

# **Cuts or *Putting People First?***

## **Having a life as well as making a saving.**

### **NAAPS 2010**

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## 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](http://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 bounded, 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](http://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](http://www.naaps.org.uk) and <http://alexfoxblog.wordpress.com>.  
Find out more about Community Catalysts at [www.communitycatalysts.co.uk](http://www.communitycatalysts.co.uk).