

Personalisation of social care for disabled children, young people, their families and carers

Opportunities, challenges and concerns

About this paper

This paper identifies some of the key opportunities and challenges around the personalisation of social care as identified by the Council for Disabled Children.

It is a review of the literature available on personalisation both from the voluntary sector and government, and highlights some of the key issues in personalisation for disabled children, young people, their families and carers. It is part of a series of papers developed by CDC and members of the CDC working group on personalisation alongside the Association for the Directors of Children's Services. These papers look at personalisation in numerous different contexts including education and transition services, as well as discuss some of the key issues for the voluntary sector arising from the implementation of the personalisation agenda.

CDC would like to extend its thanks to the wider Social Inclusion Department of the National Children's Bureau in producing this paper.

What is personalisation?

'Personalisation is a word that was hardly used in a social care context – or in any other for that matter – until a few years ago. Now, not just a buzzword, but a term that has come to signify and represent probably the biggest change in social work and social care practice for a generation'.

(Newman 2009, vii)

Newman's estimation of the potential significance of personalisation for users and providers of social care services for children and young people with disabilities and their carers, is supported by the literature on the subject, both that emanating from its (often passionate) proponents, and that written by those with concerns as to some of its possible consequences (intended or unintended).

'Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about what, who, how and when they are supported to live their lives'.

(SCIE 2008, p.3)

The proponents of personalisation cite fundamental and widely accepted principles, such as the individual's right to autonomy, choice and control over the way their life is led and how it is supported, in favour of their radical agenda for change. As such it is very difficult to take issue with key underlying principles of personalisation. Equally, in terms of the practical and organisational changes deemed necessary to implement personalisation, the menu again seems patently attractive and thoroughly humane in intent, if ambitious in scope:

- Tailoring support to people's individual needs and preferences
- Ensuring that people have access to information, advocacy and advice to make informed decisions about their care and support
- Finding new collaborative ways of working (sometimes known as co-production) that support people to actively engage in the design, delivery and evaluation of services
- Developing local partnerships to co-produce a range of services for people to choose from and opportunities for social inclusion and community development
- Developing the right leadership and organisational systems to enable staff to work in creative, person-centred ways
- Embedding early intervention, re-ablement and prevention so that people are supported early on and in a way that's right for them
- Recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities
- Ensuring all citizens have access to universal community services and resources – a total system response

(From Carr 2010, p.3-4)

To its advocates personalisation aspires to achieve two eminently desirable and,

they would argue, interconnected aims – firstly, to give the user of services greater personal control over their services and secondly, to so closely tailor services to the individual's needs as to achieve more efficient outcomes and better use of limited public funds (Commission on Personalisation 2009).

In its ideal manifestation personalisation involves '*a new script for public services*'. The individual user or consumer of services moves from being the passive recipient of whatever is currently available or whatever is considered by others to be the 'best option' to address their needs, to being the active commissioning agent and shaper of those services. The user or citizen decides their own priorities and then develops and shapes the services – the co-designer and commissioner of their own support services. In doing so they may utilise existing services or providers of care, or initiate new services, making creative use of their 'social capital' (e.g. family and friends or the relationships most meaningful and available to them):

'There are three arguments for improving public services:

- i. Public services just need more money*
- ii. Users should be set free as consumers, with funds to buy services appropriate to their needs*
- iii. Users should be set free as citizens and given a voice in decision-making'*
(Leadbeater 2004a, p.1)

It may now seem highly unlikely, given current economic circumstances and prevailing political ideologies, that any initiatives in public services will benefit from receiving more public money. Nonetheless proponents of personalisation would argue that a more efficient, or at least more acceptable, use of the resources which do exist will be achieved by involving recipients of care in allocating and spending resources. It is argued that users of support services are often the 'experts' in their own conditions and circumstances, with the best insights into how the available budgets should be spent. As equal citizens they also have the right to be consulted and to have a say in decisions made about them or their care. However, such personalisation of service planning requires a major shift in mindset and approach by service planners and support staff. This in turn needs to be supported by practical mechanisms and devolvement of power, such as the increasing use of individual or personal budgets, which put service users in a more powerful position to determine exactly when and how they receive care and who they receive care from.

In the *Foreword to Personalisation: Children, young people and families* (Crosby 2010) Philippa Russell, also argues the merits of personalisation both in terms of individual empowerment and efficient use of increasingly tight resources:

'In what the King's Fund recently called 'a cold climate' (i.e. a time of financial restraint and limited budgets) I also suspect that Personal Budgets actually offer better value for money because they deliver what families really want and use mainstream services more creatively and at less cost than their specialist

equivalent'

(Russell in Crosby 2010, p.1)

Russell acknowledges the current political and financial climate is 'challenging' but asserts that the new Coalition Government *'has embraced and will develop the Personalisation agenda with its emphasis on empowerment, user experience and community development'*.

History and Development

Personalisation: a rough guide notes that the approach has some of its roots in the disability, mental health survivor and service user movements of the 1970s, in which individuals and groups undertook direct action and lobbied for change to achieve greater control for service users over the provision they received:

'Independent living, participation, control, choice and empowerment are key concepts for personalisation and they have their origins in the independent living movement and social model of disability'.

(Carr 2010, p.20)

During the 1990's various disability lobby groups campaigned for service users to have more independent choice and control over the services they used. In 1996 the *Community Care (Direct Payments) Act* made it possible for adult care users to receive a small sum of money with which they could then purchase the services they themselves judged best to meet their needs. *The Carers and Disabled Children Act (2000)* extended Direct Payments to people with parental responsibility for a disabled children and disabled young people aged 16 and 17 years. In 2003 *In Control*, a not for profit organisation, working together with *Valuing People* and some sympathetic local authorities, began developing ways in which services users with learning disabilities could exercise more direct choice and independence in their lives by utilising direct payments, with help and support if necessary. *In Control's* work encouraged the Department of Health to fund a set of national individual budget pilots, extending the use of such budgets to all adult users of social care services (Commissioning Support Programme 2010).

Government legislation, policy and guidance have actively encouraged the personalisation process in recent years and extended their use to include children's services. *Every Child Matters* and the *Children's Plan* emphasised that services should be shaped by, and responsive to, the wishes of children, young people and their families, as distinct from services being designed around pre-existing professional boundaries. Further policy developments which confirmed or supported this trend include:

- *Putting People First* (2007) committed the government to an extension of

- Individual Budgets and Self-Directed Support to all those in need of social care;
- The *NHS Next Stage Review* (2008) indicated government support for Personal Health Budgets;
- *Aiming High for Disabled Children* (2007) outlined plans for pilots of Individual Budgets for Disabled Children, Young People and their families;
- *Budget Holding Lead Professional Pilots* provided further mechanisms for parents and children with high support needs to access personalised and self-directed use of funds in order to shape their support services to their personal priorities.

(Crosby and Duffy 2008, p.3)

To its proponents, personalisation thus represents a radical and liberating transfer of power from professionals and providers to support service users, who become in effect the commissioners and designers of the services which they receive, with the central voice in resource allocation and expenditure. Mechanisms and models such as personal health budgets and individual budgets for social care services are means towards achieving the wider personalisation goal. According to their proponents and to satisfied users cited in the literature, they give the service-user real control over their lives and make personal choice a reality in shaping their services.

Personal and Individual Budgets–self directed support

In December 2007, *Putting People First* proposed that all social care users have access to a personal budget, with the expressed intention that users could exercise choice and control over how best to meet their agreed social care outcomes. The Association of Directors of Adult Social Services ADASS reported that by early 2009 some 93,000 people were receiving personal budgets and the previous government anticipated at least 30 per cent of eligible adults would be on personal budgets by 2011, with attendant access to the information and advice services to support them in making informed choices as to how best to use those budgets to meet their needs (Carr 2010, p.8).

In both the health and social care services the provision of greater 'choice and control' for people over the services they use has increasingly been seen as critical in improving the user's subjective experience, their independence and sense of personal well-being. At the same time, it is argued, such control will drive up the objective quality of care. According to a report commissioned for the Commission for Social Care Inspection:

'Choice and control has become the key mantra of social care.... Central to this was the further promotion of Direct Payments and of models of self-directed support

and personalisation, particularly through the piloting of individual budgets maximum independence and access to information; being able to choose and control services and helped to manage risk in personal life'.

(Henwood, M and Hudson, B 2008, p.78)

Personalisation, the shaping of services around the individual needs and wishes of patients, users of services or their carers, has become a central tenet of current health policy. The *NHS Next Stage Review: our vision for primary and community care* (Department of Health 2008) set out the Department of Health's vision for primary and community care services and its strategy to support patients and the public, clinicians and the local NHS, in achieving '*continuous improvement in the quality of services*'. Amongst proposals in the Review was the offer of a personal health budget to people with '*predictable long-term conditions*'. In its declared intentions this budget would be essentially similar to the Individual Budgets and Direct Payments already available in the social care field. Personal Health Budgets it is claimed, assuming that the pilots in several PCTs announced in 2009 confirmed their effectiveness, will give patients who opt to have one greater control over the choice and design of services which they receive and over who provides them.

As indicated above, those driving forward the personalisation agenda would argue that such budgets, offer the individual, or their carers, greater flexibility, control and choice – the power to commission and shape services which fit around their individual personalities, priorities and needs, rather than service users simply having to fit with the 'one size fits all' models of services as currently provided.

'Most schemes share the same goals of improving freedom of choice, independence and autonomy and using public funds more efficiently'.

(Carr, S and Robbins, D 2009, p.1)

SCIE's video *Personalisation for someone with a learning disability* offers an example of how a personal budget works in practice for Hannah, a 22 year old, who has Angelman Syndrome and lives with her family in a rural setting. Hannah, we are told, does not like being with people she does not know. Personal budgets have enabled her family, with the agreement of Essex County Council, to pay Hannah's sister Chrissie to support her care needs within the family home, rather than her having to go into residential care. Despite Hannah's very limited communication Chrissie emphasizes that she and the rest of the family work to ensure that the support they give is a genuine expression of Hannah's own preferences (Social Care Institute for Excellence 2009).

Similarly, case studies cited in *Personalisation: Children, young people and families* (Crosby 2010) offer examples of ways in which personal budgets have provided a practical tool which empowers young people to actively express their preferences and participate in planning and shaping the services which seek to address their needs:

'One young person involved in the Individual Budget pilot felt strongly that the planning and the Individual Budget gave him a much stronger voice when it came to talking about the future. He felt that this would be really helpful for lots of other young people too'

(Crosby 2010, p.3)

Innovation, individuation, transparency and cultural change are repeatedly emphasised as the prime motive forces and gains resulting from personalisation and attendant mechanisms such as individual budgets. The concerns voiced by some that there may be unintended negative consequences or even hidden agendas behind the move to personalisation are disputed. For example, some might question whether the drive to personalisation from the government's perspective is ultimately more concerned with capping or reducing care entitlement. This has been denied by the previous government, though with the proviso that it hoped that new measures such as Individual Health Budgets would encourage *'realism as to the resources available'* and not prove more expensive than current structures:

'A personal health budget makes it clear to someone getting support from the NHS and the people who support them how much money is available for their care and lets them agree the best way to spend it. We do not think this will save money. We want to help people get a better service from the NHS without it costing more.'

(NHS Confederation, Mental Health Network 2009, p.3)

Increasing user choice or privatising risk?

Ferguson, writing in *'Increasing user choice or privatising risk? The antinomies of personalisation'* argues that personalisation, beneath its apparently benign transfer of power away from a patriarchal state and service providers in fact transfers risk from the state to the individual at a time of diminishing resources. Ferguson argues this may prove to be to the disadvantage of some already vulnerable groups. The personalisation process in effect *'marketises'* social care, neglecting the issues of poverty, power and equality which inevitably bias free markets in favour of those who are already relatively privileged groups of consumers. In the process personalisation also arguably de-professionalises the social workers who might otherwise mitigate the operation of market forces (Ferguson 2007).

Whatever the ultimate balance of gains and losses to individual service users, providers and frontline workers, in terms of increased personal choice and control, increased risk or loss of existing services, or of changes for frontline workers in their terms and conditions - it does appear likely that, if driven forward by the new government, personalisation may well represent the *'biggest change in social work and social care practice for a generation'*. However, the gap between vision and reality

may be considerable and it is essential that both users of services and providers fully consider and prepare for what personalisation could mean for them.

Increased personal autonomy

In any such assessment claims as to the potential of personalisation to bring about enhanced personal autonomy and choice for users, and therefore radically improve their well-being, require serious consideration, as this is arguably the most potent argument to be deployed in favour of the personalisation agenda.

'I just want to control my own life.... I don't want people to control my life for me I want to control it myself. That's what my mum brought me up for to control my own life'.

(Carr 2010, p.1)

Similarly the Children's Society report *'Makes your life, your life' Disabled young people's views on choice, control and support in relation to their lives and the development of individual budgets*, confirms the desire of some young people to have a more central role in the planning process and, while drawing on the advice and assistance of people who know them well, to make their own choices:

'You should be able to choose what you want – like services and support. Some people might want to choose different things'.

(Children's Society 2006, p.12)

The personalisation process seems to respond to such perfectly legitimate desires by providing greater user control over how money is spent:

'A good example is the way some local authorities allow disabled people to commission their own care packages, working with advice from professionals. In this case, users are far more knowledgeable about what they need and how to get it than many of the professionals'

(Leadbeater 2004b, p.22)

The state's or professional's role in this new distribution of power and responsibility is as an enabler, facilitating an adequate market of choices and then working in partnership with users to ensure that they have sufficient information about the expanded menu of choices available to make informed and wise choices. As Crosby argues in the *In Control* briefing, *Personalisation: children, young people and families*, personalisation involves a transformed relationship between the state and individual child, young person or family – a relationship based on working co-operatively and *'founded on citizenship and entitlement'* (Crosby 2010, p.3)

'The beneficiary-related outcomes and impacts framework currently hypothesises

that families and disabled child/young person may first experience increased choice and control, and improved quality and appropriateness of care as a result of taking up IB (Individual Budget) provision’.

(SQW Consulting 2009, p.5)

How is it done? Key stages of the personalisation process

The DCSF’s *Personalisation: the seven steps of self-directed support*, sets out one commonly-used process for providing self-directed or personalised support. Noting that the Department did not necessarily favour one model over any other, the DCSF publication draws on the work of *In Control* to describe a model used in many local authorities. This model places emphasis on the centrality of individual user in assessing their support needs and in taking a lead role in the planning process and resource allocation designed to address those needs. Once a support plan is agreed between user and local authority (as guardian of the public purse), it offers the user of services flexibility and control over when, how, and on what, money from the agreed and allocated budget is spent.

These seven steps have been developed over the last five years of work by in Control and offer a simple narrative to developing self-directed support for an individual

1. *My Money: Finding Out How Much*
2. *Making My Plan*
3. *Getting My Plan Agreed*
4. *Organising My Money*
5. *Organising My Support*
6. *Living My Life*
7. *Seeing How It’s Worked (review)*

(DCSF 2008, p.3)

The document points to what it sees as the essential difference between personalised funding and planning for social care services, and traditional approaches to resource allocation:

‘The essential difference between the self-directed support process and the more traditional way of supporting the individual is that here the funds are identified first and then used to inform the drawing up of a person-centred support plan, whereas the existing system bases the allocation of resources on a completed plan’.

(DCSF 2008, p.2)

Thus it is clear that financial ‘realism’ is the fundamental starting point and it is

obvious that, as with many initiatives, the personalisation agenda must be understood as operating within a socio-political-economic context where public expenditure is constrained and is currently likely to shrink sharply rather than remain stable, let alone increase. Personalisation: the seven steps of self-directed support notes that traditional funding arrangements have previously resulted in large amounts of local authority budgets being allocated to relatively few children and young people – *'often due to the costs of specific interventions or services, rather than there being a huge difference in need compared to the wider eligible population'* (DCSF 2008, p.2).

It is claimed that personalised models of resource allocation, based on professionals and users jointly identifying and prioritising support needs and then the resources best able to meet those needs, will result in fairer, more efficient and creative use of available resources and funds. Moreover, it is argued, users and families will be better able to accept, understand and take ownership of the process, since they will have been central to identifying and agreeing their support needs and priorities, and to the subsequent planning and allocation process designed to address those needs. Thus *'a fairer decision can be taken about the money available to support a child or young person'*. Furthermore, given that the money available is always likely to be limited, people will be encouraged to use it creatively and wisely, making effective use of their existing 'social capital' (e.g. family and friends) where this is possible. The document states that often-expressed concerns that individuals will seek to exploit the allocation process by over-stating their needs have proved groundless in the local authority trials – with family members more likely to *underestimate* their needs and professionals in contrast more prone to *overestimate* them.

Personalisation: the seven steps of self-directed support acknowledges that not every family will either want, or feel able, to manage a personal budget allocation, or wish to take on the various legal and financial responsibilities entailed in directly employing people, although it re-iterates the fundamental principle that all can take part in the decision making process as to how 'their' money, available for their care, is best spent:

'There needs to be range of options for managing Personal Budgets, from which families can choose. These might include the services of a nominated representative, and Independent Living Trust, a broker or support provider, a Budget Holding Lead Professional, a care manager or other representative of Children's services. How the money is managed, and by whom, will be set out in the support plan'.

(DCSF 2008, p.6)

The paper concludes with Pen Pictures of young people, including those with complex health needs and learning difficulties, their families and carers, who have used the devolved control over budgets. Their accounts apparently substantiate the claims of personalisation advocates as to how the central involvement of users

in the decision-making process and how budgets are spent is likely in practice to improve individual quality of life. Examples given include 'innovative', rather than traditionally accepted, uses of expenditure, such as the part-purchase of a caravan and use of family members as paid carers to maximise opportunities for more enjoyable quality of life. It is very hard to argue with the experience of individuals, as evidenced in this and other publications, for whom the process has, by their own account, worked well and effected a positive transformation in their quality of life.

'Staff treated me with respect because I was in control of who was employed and what they did to assist me, both in my home and in the wider community. I would not employ someone who decided they would take over my life and decide what was best for me'

(Carr 2010, p.7)

Concerns and reservations expressed – the balance of 'losers' and 'winners'?

It should be noted, as already indicated, that much of the literature and evidence advanced on personalisation has related to adult services and users. In seeking to apply the model to children and young people it may be that there are particular factors and vulnerabilities, and that assumptions about individual agency and need for advocacy, and about safeguarding concerns, need to be given extra scrutiny and consideration. Moreover, whilst one welcomes the personal success stories, the caveats remain.

- Does the personalisation process, even allowing such examples of the gains from personalisation for particular individuals from the personalisation agenda possibly entail unacceptable risk for others, notably in terms of safeguarding and the potential for exploitation of vulnerable young people?
- Could the undoubted gains for some articulate and motivated individuals and families be offset by diminishing the choices of others? Could personalisation decrease choice for others less able to make the system work to their advantage?
- Could personalisation increase safeguarding risks?

Whilst it is impossible to object to the aspirations for greater individual choice and autonomy in principle, concerns and reservations have been expressed as to the possible implications of policies such as individual budgets in practice, and the (possibly unintended) impacts on both those who choose to embrace them, and those who do not. The 2008 *Evaluation of the Individual Budgets Pilot Programme*

– *Final Report*, whilst noting the very real advantages of individual social care budgets in terms of flexibility – for example being able to choose one’s carer and develop a regular relationship with them, or prioritizing one’s own needs – also identified anxieties and concerns amongst some recipients of services:

‘... three types of experience emerged: those who did not want anything different; those who were anxious but could see some potential benefits; and those embracing the potential for choice and control over their own support’.

(Glendinning and others 2008, p.72)

The evaluation found that, whilst Individual Budgets were relatively popular with people with physical and sensory impairments, people with learning disabilities and their carers could find the attendant processes and bureaucracy stressful. The report found that Individual Budgets seemed most suited to the most competent and articulate. Arguably such concerns over the increase in personal responsibility attendant on having a personal budget, perceived or real, could to an extent be allayed by local authorities ensuring that people have access to the support, advice and expertise necessary to get the best use out of the money available and in exercising informed choice, as recommended in *Personalisation: the seven steps of self-directed support*. It is clear that people should be supported, to the extent they require such support, in managing their budgets.

There were also some concerns as to inappropriate use of budgets, and perhaps more worryingly about safeguarding and monitoring issues and the possible exploitation of vulnerable people. *Individual Budgets for Families with Disabled Children* (Prabhakar and others 2008), whilst also noting the positive potential of budgets, found that some parents and young people experienced difficulties in coping with the new role of being an employer, with the financial management and administration of the budget and in finding good quality personal assistants and care workers. Individual Budget payments might be subject to delay and the theoretical increase in choice could be limited in reality by lack of service availability.

Glendinning’s study of the impact of Individual Budgets in social care provision also noted concerns that in practice the introduction of consumer choice for some service users could destabilize the wider market of care providers for others. That whilst in theory, increased consumer choice and power of the markets ought to ensure that providers who are more flexible and responsive to consumer demands prosper while those who do not provide as good a service fail, in practice the exercise of such ‘choice and power’ by some might result, for example, in the loss of community or accommodation-based services for others as these services became financially non-viable. Extended choice for some might in effect ultimately reduce choice for others.

The King’s Fund, while noting that Individual Budgets may work perfectly well in the social care field for users with stable and predictable long-term conditions, has also

expressed doubts as to the wisdom or applicability of individual budgets in respect of health care:

'In health care the problem is more difficult. The need for medical care is uncertain even for people with stable illnesses, and the risk of ill-health cannot be accurately predicted at individual level'.

(Dixon and Ashton 2008, 28 August, p.1)

Developing the Market - Provider and Workforce Issues

'Choice is only possible if the services they want to purchase are readily available, of good quality and have spare capacity to respond to choice'.

(Carr 2010, p.47)

Having a personal budget is obviously of limited value if the choice of provider or service is limited, inflexible or of dubious quality. The Commissioning Support Programme, in *Learning Together Report: Personalisation in Children's Services* acknowledges that the extent to which mechanisms such as individual budgets or Budget Holding Lead Professionals can help to transform services is limited by how far providers respond to changing requirements by personalising their services. Contracting and commissioning arrangements and the use of personal budgets can stimulate such change but some providers will need help in transforming their current range of services (CSP 2010).

Nonetheless, it is clear that it will take time for a social care "market", which is currently largely geared to an entirely different model of commissioning, to re-align to address new requirements and demands. Studies such as SQW Consulting's *Individual Budgets for Families with Disabled Children* (SQW 2009) have identified that for some services – for example short break schemes for disabled children and young people – there is currently insufficient capacity to meet any increases in demand.

The SCIE report *Personalisation: a rough guide* and DCSF's *Personalisation: the seven steps of self-directed support* both acknowledge that direct payments and individualised budgets have the power to both develop and to destabilise existing care markets. Carr (2010) suggests for example that an increase in the use of self-directed support and personal budgets may well mean there will be a smaller role for block-contracting and in-house service provision. This may seem an acceptable way of consumer choice driving and shaping change, rejecting '*one-size fits all, service-driven*' menus of choice which are based on matching users needs to existing services. As users of services, or their agents, deploy their budgets to commission new, personally-tailored provisions which express and address their particular personalities and preferences, it is argued that a new range of provision

or market of care options will develop. Proponents of the change would argue that any attendant risks may be no different to those already accepted, contracted for, and managed in the private care market:

'Increasingly people will make arrangements with private individuals to provide the support they need, and this will raise a range of issues about employment rights, pay, health and safety and safeguarding. This already applies to people who make their own private arrangements for care in their own homes without recourse to public funding'

(Carr 2010, p.32)

Training needs

There seems likely to be an increase in the individual contracting of, for example, personal assistants employed to carry out a very flexible range of care tasks and social functions. Concerns have been expressed at the idea of clients employing untrained or otherwise unsuitable assistants, using their budgets to do so. Lord Victor Adebowale, CEO of Turning Point agrees that:

'The idea of clients employing untrained personal assistants under the new system of individual budgets raises alarm bells for many, but whilst some form of regulation is certainly needed, it's important that we don't deny our service users the greater level of choice and control that individual budgets can bring'.

Adebowale in Newman, S (2009) *Personalisation: practical thoughts and ideas from people making it happen*. OLM-Pavilion. p.95

The Commissioning Support Programme's *Learning Together Report: Personalisation in Children's Services* sees commissioning as a tool for implementing personalisation, ensuring that the services provided are well understood, wanted and 'highly likely' to improve outcomes for each child and family and, most importantly, ensuring that parents, children and young people are fully involved in decisions about their lives:

'Doing with rather than doing unto means working appreciatively with families to find out and build on their strengths and to encourage them to suggest ways in which their difficulties can best be addressed'.

The report suggests that the care solutions co-produced by professionals and service-users in an 'equal and reciprocal relationship' may well include the use of family and friends and that the personalisation process can '*reveal a lack of support for traditional services*'.

(Commissioning Support Programme 2010, p.2)

The report acknowledges that frontline staff from every profession involved will need training and development support to change their orientation and way of

working with parents and young people as both active citizens and as equals in the planning and delivery of care. Staff unaccustomed to working in such a person-centred and directed way may well need further training and support. Equally, some critics are concerned there may be a danger that requirements for 'flexible working' by commissioners and providers could become a euphemism for exploitation. There are further concerns that unregulated 'markets' for care within prescribed and limited budgets can produce a drive for the lowest and cheapest option, which undermines, rather than drives up, standards. In the recent independent report conducted for UNISON entitled *Who Cares: Who Pays? Personalisation in social care*, the authors point to several potential concerns or issues requiring further consideration. These include:

- Staff need to have adequate support, training and pay levels and the skills and experience to facilitate assessment of needs and to help find the services which best address those needs;
- Assessments should be 'carer blind' (i.e. not take account of whether there is an existing family carer) – *'The interests of family carers may not always coincide with those of the person needing care and could open the door to future restriction of publicly funded care to those who do not have any family support'*;
- Better support is needed for carers to combine caring and employment;
- Direct payment or personal budget holders need guidance about their responsibilities and reasonable employment expectations with a range of standard contracts produced which local authorities can ethically endorse;
- *'While not wishing to lose the benefits of informal working arrangements, it is not acceptable to create a large class of employment effectively exempt from good employment practices'*;
- Alternative models, including ones where the local authority remains the employer need to be developed *'As is the case in other countries with longer experience of personalisation'*;
- Agencies to prevent exploitation of vulnerable workers;
- Career paths, training and reward opportunities should encourage stability, retention and development of the workforce.

The report raises other concerns as to whether the personalisation process has the potential to make trained social workers increasingly redundant as users take more control over their own needs. Conversely, other articles record concerns among some professionals as to whether the process will make even greater bureaucratic demands on those individual social work staff charged with helping clients to expedite the necessary paperwork involved:

'It can take six to eight months to instigate [self-directed support] – from filling the forms in, getting a separate bank account, getting the money in there. It has to go to a panel as well. They may have questions and it may come back to you three or four times to get it agreed'.

(Social worker in Samuel 2010, 20 May, p.16)

Echoing the concern of others, the UNISON report also raised the concern that the increase in use of personal budgets and personal care assistants could be at the expense of some current care providers and those who do actually benefit from and enjoy their services.

Providers of care services might claim that traditional systems of resource allocation such as block contracts, far from operating purely to suit their own interests, have hitherto allowed for economies of scale, for a degree of predictability and stability, forward planning and the retention of trained and skilled staff. According to a recent article in *Community Care*, '*Personalisation: cuts threaten transformation agenda*' (Jeremy Dunning, 19 May 2010) the cost pressures on councils faced with having to run traditionally commissioned services alongside personal budgets, whilst simultaneously facing unprecedented cuts in funding from central government, can only increase pressures on an already overloaded system. The eminently desirable aim of giving greater individual choice, and the insistence of some individuals on more flexibility, could thus adversely affect providers of traditional services such as residential homes, day centres and domiciliary support services, which rely on a predictable and relatively constant market for group care solutions. This could in turn mean that those who still prefer, or require such facilities, find that such options are no longer available as they become financially unviable.

'There is an anxiety that the traditional menu of collective social care services – such as day centres and respite care – will wither away, leaving people adrift in a complex and inadequately regulated market: existing collective services may be closed without adequate alternative support provision being offered in replacement'.
(Beresford 2009 p.3)

Kevin Williams, Chief Executive of KIDS, writing in *Personalisation: children, young people and families*, articulates the major shift in thinking, planning, delivery and administration which has been required for his organisation. Personalisation has required a shift in focus from the local authority being 'the customer' to the disabled child/family being the customer. This in turn means a shift from providing '*wholesale services*', bulk purchased by the local authority, to '*retail services*', purchased individually, family by family. Marketing formerly aimed at just 150 local authorities now has to be aimed at 700,000 disabled children, and finance systems geared up to manage '*low numbers of large value invoices*' now needs to manage very high numbers of small individual transactions, purchased as and when required by individuals, with no guarantees. As Williams comments:

'Personalisation might work well for families but it's a big challenge for a service provider'

(Crosby 2010, p.11)

Safeguarding concerns

Another recurring concern in the literature is a perceived difficulty in reconciling safeguarding and risk concerns against increasing user choice. Obviously choice entails the risk that individuals may choose unwisely or take greater risks. One may ultimately take the view that, as equal citizens, service users are free to take such risks, providing they have been given the best possible advice and support. Russell, while welcoming the personalisation agenda for its potential to empower the individual and improve their quality of life, acknowledges that there are safeguarding concerns:

'Of course there are safeguarding issues. Of course families will need support But the emphasis is on informed choice'.

(Russell in Crosby 2010, p.1)

In the same publication Kevin Williams, Chief Executive of KIDS, records that he had encountered many concerns about safeguarding in his discussion groups on personalisation:

'Particularly following publicity around a number of system failures in keeping children safe'.

(Williams in Crosby 2010, p.12)

Neill and others writing in *'A positive approach to risk requires person centred thinking'* (Neill, M, Allen, J, Woodhead, N, Read, S Irwin, L and Sanderson 2008) argue that those with a duty of care can be understandably risk-averse in a society where the news media can savage services and ruin the lives of professionals deemed to have been neglectful. Nonetheless the rights of individuals to make their own choices and decisions cannot be ignored. In balancing such competing imperatives it is argued by some that the individual should be enlisted as a partner with professionals in risk assessment and management:

'Regulators too want to see the balance of risk decision shifting toward supporting individuals who choose to take informed risks in order to improve the quality of their lives'.

(Neill and others 2008, p.3)

Viv Slater writing in *'Risk and safeguarding risk'* cites various sources in support of a negotiated approach to risk management. For example the Department of Health's 2007 *'Choice and Risk'* framework makes the point that avoiding risk altogether is not an option and would constrain the choices people make and their right to self-determination. Trying to remove every risk can destroy a person's quality of life and it may be better to accept an element of risk as long as it is understood, explained and managed. Slater, writing on *'Risk and safeguarding risk'*

in Newman 2009 cites Duffy and Gillespie's work on personalisation and safeguarding:

'By shifting the role of the local authority towards that of interrogator, checker and approver (of the plan) it encourages a creative dialogue that radically reduces the risk of ill-considered plans or services'.

(Slater in Newman 2009, p.72)

The vexed question of who exactly would need CRB checks, something not actually required under Direct Payment guidance, but nonetheless felt by some authorities to be a reasonable safeguard in checking the employees a family or individual chooses to recruit, could constrain a family's choice and ability to innovate. Yet setting such constraints is arguably a rational safeguard where public money and professional judgement, reputation and risk, are concerned. As ever there are delicate decisions to be made where a vulnerable person's self-interests are concerned, resting upon assumptions about the relationship between the individual and the state, personal autonomy and professional judgement:

'Does the provision of an Individual Budget help to improve safeguarding? e.g. by ensuring that those who know the child best (their family) are more directly monitoring their child's support, and providing support more closely tailored to individual need, and also supporting families to construct support that nurtures good family relationships and reduced stress'

(SQW Consulting 2010, p.2)

SCIE's *Personalisation: a rough guide* (SCIE 2010) recognised that approaches to service delivery which increase choice and control operate at the:

'... intersection between the demand for safety for the individual, and the increased demand for choice and control in social care'.

(SCIE 2008, p.62)

The guide notes the view of former Commission for Social Care Inspection that, while it is important not to be over-protective, or prevent people from living 'ordinary lives', the desire for choice and control must be weighed against the individual's fundamental right to be protected and safeguarded from harm from those involved in their care. On the other hand, Gareth Flemyng, Head of Safeguarding and Assessment at Newham Children's Services refutes the proposition that personalisation adds to risk, confidently asserting this is '*entirely false*'. Writing in the *In Control* Briefing *Personalisation: children, young people and families*, he maintains that safeguarding and personalisation in fact represent a single agenda. Pointing out that traditional services are neither necessarily safe nor free of financial fraud, he maintains that placing control with individual children and their families in fact:

'...increases the level of accountability and acts as a control measure in avoiding

fraud and abuse in the majority of cases'.

(Flemyng in Crosby 2010, p.12)

He maintains that the use of an Individual Budget to commission a small team of staff delivering individually tailored support which follows the child/young person through their daily routines actually minimises the numbers of workers involved, helps to develop skills in particular support needs, thereby increasing accountability and minimising risk.

However, given that public money and a professional duty of care are also involved, and where the clients are children and young people who may be considered to have particular vulnerabilities to exploitation, concerns about possibly creating new risks or ethical dilemmas are not to be lightly dismissed. A recent article in *Community Care* entitled '*Putting sex on the budget*' (Pitt 2010) rehearses the ethical dilemmas which can be posed for social workers if people should choose to use direct payments to do something which others might consider personally dangerous or ethically questionable. In this instance the question is whether an individual budget could and should be used to buy sexual services for lonely or frustrated clients in the pursuit of their personal 'well-being'. Does personalisation and choice extend to councils subsidising such activity? Neil Coyle, Director of Policy at Disability Alliance argues that, while councils have a duty not to curtail people's rights:

'Public bodies don't exist to find people sexual partners'

(Pitt 2010, p.25)

However, other professionals cited in the same article strongly maintain the opposite view. A social worker argues the case for one of his clients, a socially isolated young man with a moderate learning disability, to be allowed and supported in using his personal budget to take a holiday in Amsterdam and pay for sex in their legally licensed sex industry. Clearly disabled people should have the same rights/freedoms to pursue a satisfying sexual relationship as any other person. Nonetheless, as the article points out, cases such as this do raise real concerns, not to mention containing the potential for public relations disasters. Moreover, the social work value of user empowerment could clash with other ethical standards, for example if it led to the purchasing of services which involve exploitation of others. According to Ruth Cartwright, BASW joint manager for England, this requires careful thought:

'What social workers need to be sure about is that no one is being exploited, both the service user themselves and anyone they were buying sex from'.

(Pitt 2010, p.24)

Such cases illustrate the need for councils to draw up very clear policies on what services can and cannot be purchased with direct payments or personal budgets. Moreover, while it can be rightly argued that current social care provision has a far

from blameless record in terms of safeguarding and managing risk, this does not necessarily support the case for adopting new models of care unless they have been rigorously risk-assessed. The use of public money to fund or encourage greater risk for no clear off-setting gain would also be hard to defend in the event of someone coming to harm. The assumption that families can always be relied upon to have the best interests of their children at heart or that they are necessarily the best judge of their children's needs, is also questionable in some instances. The literature on personalisation points to some very significant unanswered questions:

'Questions of cost-effectiveness and risk management are not yet fully dealt with in the existing literature'.

(SCIE 2007, p.1)

The Mind guide to personal budgets (2010) acknowledges that local authorities have a duty of care and a responsibility to only agree to a care plan if it demonstrably meets the young person's needs and does not place them in danger. The plan should identify, after discussion and negotiation, how any identified risks which may arise in future are to be managed.

'For example, when you are unwell, you might be tempted to isolate yourself and not let a support worker visit you. You should think in advance about how you could manage this risk'.

(MIND 2010 @ www.mind.org.uk)

Equality concerns

McIntosh, writing in *Personal Health Budgets: the patient is always right* rehearses both the claimed merits and expressed concerns around personal budgets. Predictably the merits centre on increased personal control and flexibility and on the facilitation of personally-tailored services matched to individual personalities and priorities. Concerns focus on the potential of such budgets to impact adversely on wider services which in turn raises ethical concerns about the impact on equality. There is a concern as to whether budgets will in fact actually meet the costs of care and what will happen if and when budgets run out but need remains:

'The King's Fund view is that we will eventually have to accept top-ups in certain areas of care but there is an ethical issue here about equity'.

(McIntosh 2009, p.3)

Conclusion

'Personalisation is about much more than personal budgets and requires a significant change in how staff work, to enable clients to be genuine partners in

care.....providers will need to be more flexible about how they offer services. While many clients may actually prefer to receive services in a traditional way, an increasing number will seek greater control over their own budgets and commission their own care’.

(Newman 2009, Personalisation: practical thoughts and ideas from people making it happen. OLM-Pavilion,p.94)

The above assumes that personalisation will not, in practice, so de-stabilise the current ‘market’ for social care as to put ‘traditional’ services out of business and that ‘flexibility’ will also be acceptable to, and safe for, all sides or partners in the new market for care.

Shaping Personal Health Budgets: A view from the top noted concerns of ‘numerous’ providers and commissioners of services that:

‘the current presentation of the personal budgets agenda was failing to take seriously enough the risks of the model. There was considerable frustration from many at the ‘evangelicalism’ of some proponents of personal budgets’.

(NHS Confederation, Mental Health Network 2009, p.8)

Critics cited in the above report feared that claimed benefits were being overstated or going beyond the evidence base. They feared that potential costs and safeguarding concerns were being ignored or underestimated in the rush to implement the new initiative. A minority of providers and commissioners of services interviewed for the NHS Confederation, Mental Health Network report, were already suspicious that any conclusions to be drawn from the pilots of Personal Health Budgets were a foregone conclusion:

‘This group was mistrustful of the Department of Health’s record in translating the results of previous trials into new models of health provision. They wanted assurance that if improvements to outcomes were poor...this would be acknowledged’.

(ibid)

Bartlett (2009) writing in *At Your Service: navigating the future market in health and social care*, concluded that at that moment personal budgets were working well for the relatively small number of people using them. For these people such budgets did give more control than previously over the shape of the services they received and the freedom to personalise these services to their specific wishes, needs and lifestyle choices. However, Bartlett felt that for others the innovation might hold less attraction:

‘There will be a large group of people who want real change in what they use, and to chart their own courseAt the same time there will be many people who do not want to take on personal budgets, or at least want varying levels of

control and responsibility, which could even change year on year.'

(Bartlett 2009, p.36)

As ever there are concerns that in any free market system the weakest and least articulate may be at a disadvantage without some form of support or advocacy to get their fair share of limited resources. Steven Rose, a Chief Executive of a national learning disability charity, with 30 years experience of working in the health and social care sector, described his struggle as someone with 'vast experience' of the system, and even with the additional help and support of his equally articulate brother, to get a decent service for his parents. This left them with a feeling of disbelief at how many unnecessary obstacles they experienced as having been put in their way:

'If my brother and I, who are both reasonably educated, articulate and when necessary, assertive people, who had knowledge of the system, had struggled so hard, what was the experience of others – people who may not be so well-positioned as we are to challenge the inadequacies of the social care system?'

(Rose, cited in *'Making choices: information and advice'* in Newman 2009, p.163)

There may be a danger that the enthusiastic proponents of personalisation, sometimes drawing evidence from the atypical experience of other sectors and specific user-groups, underestimate the relative powerlessness of others, or simply 'oversell' an idea which has flaws and potential pitfalls as well as merits:

'Co-production is not a magic fix. It does not dispense with the need for promoting equality, enforcing standards or improving delivery. However, it offers a different way to think about the relationship between the state, service providers and users'.

(Hunter, S and Ritchie, P 2007, p.15)

Beresford questions the 'precipitate rush' to implement personalisation ever more widely, querying some of the assumptions and conclusions drawn from what he concedes are '*heart-warming stories of service users whose lives had been radically renewed by personalisation pilot schemes*'. Beresford asks if these represent a sufficient basis for the 'new orthodoxy of personalisation' and why, on the basis of limited evidence and analysis, it is not a case of whether, but rather how fast and far the personalisation or 'transformation agenda' proceeds. Beresford argues that important questions still remain unanswered. For example will 'increased choice' be real or remain prescriptive and bureaucratic? Will valued traditional, but higher cost, collective services such as day care or respite care be closed without alternative and better support being offered in replacement? Will vulnerable users and carers be 'cast adrift' in an increasingly complex and unregulated market, increasingly reliant on either a 'black economy' of unregulated care or left bridging the gaps in care themselves as 'informal careers'?

'What is perhaps most interesting – and concerning – about personalisation in social care is that the government has made such strong commitments to it, not only without having clear answers to such questions , but without such questions having been properly considered at all'.

(Beresford 2009, p.3)

Equally, and despite these major caveats, when judged by the personal accounts of people for whom personalisation has brought a profound improvement in their quality of life, the potential gains also seem immense:

'Personalisation, if implemented correctly will be incredibly beneficial to both service users and providers within the health and social care sector. Not only does it put control back in the hands of the individual but it also gives the opportunity to do things differently for our clients, which is very exciting' .

(Newman, S 2009, Personalisation: practical thoughts and ideas from people making it happen. OLM-Pavilion, p.95)

References

Adebowale in Newman, S (2009) *Personalisation: practical thoughts and ideas from people making it happen*. OLM-Pavilion.

Bartlett, J (2009) *At Your Service: navigating the future market in health and social care*. DEMOS

Beresford, P (2009) *Whose Personalisation?* (Think Pieces No.47). Compass

Carr, S (2010) *Personalisation: a rough guide*. SCIE

Carr, S and Robbins, D (2009) *The Implementation of Individual Budget Schemes in Adult Social Care*. (Research Briefing 20). SCIE

Children's Society (2006) *'Makes your life, your life': Disabled young people's views on choice, control and support in relation to their lives and the development of individual budgets*. Children's Society

Commission on Personalisation (2009) *Surveying the landscape*. (Briefing 1) ACEVO.

Commissioning Support Programme (2010) *Learning Together Report: Personalisation in Children's Services*. CSP

Crosby, N (2010) *Personalisation: children, young people and families*. (Briefing 2). In Control

Crosby, N and Duffy, S (2008) *A whole-life approach to personalisation: self-directed support for every child and young person*. In Control

Department for Children, Schools and Families (2008) *Personalisation: the seven steps of self-directed support*. DCSF

Dixon, A and Ashton, B (2008) Super patients should use their powers wisely, *Health Service Journal*, 28 August, p.1

Ferguson, I (2007) Increasing user choice or privatising risk? The antinomies of personalisation, *British Journal of Social Work*, 37, 3, 387-40)

Glendinning, C and others (2008) *Evaluation of the Individual Budgets Pilots Programme: Final Report*. Social Policy Research Unit, University of York.

Henwood, M and Hudson, B (2008) p.78) *Lost to the System? The Impact of Fair Access to Care: a report commissioned by the Commission for Social Care Inspection for the production of 'The State of Social Care in England 2006-7'*. Commission for Social Care Inspection

Hunter, S and Ritchie, P (2007) *Co-production and Personalisation in Social Care: changing relationships in the provision of social care*. Jessica Kingsley.p.15

Land, H and Himmelweit, S (2010) *Who Cares: Who Pays? Personalisation in social care*. UNISON

Leadbeater, C (2004a) *A Summary of 'Personalisation through participation': a new script for public services*. DEMOS

Leadbeater, C (2004b) *Personalisation through participation: a new script for public services*. DEMOS

McIntosh, K (2009) Personal health budgets: the patient is always right, *Health Service Journal*, 2 March, p.3

MIND (2010) *MIND Guide to personal Budgets*. MIND

Neill, M and others (2008) A positive approach to risk requires person centred thinking. www.puttingpeoplefirst.org.uk/_.../Personalisation/Personalisation.../A_Person_Centred_Approach_to_Risk.pdf

Newman, S (2009) *Personalisation: practical thoughts and ideas from people making it happen*. OLM-Pavilion

NHS Confederation, Mental Health Network (2009) *Shaping Personal Health Budgets: A view from the top*. NHS Confederation

Pitt, V (2010) Putting sex on the budget, *Community Care*, 12 Aug, p.24-5

Samuel, S (2010) The doubts remain, *Community Care*, 20 May, p.16

Social Care Institute for Excellence (2009) *Personalisation for someone with a learning disability*. SCIE Social Care TV

Social Care Institute for Excellence (2008) *Personalisation Briefing: implications for housing providers*. SCIE

Social Care Institute for Excellence (2007) *Choice, control and individual budgets: emerging themes*. (Research Briefing 20). SCIE

SQW Consulting (2010) *DCSF Individual Budgets (IB) Evaluation*. Thematic Case Studies 2009-10. SQW Consulting)

SQW Consulting (2009) *DCSF Individual Budgets: evaluation and challenge/support*. SQW Consulting

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. CDC is a semi-independent council of NCB, and has a staff team reporting to its director. The CDC Council is made up of a wide range of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations. CDC hosts the following networks;

- The National Parent Partnership Network
- The Special Educational Consortium
- The Transition Information Network
- The Every Disabled Child Matters Campaign
- Making Ourselves Heard

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