduce the number of admissions to hospital and hospice;
• reduce the length of stays in hospital.

It is hoped that savings made by minimising time spent in hospital, reducing emergency admissions and avoiding admission to hospital will make the business case for the PCT to contribute to funding during and at the end of the Macmillan funding period.

For more information please contact: Maureen Hayden, Care Manager, at care@westangliacrossroads.org.uk

Carers at centre of planning for Northamptonshire’s mental health services
Northamptonshire Carers’ mental health project is co-funded by the Northamptonshire Healthcare NHS Trust and Northamptonshire County Council. The Centre manages nine Carers Support and Development Worker posts based within the local Community Mental Health Teams (CMHTs). A reference group ensures carer involvement in all development of the Project and local services, and is made up of key local professionals and mental health carers. This group will occasionally create sub-groups to work on specific initiatives or issues, such as devising a new Carers Assessment form, which was rolled out to the CMHTs last year, and devising carers’ leaflets and an information pack with Northamptonshire’s County Council.

For more information please contact: Mark Major on markm@northamptonshire-carers.org
The Commission for Social Care Inspection (CSCI) says in its State of Social Care report 05-06 that “Only 20% of councils are taking a strategic approach to meeting the needs of carers and thus there is a significant disparity between councils in the type, level and quality of services”. In the same report for 06-07, it states that: “Whilst this year we report some improvements in support to carers, this continues to be far short of the systematic provision needed.”

The commissioners in this chapter are bucking that trend, focusing on outcomes first and building solutions around them. We know that there are still groups and communities who are under-reached or who find existing services do not meet their needs. Future solutions will, increasingly, be built on partnerships between carers’ organisations and the wide range of community and statutory partners highlighted below.

Working with libraries in North Wiltshire

The Princess Royal Trust for Carers network member Carers Support North Wiltshire has built a relationship with its ten local libraries, delivering ‘Well Being Days’ which offer alternative therapies to carers alongside a creative partnerships approach to carers. As well as delivering activities rated as ‘valuable’ by carers in accessible settings, this partnership helps the Council achieve its goal of diversifying library use. The Carers’ Centre is now reaching some previously hard to reach groups and has increased its referrals.

For more information please contact: Lindsay Poulsom, Joint CEO at lindsay@carersnw.co.uk or on 01249 444110.

Housing association partnership in North Wiltshire

Carers Support North Wiltshire has also worked with Westlea Housing Association to cross reference their databases. They found that almost half of carers on the Carers’ Centre database reside in an association property and of those almost half were parent carers. As a result, the housing association has provided £165k pa for three years to develop a Volunteer Coordinator/Activities Worker to help sustain tenancies and support carers.

For more information please contact: Lindsay Poulsom, at lindsay@carersnw.co.uk or on 01249 444110.

Respite services for the Bangladeshi community in Camden

In response to the needs identified by the local community, Camden Crossroads, funded by Camden Council, offers respite services provided by bilingual workers (English and Bengali/Sylheti) with specific information and leaflets tailored for this community. This has increased the numbers of carers from this community accessing their services and their satisfaction with it. Other Crossroads schemes such as Essex Crossroads have piloted outreach projects for black and ethnic minority carers focusing on building relationships and awareness with communities.

For more information please contact: Mohammed Muhith, Service Development Manager, at camden@crossroads.org.uk or on 020 7485 7416.

HIV support in Lanarkshire

The Princess Royal Trust Lanarkshire Carers Centre works in partnership with NHS Lanarkshire Blood Borne Virus Network who part fund their support for carers affected by HIV and other blood borne viruses. This includes a part-time bilingual support worker working with BME carers affected by blood-borne viruses (bbv).

The Centre works in partnership with The Lanarkshire HIV, AIDS and Hepatitis Centre and the Terrence Higgins Trust (THT) in sharing information, holding joint meetings and support groups, and in providing carers workers with Lesbian, Gay, Bisexual, Transgender (LGBT) training and blood-borne virus awareness sessions. Carer Support Workers are supported and receive time off to access Hepatitis B vaccinations.

For more information please contact Lesley Fishleigh on Lesley.Fishleigh@ptricc.org.uk

Specialist support for carers of people with drug and alcohol problems

Regents House in Nottingham acts as a safe haven for carers looking after someone with substance misuse problems to come and meet with support workers. The Princess Royal Trust for Carers network member Carers Federation set up this service in 2002 with joint funding from the County Drug Action Team and Nottingham Crime and Drugs Partnership. The services offered include:

- drop-in support at Regents House;
- telephone support;
- outreach support – one-to-one support;
- group support – groups arranged geographically;
- specialist group support – parents of young people group; cannabis group; bereavement group;
- youth education programme, including supporting drugs education in schools.

For more information see: www.carersfederation.co.uk

The need for a specialist approach is highlighted by research from Crossroads Norfolk, which was funded by Norfolk DAAT. It found that whilst many carers of people with substance misuse problems had been caring for over ten years, and faced difficulties familiar to all carers but with added burdens of stigma and worries over the criminality attached to substance misuse, none were being supported by carers’ services. The DAAT used this information to inform commissioning of a specialist carers service.

For more information please contact: Jenny Leitch at jenny.leitch@crossroads.org.uk

Giving carers access to leisure services in Salford

The Princess Royal Trust Salford Carers Centre is piloting a Carers Leisure Pass, which gives carers unlimited access to council swimming, gym and leisure facilities. Following their carer’s assessment, the assessment worker can request a pass electronically.

The Princess Royal Trust Salford Carers Centre is giving carers access to leisure services in Salford

The Centre works in partnership with the County Drug Action Team and Nottingham Crime and Drugs partner to give carers access to leisure services in Salford

Putting People First without putting carers second
Partnerships for Older People in North Somerset

Crossroads Somerset has developed a scheme to assist carers aged 50 and over to access services of their choice and has produced a ‘menu’ to give older carers ideas of potential services. It uses a budget allocated for each carer and funded by Partnership for Older People (POPP) to design the service needed by the individual to help them continue to care. The menu includes day trips; night sitting; gardening; personal development courses such as cookery and relaxation techniques; courses relevant to caring such as moving and handling; complimentary therapies; and help to access short-term nursing care.

For more information please contact:
carescheme@nscrossroads.org.uk

Culturally appropriate dementia care for families in the Heart of Birmingham

West Birmingham Crossroads Care set up DISC (Dementia Information and Support for Carers), which is funded by Birmingham City Council and Heart of Birmingham PCT, in 2003. The DISC team of six specialist dementia care workers offers practical and emotional support to people who care for someone living with dementia. Support offered includes counselling, group training in dementia care, (including a dedicated Asian carers support group) and social activities for carers, whilst Crossroads Care staff support the person with care needs. The DISC Asian Carers helpline is available to any person from Birmingham’s many South Asian communities who may prefer to speak to a support worker in a South Asian language. This helpline has proved very popular with carers seeking ongoing support as well as increasing the numbers of carers from South Asian communities seeking advice or information on dementia. Over 60 carers are currently supported. Most have used the helpline number to access the full-time Asian support worker.

For more information please contact: the DISC team:
carers@discbirmingham.co.uk

Reducing the risk of fire in Suffolk

Suffolk Family Carers, network member of The Princess Royal Trust for Carers, works in partnership with Suffolk Fire and Rescue Service to provide home fire safety checks for family carers and vulnerable people so they can discuss how to prevent fire in the home. The Fire and Carers Together (FACT) scheme is a free service which recognises that some people may have particular difficulty in leaving their home in the event of a fire. FACT also offers an emergency database within the Control and Command Room to identify households registered with the scheme.

For more information please see www.suffolkfamilycarers.org
Putting People First without putting carers second

This report was written by: Alex Fox, Director of Policy and Communications, The Princess Royal Trust for Carers (afox@carers.org; 0113 2688817; 07896291846) with generous assistance from the network members of The Princess Royal Trust for Carers and Crossroads Caring for Carers.

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