Cuts or *Putting People First*?

Having a life as well as making a saving.

NAAPS 2010

Contents

Cuts or personalisation?

Soon we will have Putting People First 2: a new Vision and Concordat for personalisation. What progress will it report and which of personalisation's aspirations (self-directed support; informed choices; increased community activity and better prevention) will survive the current round of cuts in public service budgets?

In some areas, the most visible change is in how the money moves around the social care system. These areas have dazzlingly complex Resource Allocation Systems to generate personal budget allocations, but retain the same narrow range of services from which budget holders can choose.

Those are the areas which are already cutting services which are preventative and low level: some of the same services which help people connect in new ways with their local communities. If commissioners respond to the need for cuts by retreating to traditional, centralised decision-making, the aspirations of *Putting People First* will swiftly become a memory.

Complex "framework" commissioning agreements, "reverse auctions" (where the cheapest provider wins) and gate-keeping preferred provider lists through aggressive price-setting, all have the potential to shave percentages off the costs of large swathes of social care provision. And they all limit the role of people who use services and their carers to being consumers at best and at worst, passive recipients of whatever can be piled high and sold cheap.

In contrast to the current vision for an NHS led by clinicians, with patients as informed consumers, the vision for social care has been one in which people who use services and their carers are not just consumers, but also commissioners, of care and support. If procurement is the simple act of buying things, genuine commissioning is the strategic activity of using money and influence to shape the local marketplace of care provision. Good commissioning avoids thinking in terms of broad categories and average needs and instead is based on a real, gritty understanding of the complete range of local people's needs and choices. No one is in a better position to shape that understanding than people who use services and their carers, working with front-line practitioners.

The financial climate has changed utterly since the launch of *Putting People First*. But the impact of cuts can be mitigated, if only partly, if we give genuine ownership of the care and support system to the people closest to its delivery. Small can often mean cheaper, because micro approaches cut out layers of bureaucracy which add no value, but this won't simply be about the state stepping back and relying on free market economics, which are so often the enemy of genuine competition and choice. There will need to be investment, but investment in different places. Investment in advocacy rather than in gate-keeping. Investment in helping people, families and front line workers to share ownership of services, rather than in endless consultation. If parents can set up "free schools", couldn't disabled and older people set up their own services?

This report outlines how a highly tailored service called Shared Lives (formerly Adult Placement) creates huge savings whilst outperforming alternatives on the key indicators of personalisation: inclusion, choice, flexibility, control. It illustrates how those values have been taken up by a new generation of micro-enterprises. It demonstrates that savings and personalisation are not incompatible. That makes it an uplifting story which we hope you will find inspirational.

And if there was ever a time we needed inspiration, it's now.

Alex Fox, CEO, NAAPS. September 2010.

Introduction to NAAPS and Shared Lives

NAAPS is the UK network of very small, family and community based care and support solutions for people who are older, disabled or have a long-term condition: we are all about ordinary people and families contributing to the care and support of local people, sometimes in fairly extraordinary ways. Our membership includes Shared Lives, Homeshare and micro-enterprise.

NAAPS' members deliver services which:

- help people live ordinary lives within their chosen families, communities and relationships;
- are built around individuals, their strengths and potential and which put people in control;
- support personal development or provide stability, according to the individual's choice;
- are safe and support people to take risks in pursuit of their goals;
- promote equality and value diversity;
- are cost-effective, with consistently better outcomes than alternatives.

Shared Lives is where an individual or a family chooses to include an isolated or under-supported older or disabled person in their family and community life. In many cases that person becomes a permanent part of a supportive family, although Shared Lives is also used as day support and as regular respite care for unpaid family carers.

There are around 10,000 SL carers in the UK, of which 3,800 are NAAPS members (www.naaps.org.uk). Shared Lives carers are recruited and approved by a Shared Lives scheme, which is regulated by the Care Quality Commission in England and its equivalents in the other UK nations. Shared Lives is unique in adult support, in that Shared Lives carers are paid a flat rate (like a foster carer) rather than by the hour, are expected to form two-way relationships including mutual links to family and social networks (as opposed to the highly boundaried, one-way "professional" support relationship), and because Shared Lives is based on matching individuals who need support with compatible Shared Lives carers and families.

NAAPS also supports Homeshare, where someone who needs some help to live independently in their own home is matched with someone who has a housing need and can provide a little support. "Householders" are often older people who own or are tenants in their own home but have developed some support needs or have become isolated or anxious about living alone. "Homesharers" are often younger people, students, or key public service workers who cannot afford housing where they work.

Thanks to the work of our social enterprise, Community Catalysts, our fastest-growing membership is in our Small Community Services category. Micro-enterprises in this category are set up to meet the needs of an individual or small group. Some are set up by front line workers previously based in large organisations, others by disabled or older people themselves. They often draw on the resources of the local community. Some are funded through personal budgets or paid for with people's own money, others carried out on a voluntary basis, with any payments simply covering the cost of providing the service. Some are co-operatives which may be owned jointly by people who deliver and people who use and pay for the service. Many operate "below the radar" of local government and NHS. Micro providers face growing regulatory, legislative and other barriers and as a result many fail. A growing number of areas are working with Community Catalysts to overcome these challenges. In these areas, micro-enterprises are beginning to flourish.

See www.naaps.org.uk and http://alexfoxblog.wordpress.com for more stories from our work.

Sharing ownership, sharing control

Collaborative approaches to designing and delivering services ("co-production") can often be limited in two ways. Firstly, creativity may be constrained by taking place within a fairly rigid set of parameters and boundaries, often backed up by regulation, which define the service in question. Those who use a service may put friendships at the top of their wish list, but find that this is outside of the scope of a regulated service delivered within professional boundaries. Secondly, co-production as an approach rarely challenges an organisation's ownership or power structures.

One way of tackling this is through supporting people to employ their own personal assistants (PAs) according to job specifications which they have helped to draw up. This approach can lack the economies of scale of more organised approaches. There may be a limited pool of willing and suitable PAs and of course, not all support needs can be met through the use of PAs.

Genuine mutuality is demonstrated by one Community Interest Company (CIC) which supports people who have a learning disability to live independently and become part of their communities. This CIC has five unpaid directors - two people with a learning disability, two family carers and one person from the voluntary sector. The service supports disabled people to recruit, train and employ personal assistants and other forms of support, thus combining the strength and support of mutuality with the freedom of individual choice.

Celia (who is also a Shared Lives carer) launched Funky Fitness and Fun in 2007 as a small social care enterprise after realising that the closure of day services had resulted in a lack of activity for some people. The programme of activities is co-designed by the 15 people who use the service and takes place in a community centre. Celia has gained business support from Oldham Collective (a support organisation for social enterprise) and NAAPS. Michael, who sometimes has to use a wheelchair, pays for the service using his personal budget. He found traditional services too rigid and didn't like the constant changes of staff. He feels Celia's service is cheaper and better than using a PA, particularly valuing the opportunity to meet old friends and make new ones.

What can large and established providers learn from this? Shared Lives combines the infrastructure of established, regulated, service provision with the freedom and flexibility of constructing relationships between self-employed Shared Lives carers and people who choose to live with or be supported by them. Successful matches feel less and less like a service as the participants gradually shape and take ownership of real and lasting relationships.

Even large providers and their commissioners can consider how to segment their services into a number of separate offers, with budget holders able to choose from a menu for each support element. For instance, day centres are seen as inflexible and outdated, but their closure can be devastating for some long-time users. A day centre is a building, but also a bundle of services and relationships. Which of those services do people want to keep? Which would they end or change? Where would they like to spend their time and with whom? And what could the community do with this building if it is no longer needed for its current purpose? Those are questions which can only be answered by helping people who use services to come together with the rest of the community to discuss how they might manage resources and work together to meet support needs and build real relationships. That would be real commissioning power and real inclusion. And it would be very different to giving everyone a personal budget and sending them on their separate ways.

Combining paid and unpaid support.

A CEO of a large provider said recently, "Personalisation is all very well, but the councils I contract with will pay me – just about – to deliver the basics. The bits that make for a good quality of life are seen as extras." This is not an unreasonable point. It highlights the huge challenge of trying to keep the momentum going around personalisation at a time of huge cutbacks. But it is also true that even in times of relatively good funding, providers have not always been successful in helping people make real friends, or find a niche within their community. Such things are simply not services which can be provided.

Think of a spectrum of care and support. At one end, we have formal, unit-costed, by-the-hour, professional care. At the other end, there are the families who provide completely unpaid care within the privacy of their own homes. But there is now a growing range of services and solutions which come somewhere in between those extremes. They mix paid care with relationships which cannot be bought. They have boundaries and limitations but they are incredibly flexible.

Shared Lives carers are paid a flat rate rather than by-the-hour. They contribute beyond what they can be said to have been paid for and when a match works, it stops looking like a service and starts feeling like life. This is partly why Shared Lives is cheaper than residential care, domiciliary care and supported living, despite outperforming all of those services in star ratings. The flexibility comes from unleashing the creativity of Shared Lives carers from the boundaries of risk management and being "appropriate" which can sometimes stifle traditional forms of support.

SWAPS Shared Lives service in Devon took a self-referral from a lady with a learning disability who lived with her now ageing mother on a smallholding and wanted to move out of the family home, not least because her mother wasn't going to be able to support her indefinitely. Her only specification was that she had to be able to take her flock of geese with her. SWAPS like a challenge and were delighted when they were able to match the lady with a Shared Lives carer in a rural family who shared her enthusiasm for geese. It is hard to think of another kind of service other than Shared Lives that would have been able to meet that request in a referral.

Shared Lives does not have a monopoly on flexibility and harnessing the kind of contributions which money cannot buy. Unpaid family carers have always provided vast quantities of care, often at great personal sacrifice. Now some are receiving payments via personal budgets which help them sustain their caring role. Another example is Homeshare, a bartering arrangement in which people who need support to continue to live independently in their own homes, trade accommodation for support from people who need accommodation.

The charity Keyring helps people live in supported accommodation within a neighbourhood. A community living volunteer also lives in the neighbourhood and helps the individuals to provide peer support to each and to build and share informal networks of support. Keyring uses a volunteer in this role, alongside paid support workers providing more formal support, because the individuals can (and indeed must) have a different relationship with a volunteer to that which they may have been used to having with paid supporters.

In all of these examples, bringing unpaid contributions into people's lives is not free. But it is affordable. And very different to providing a package of care.

Family life or independent living?

A family carer was recently desperately worried about her son, who was being pressured into moving from group living into his own flat, so that he could achieve "independence". No doubt some professionals saw her as "over-protective", perhaps the cause of her son's reluctance to "progress". The problem was, her son, who had schizophrenia, was most troubled by hearing voices when he was alone. Group living was working for him and it was his choice. As his mother put it, "If he's moved to that estate I won't be able to visit him as often and I don't think the community will be turning up on his doorstep bearing casseroles."

Living in your own place is a valid, hard-won choice and one that we should all have, but many of us do not aspire to live alone. We are all inter-dependent to some degree and being isolated does not tend to be empowering. The new vision for social care should recognise that being able to choose and form all kinds of close and family relationships is just as important to being in control as being able to choose where we live and who supports us.

Karina is a Shared Lives carer who also rents out a second home to adults with mental health problems. Elise wanted to move to a more independent lifestyle and shared Karina's two bedroom property with another young woman. Housing Benefit funded the accommodation and Elise's personal budget funded the support she chose to receive from Karina, until she was ready to move on to her own flat. It was unlikely that she would have made the transition without this interim step.

Cut advocacy? Cut care management? Cut choice.

There is a certain irony in the fact that we are constructing a system which is based on people expressing informed choices about all aspects of their lives, at a time when advocacy and support to make decisions is becoming ever scarcer. Too often we hear from Shared Lives carers who feel uneasy that they are the sole advocate for the person living with them. Hard-pressed care managers see a stable care arrangement, sigh with relief and turn their attention elsewhere. Shared Lives carers are often heroic in fighting for the rights of the person they support, but they are also aware that, should there be a real or perceived conflict between their wishes and those of the individual, they will be in a very difficult position. This was a point brought home by a recent High Court case involving a decision made on behalf of a young man about where he would live, made in the midst of what later transpired to be groundless safeguarding concerns. When it really counted, the young man's choices and indeed right to private and family life, fell by the wayside through want of independent advocacy.

If this trend towards reduced care management and funding cuts for advocacy services is not reversed, we will see real choice become the preserve of those who are most able to self-assess, or who have articulate families. Is there a low-cost solution to this problem? Possibly not, but there may be costs which can be redeployed from gate-keeping and from fighting the increasing number of challenges we will see where people's rights have been neglected. And having a voice is not all about access to advocacy in a crisis. The groundwork for empowerment can be laid partly through enabling peer support, through ensuring that people have real relationships as well as paid ones and through opening up power structures within provision and commissioning.

Not just better care, but an ordinary life

The idea behind personal budget control was that people would be able to choose more freely from a wider menu of care and support solutions and that this would result in care that more closely matched their needs. We need to get even more ambitious than that. An increasing number of individuals, often with lots of support from their families, are spending their personal budget on the kind of support that doesn't just result in better care, but also in new friendships, a more meaningful place within a community, and for some, a real job.

Adam and John have been living with Shared Lives carer Mitch for three months. John now has a work placement for one day a week and Adam attends the local College. Adam, who has Aspergers' Syndrome, has shown a great interest in music, so Mencap and Mitch arranged for him to spend some time with a mobile DJ. Adam spent his savings on disco equipment and now has bookings for discos including one for a social services day centre. He charges a minimal fee that is donated to Mencap.

Jenny and her personal assistant have a passion for dancing. With support, they have established a social enterprise to take all things dance into the homes of people with a learning disability to increase their overall wellbeing. Jenny happens to have Down's Syndrome.

Jenny is currently undertaking training designed for people with a learning disability to develop their skills as dance leaders. DanceSyndrome relies on the strong involvement of Jenny's family, but Jenny is also seeking the support of a project manager and has 14 other dancers, learning disabled and non-disabled, who are keen to work with her.

Community Catalysts, a new social enterprise wholly owned by NAAPS, has received Department of Health funding to support initiatives like DanceSyndrome. Jenny's business, 'DanceSyndrome', has been publicised to stakeholders and has shared learning and challenges with other small community services at a networking event. It now targets dance workshops at small groups rather than individuals and has identified four groups as potential customers. Jenny was also helped to secure start up funding from local and national funding bodies relevant to her enterprise.

Community Catalysts employs "fixers" who are embedded in the local area to find existing enterprises and offer them the support they need to operate lawfully and sustainably, whilst also helping others to set up. The professional will work with different arms of the local state to ensure that regulatory approaches and commissioning practices are as helpful as possible and avoid stifling enterprise.

Better lives, cheaper support. Prove it.

Many of the models of support outlined in this report are new or emerging and as yet under-evaluated. At NAAPS, we see addressing this gap as a key part of our responsibility as a national organisation. Our new social enterprise, Community Catalysts, is working with Manchester Metropolitan University to evaluate the cost-benefit of promoting micro-enterprise. Less than a year old, Community Catalysts is now working in 11 local authority areas, with several large care and housing providers and a prison, so there will soon be plenty of evidence on which to draw.

Shared Lives outperformed all other regulated services under the star rating system. The inspection results published in 2009 for the previous year show that 94% of Shared Lives Schemes were rated Good or Excellent, 4% adequate and 0% poor (the remaining 2% were not then graded).

Shared Lives is also cheaper than alternatives. The business case produced in partnership with Improvement and Efficiency South East demonstrates that, depending upon the complexity of an individual's needs, Shared Lives schemes can deliver savings of between £35 and £640 a week per person in comparison to traditional services. The average saving for someone with a learning disability in residential care, for example, is 60%. Ten new long term arrangements generate per annum savings of between £23,400 (older people) and £517,400 (learning disabilities). To develop a Shared Lives scheme to support 85 people requires investment of £620,000 over five years but generates savings of almost £13 million. The larger the scheme, the greater the efficiencies.

The new Vision and Concordat for social care will be presented to a sector undergoing a radical transition and that, in some places, feels under severe pressure. It would be easy to throw up our hands and declare that personalisation was a great idea, now sadly killed by cuts. The disabled entrepreneurs, community groups, families and professionals whose stories have formed this report demonstrate that there is cause for hope, as well as fear. We owe it to their creativity, dedication and sheer bloody-minded determination, to create a new vision for the sector that is every bit as radical and optimistic as *Putting People First*.

Find out more about NAAPS at www.naaps.org.uk and http://alexfoxblog.wordpress.com.
Find out more about Community Catalysts at www.communitycatalysts.co.uk.

Regulatory and legislative barriers to micro enterprise

Summary July 2010.

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Local Authority Procurement Rules (CLG)

These rules apply where the micro provider is contracting directly with the local authority, including the situation where someone with a personal budget has chosen to have that budget managed for them by the local authority (rather than as a cash direct payment). Local authorities interpret these procurement rules in different ways.

Services that do not fit current regulatory frameworks can be treated with suspicion by commissioners and social workers. Most services want a method of demonstrating that they are delivering a quality service and the current lack of a recognised, robust, yet proportionate and relevant means of quality marking unregulated services is a barrier to micro enterprise.

Approved/Preferred Provider list:

Local authorities can only contract with providers on the approved list. Providers who deliver personal care can only be included on the approved list if they are regulated by CQC. Each local authority sets its own rules of access on to the list.

Case example: In a South East authority, staff state that they would be breaking the law if they had a contract with an unregulated provider who was providing personal care. This is a barrier for micro providers but also impacts on choice for people with personal budgets managed by the local authority.

This poses a particular problem for:

- Self-employed domiciliary care workers who are exempt from regulation with CQC.
- Day services that deliver personal care and day services exempt from regulation by CQC.

Rochdale Council: Domiciliary providers, whatever their size, are required to have an electronic call monitoring system. Sunshine Care, a cooperative, has over a lengthy period registered their domiciliary care service with CQC. They provide services for about 12 individuals. The requirement for an electronic call monitoring system has effectively blocked their application to be an approved

provider. The system is expensive, but more importantly Sunshine Care feels that this approach would undermine their highly personalised approach to service delivery.

CRB Checks (HO)

The majority of micro-providers are sole traders. Self-employed individuals are currently unable to access their own CRB checks. They cannot therefore provide evidence that they do not have a criminal record to potential customers. The same is true of people who want to offer help voluntarily to someone in their community, outside of an existing charity or state run programme.

Private Hire Vehicle Legislation (DT)

A number of current and emerging Small Community Services (SCS) want to offer transport as part of their service. This is particularly valuable to people where local transport is inaccessible or inflexible and is essential to the success of many tailored day/work support provisions.

Section 53 of the 2006 Road Transport Act repealed the Private Hire Vehicle Contract Exemption which currently exempts from PHV licensing requirements vehicles engaged on contracts lasting not less than seven days. In doing that providers that provide transport as part of their service, who were previously exempt from the requirement to have a Private Hire Vehicle Licence, were brought under the Act.

Obtaining a PHV Licence is a costly and time -consuming exercise aimed at taxi drivers:

- A vehicle license costs £318.
- Vehicles must be less than 4 years old.
- An operator's license costs £358.
- A driver's badge costs £94.
- Drivers must undertake an independent medical check (up to £100) and CRB check.
- Drivers have to undertake two written tests (Highway Code and destination knowledge) and a driven test in which they are required to find the shortest routes whilst driving in the area.

The Department has issued guidance relating to volunteers and child minders (also caught by this piece of legislation), which suggests that there is no requirement for a provider to obtain a PHV licence where:

- There is no charge for the driver's time and the charge for transport is within the HMRC limits.
- Transport is provided for more than one person at the same time under separate contracts.

This is however open to interpretation by local transport regulators. Often the PHV licence requirement is applied, even where the SCS provider makes no charge for their time while driving. The argument being that the transport provision is part of the day service, which is charged for.

A number of excellent providers have had to restrict their service against the wishes of their customers.

Companions is a micro-domiciliary care service established to provide consistent, responsive and flexible care for a small group of older people, who pay for the service from personal budgets or their own money. The providers consulted widely with potential customers before setting up the service. These older people found it difficult to use public transport and were essentially confined

to their homes, isolated and lonely. Top of their 'wish list' was help to go out into the community and to meet their friends. Companions designed a service which included using their own cars to take people out but were told that they would have to be licensed as private hire vehicles. The costs and complexity of obtaining a licence were insurmountable, so they have not been able to provide the service most desired by their customers.

Regulated care and support services (DH, CQC)

Perhaps the single biggest barrier to micro enterprise has been the 'one size fits all' regulatory framework for registered providers introduced by the Care Standards Act 2000. CSCI / CQC reports and UKHCA evidence suggests that the rate of closure of very small care homes and domiciliary care agencies has increased since its implementation.

Companions (see above) have attempted to become registered but found the requirements too expensive and inappropriate to a very small scale personalised service, such as the need for domiciliary care workers to carry identity cards. They are committed to providing a high quality personalised service and do not want to grow into a larger business. They have reluctantly decided that they cannot offer personal care and are now in a position where they have to turn work down if there is any element of personal care, passing the work on to a large registered provider in the area. A more proportional system that would allow Companions to deliver some personal care would be beneficial to customers and to this small business.

It is not clear whether this approach will change with the implementation of the Health and Social Care Act 2008 in October 2011. Theoretically an outcomes approach will be beneficial for regulated micro providers. It is encouraging that CQC have talked about a proportionate approach to implementation.

However some of the processes that are being put in place are not encouraging. For instance, a key CQC document is a guide to the new system for providers. This is a long document which micro providers are finding confusing and inaccessible. While it is less prescriptive than the old National Minimum Standards, understanding what has to be done to comply with the new regulatory framework has become harder.

Some advice from CQC seems inconsistent and can be confusing. For instance, NAAPS spent some months attempting to clarify the position for self-employed individuals providing domiciliary care which includes personal care. Under the old domiciliary regulations these individuals were clearly exempt from the requirement for regulation. The position as finally stated by CQC is much less clear, causing concern to a number of sole traders who fear that they may be acting illegally by remaining unregistered. Providers who seek individual advice from CQC continue to receive inconsistent guidance - a number report receiving one answer from the local CQC office and a different answer from the national team

Benefits Rules (DWP)

These rules provide a major barrier to people on welfare benefits who want to set up an enterprise. Getting off benefits can feel very risky and the plethora of welfare to work programmes confusing.

Loss of long term benefits.

This is particularly true for people with disabilities or other long term conditions, who need support and services and who have been supported by the benefits system for many years. People in this

position who set up an enterprise lose their long term benefits, which are often protected as long as they continue to claim them. So if the enterprise fails, they have to reapply for the new Employment and Support Allowance instead. The fact that they have set up an enterprise, even one that failed because of their disability, may lead to their being categorised as fit for work.

People on long term benefits with a disability or long term condition need a period of benefit protection while they test whether they can sustain self employment.

Test Trading: This is an option which is available in some areas across the country. In Test Trading, the individual's benefits are protected for six months while they test their business. They are allocated a business advisor. At the end of the six months, the individual can either go back on benefits or sign off to become self-employed. In practice this option is not widely known, even among Disability Employment Advisers. The requirement for the individual to have a joint bank account with the Test Trading provider can cause problems as few banks understand the Test Trading regulations and many are not prepared to set up this kind of joint bank account.

There is an even greater challenge for people with fluctuating conditions who may be well enough to work one day and not the next. It is possible to design a business model which allows individuals with fluctuating conditions to deliver a consistent service (usually by the imaginative use of co-workers), but inevitably income and costs fluctuate with the condition. People in this position need a much more flexible benefits system which allows them to receive an income supplement when their income drops or costs increase because of their condition.

Permitted Work: these rules allow people to earn up to £93 per week as well as their benefits for up to 12 months, without getting less Housing and Council Tax Benefit. The earnings disregard now matches the permitted work limit. Supported Permitted Work is a similar scheme which is not capped at 12 months. There is a need to increase awareness and uptake of these options and to make them suitable for those with fluctuating conditions or who have the opportunity to experiment with an enterprise which may earn more than the earnings disregard, without the risk of losing all benefits entitlements permanently.

Access to Work

Access to Work is designed to help individuals if their health or disability affects the way they do their job. It gives them and their employer advice and support with extra costs which may arise because of their needs. Access to Work is theoretically available to disabled entrepreneurs starting up a new business but the business has to demonstrate its viability. Disabled entrepreneurs are not able to provide evidence of the profitability of their start-up business, as the business has not been operating long enough to generate that evidence. They are therefore in practice denied access to help from Access to Work.

Use of Direct Payments to purchase Shared Lives (DH)

Shared Lives is where a family includes an individual in their family and community life. In many cases a disabled or older person becomes a permanent part of a supportive family. Shared Lives is subject to a specific registration and inspection regime from CQC and Shared Lives carers are carefully selected and trained. They are paid a fixed amount, rather than an hourly rate. Some receive up to four weeks paid breaks per year, where the person living with them receives respite care. Shared Lives aims to enable people to experience ordinary life, with real relationships, rather than to provide a service. Shared Lives is not an "off the peg" service – it is highly personalised,

relying on achieving a match between the individual requiring support and the Shared Lives carer who wishes to support them. Around 10,000 Shared Lives carers support around 20,000 people in the UK.

Whilst Shared Lives carer are self-employed, many Shared Lives schemes remain delivered 'in-house' by a local authority. Direct payments cannot be used to buy support and services from a local authority or (according to local authorities' interpretation of the rules) which are arranged by the local authority.

So people could only use direct payments to buy Shared Lives if the service user contracted directly with the Shared Lives carer. We have examples of this happening: it involves circumventing the Shared Lives scheme which normally provides safeguarding, induction, training and supports and monitors arrangements. The risks to both parties are considerable.

We are having mixed results in encouraging local authorities to use a personal budget approach, rather than Direct Payments, in order to make Shared Lives accessible to those who wish to manage their own resource allocation.

Some authorities are also limiting the access of current users of Shared Lives services to Direct Payments or personal budgets, on the basis that the Shared Lives arrangement should meet all of their assessed needs. As Shared Lives arrangements provide a supportive family environment, they can often meet a greater range of needs than equivalent services (we have a business case demonstrating that this creates substantial savings), but they cannot usually meet all of a person's needs, such as the need to pursue employment, or social and leisure activities outside of the home, so we are challenging this view. This is poor implementation, rather than poor legislation.

PCT Rules for the use of Personal Health Budgets (DH)

There are two main delivery mechanisms for personal health budgets:

1. A notional budget is awarded and the PCT directly commissions the service(s).
2. A third party arrangement (through a trust established to manage the budget).

Personal health budgets cannot normally be taken as cash payments (although there is a newly established facility in the pilot sites for the personal health budget to be taken as a cash payment with the approval of the Secretary of State). However, people are attempting to develop a personalised and effective care package through creating a third party organisation to manage the budget. These are micro-providers set up specifically to meet an individual's often very complex needs. Some PCTs are asking those third party organisations to be registered with CQC. However, CQC take the view that a third party organisation providing support for just one person is not eligible for registration.

Contact details:

Alex Fox, CEO, NAAPS (www.naaps.org.uk):

Roles of local/ national government in creating the conditions for community- and family-led action in care and support – outline, September 2010.

At present, exceptional people are taking risks and making personal sacrifices to help people around them, sometimes in the face of indifference or even suspicion from the state. When we see solutions created from close relationships, rather than asking "How we can scale this up?" we should ask, "How can we create the conditions in which ordinary people can do this, without having to take undue risks or abandon the rest of their working and social lives?"

Prerequisites for Big Society	**Barriers**	**Strategies**
• Families and other small intimate networks as building blocks.	• Families under pressure. Geographically scattered families.	• New networks built on shared interests and reciprocal needs (not just proximity). • Replace 'all or nothing' caring with clear choices around work/ caring balance plus package of access to info, training, recognition, emergency back-up.
• Visibility of people with care and support needs as assets and leaders.	• Discrimination. • Isolation. • Disabled people dependent upon state.	• Accessible, inclusive communities. • Asset-based and co-produced commissioning. • Micro-enterprise, including support for disabled entrepreneurs
• People with time to give.	• Low incomes, long hours, lack of engagement of people not of working age.	• Flexible working and staggered retirement; older people as assets not 'time-bomb'.
• Motivation to give time –awareness of rewards and reciprocity.	• Lack of non-monetary rewards, recognition. Lack of awareness of options.	• Social networking (e.g. Tyze), Fureia Kippu, Time banking, Slivers of Time; new routes into wider workforce e.g. Shared Lives, micro-enterprise.
• Proportionate regulation and cross-departmental local and national approach.	• Outdated or ambiguous legislation; risk-averse interpretation of legislation.	• High level statement of intent across local/ national government. Clarification of conditions needed. Advocates and fixers on the ground. • Risk-sharing approach: providing training/ loans/ insurance etc.

[Continued....]

Registered charity: 1095562. Registered company: 4511426

National government / regulator activity:

1. A cross-departmental and national/ local statement of intent on the importance of encouraging combinations of paid and unpaid care (e.g. family caring supported via personal budgets, Shared Lives caring, micro-enterprise).
2. Clarification of areas of regulation open to risk-averse or inflexible interpretation (e.g. use of care-workers' cars; wider access to CRB).
3. Consider banning exclusive use of preferred provider lists, reverse auctions, framework agreements. Promote quality mark for micro-enterprise (in development).
4. Introduce more flexibility into benefits rules around trial work periods and rationalise/ simplify welfare to work programmes for disabled people and carers.
5. Rights: "not just the right to control your budget" but "the right to influence or create provision and commissioning". If parents can create their own schools why can't disabled and older people create their own services?
6. Responsibilities: a greater ambition for employment for disabled people alongside a more flexible and tapered benefits system and support for disabled entrepreneurs.
7. More publicity and non-monetary rewards (e.g. training, vouchers, travel access, entry to proposed care insurance scheme) for family carers and volunteers.
8. Fund start-up of online dating-style web-based tool which people can use to make new connections and communities around shared interests/ concerns, shared/ reciprocal needs.
9. A jointly-owned commissioning guide, setting out in more detail how commissioners and planners can create the conditions in which micro-enterprise flourishes and avoid maintaining structures which are designed for monolithic and in-house provision.

Local activity:

1. Investment in micro-enterprise and entrepreneurial volunteering, via micro-finance, social impact bonds but also making widening access to training, insurance, sickness cover etc beyond traditional/ in-house workforce.
2. Avoid commissioning practices which are inaccessible to micro-enterprise.
3. Actively promote "right to request" and support creation of mutuals whenever provision is out-sourced.
4. Publicise the ways in which ordinary people can get involved in care and support and celebrate those that do. Promote non-monetary rewards for carers and volunteers.
5. Support micro-entrepreneurs and small community groups to come together and support each other. Reform role of CVS in relation to micro-scale activity. Local "fixers" and one stop shops for those developing micro-enterprise.
6. Pursue not just control of budgets for individuals, but shared control of commissioning. Provider organisations should demonstrate joint-ownership, not just engagement or consultation.
7. Focus on employment and community activity when measuring provider outcomes.
8. Engage local NHS in development of micro-enterprise.

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Research opportunities in Shared Lives, Homeshare and micro-enterprise

Contents

What is NAAPS?

NAAPS is the UK network of very small, family and community based care and support solutions for older and disabled people: it is all about ordinary people and families contributing to the care and support of local older and disabled people, sometimes in fairly extraordinary ways. Our membership includes Shared Lives (formerly called Adult Placement), Homeshare and micro-enterprise. These forms of support are described below.

We believe people should be in control of their services and able to pursue ordinary, valued lives within their chosen families, relationships and communities.

NAAPS values and supports care and support approaches which:

- are built around individuals: their strengths, gifts and potential;
- promote equality and value diversity;
- are safe and support people to take risks in pursuit of their goals;
- focus on personal development or on stability, as the individual chooses;
- are cost-effective, with consistently better outcomes than alternatives.

We are an infrastructure body with the mission to put people who need support in control of their services and of their lives, through creating caring relationships and networks which are built around the individual's wishes, needs and gifts.

NAAPS works with its members to:

- provide resources, training, insurance and one-to-one support;
- help members to talk to, support and learn from each other;
- ensure that members' voices influence national and local decision makers;
- raise awareness of the value of members' work;
- commission research and strengthen the evidence base for our work.

NAAPS' most recent brief report is *Cuts or Putting People First* (October 2010), endorsed by Richard Jones, President of ADASS, in which we outlined how Shared Lives, Homeshare, micro-enterprises and other approaches which draw on reciprocity and mutuality appear to have the capacity to make savings as well as addressing challenges to the personalisation agenda.

Micro-enterprise in the UK

NAAPS supports ordinary people who set up micro-enterprises which meet the needs of a local individual or small group. Some of these enterprises are set up by front line workers previously based in large organisations, others are set up by disabled or older people themselves. They often draw on the resources of the local community. Some are funded through personal budgets or paid for with people's own money (self-funding). Some are carried out on a voluntary or part-voluntary basis, with any payments simply covering the cost of providing the service. Some micro-enterprises are co-operatives which may be owned jointly by people who deliver and people who use and pay for the service.

Many micro-enterprises operate "below the radar" of local government and NHS. Micro providers face growing regulatory, legislative and other barriers and as a result many fail. In most areas their

numbers are falling, but some areas draw on the support of our social enterprise, Community Catalysts to create the conditions in which they can survive and thrive.

Existing research into micro-enterprise

There has been extensive research on social enterprise in general in the UK and a smaller amount which covers or focuses on micro-enterprise and social enterprise in the provision of care and support for adults.

Research (e.g. Fiedler (2007) *Supporting social care micro providers – A review of the literature*, SCIE / NAAPS; Phillimore et al (2009) *Under the radar? Researching unregistered and informal third sector activity*, University of Birmingham;) suggests that there are many more micro-enterprises than registered charities, with around 240,000 people attempting to start a social venture at any one time (Harding (2008) *Social Entrepreneurship in the UK*, Delta Economics). NEF research estimated that in 2001 there were a staggering 600 – 900,000 micro-enterprises in the UK, but that micro-enterprises often operate "below the radar" and sub-legally, with many failing within 18 months (MacGillivray et al (2001) *Low flying heroes. Micro social enterprise below the radar screen*, New Economics Foundation).

Their numbers are falling in most areas, as they lack access to information and training in relevant regulatory and commissioning issues. Many micro-entrepreneurs are embarking upon their first business venture and they can lack confidence and business skills. These problems, such as difficulty in finding funding or finance, can become more acute as the enterprise progresses (Harding, 2008).

In our report, *Cuts or Putting People First* (October 2010), endorsed by Richard Jones, President of ADASS, we outlined how micro-enterprises and other approaches which draw on reciprocity and mutual ownership are making savings as well as addressing challenges to the personalisation agenda.

There are other organisations working at a national level to fund or support social enterprise, but none focused on micro-enterprise in the field of care and support. NAAPS, along with its social enterprise, has developed expertise in this area of work which we can use to bring awareness of what works (and what doesn't) in micro-enterprise to a wider audience. Our work was referred to in a number of places in the Department of Health's new Vision for social care (October 2010) and supporting documents as examples of the kind of initiative which the Department would like to see more widely developed.

We have commissioned a cost-benefit study into our work supporting micro-enterprise (through putting a "fixer" in a local area to locate, encourage and support micro-enterprise), which is being carried out by Manchester Metropolitan University.

Research needs in micro-enterprise

Personal budgets have not led to provider diversity (it would be interesting to test this generalisation). What are the factors that lead to provider diversity? To what extent are people purchasing from a changed or unchanged menu of services?

It is still relatively rare for people who use services, family carers and front line workers to set up new services and micro-enterprises. What are the barriers and the factors which promote this happening? What are the reasons for micro-enterprises failing or thriving? What are the roles of councils, the NHS, regulators and national government in supporting micro-enterprises? What risks

do commissioners perceive in new provision options, including micro-enterprises, how evidence-based are those perceptions and how can they be encouraged to risk-share with new providers?

Mutual ownership is still rare. What models of mutual ownership between service providers, service receivers and others are developing? What impact if any does the form of ownership have upon the nature of the service/ outcomes / user satisfaction/ worker motivation?

What can established and large providers learn from micro-enterprise? For instance, Community Catalysts is working with McIntyre to help it support its users to develop micro-enterprises and to explore the potential for McIntyre staff to use entrepreneurial approaches to innovating within MacIntyre.

Social care is still siloed. To what extent is the flexibility of personal budgets bringing new workers into the social care workforce/ challenging the notion of a social care workforce?

To what extent do different approaches to support combine paid and unpaid elements of support?

For many in the sector and by extension, for many budget holders, the goals of personalisation have been restricted to a better support package. It is still relatively rare for budget holders to use their budget to gain a job and/or to contribute to community life (e.g. through volunteering or developing a micro-enterprise). What is the extent of this happening? What are the success factors/ barriers? How might we promote the outcome of budget holders contributing to communities as well as receiving support? What responsibilities should/ would accompany greater rights?

What is the range of people's choices in living a) alone, b) with families and c) in other forms of close relationships? To what extent to people have choice in this area of their lives? Models such as Shared Lives (significant, with 10,000 Shared Lives carers across almost every area of the UK) and Homeshare (tiny in the UK, much bigger in other countries) appear to demonstrate people's desire to live inter-dependently as well as living on their own. What does "independent living" mean to people who live with family, friends, partners or Shared Lives carers? Do choices about living arrangements have an impact upon the success people have in living within their community? How do independent living outcomes (and support costs) vary between various forms of living alone, various forms of living with non family members and living with your birth family?

To what extent are people who use services and their carers able to act as commissioners, rather than merely consumers? Whilst co-production often limits people to stating preferences about existing services, in which they have little ownership, genuine commissioning power is characterised by:

- Involvement in designing new services and service specifications.
- Working collaboratively rather than as individuals. This can be through pooling budgets or setting services up with pooled budgets.
- People who use services involved in decision making bodies on an equal basis with professionals and other members of the community.