

Keeping it personal: supporting people with multiple and complex needs

A report to the Commission for Social
Care Inspection

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January 2009



Acknowledgements

This report was written for CSCI by independent consultants Melanie Henwood and Professor Bob Hudson. In addition, supplementary analysis of the data from the independent evaluation of the Individual Budgets pilots (IBSEN) was undertaken for the study by Professor Caroline Glendinning and Dr Nicola Moran, both of the Social Policy Research Unit, University of York. This analysis particularly informs Section 3 of the report.

We are grateful to Penny Banks, Head of Information and Reporting at CSCI, for managing the project with her customary patience and good humour, and for her support and advice throughout the process. Thanks also to Suzanne Mathison for her support with documentation and inspection reports.

We are also grateful to the five councils that agreed to participate in this study, and for their cooperation throughout the fieldwork, despite the pressures of managing the day-to-day demands of extremely busy departments. We are especially grateful to the many people who agreed to be interviewed, and particularly to the people with personal experience of using social care services who answered our questions, and allowed us insight to their lives. The voices of many of the people we spoke to are heard throughout the report, but the identities of all have been disguised.

Finally, we would like to acknowledge the three people who provided the support in transcribing numerous interviews, and who did so with enormous speed and efficiency; our thanks to Linda Christie, Joy Martin and Julie Prudhoe.

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Executive summary

- 1 What is the effectiveness of the response of councils – and other agencies – to people who are judged to have ‘complex needs’? Two years ago the Commission for Social Care Inspection (CSCI) raised its concern about people with complex needs and asked whether their specialist, *and ordinary*, needs are being properly met. While the numbers of people with highly complex needs are relatively small, the costs of meeting their needs can be high, and all councils will be aware of the consequences of such needs. However, high cost does not automatically equate with high quality, and the history of long-term care for many people with learning disabilities, mental health problems and physical disabilities is littered with accounts of poor quality containment.
- 2 The new agenda in adult social care is characterised by the paradigm of personalisation. In contrast to offering support from a standard menu of services, the personalised response is to maximise the choice and control available to people, in many cases by placing commissioning and purchasing power in their hands by means of a Direct Payment or Individual Budget. The test of this model is not simply whether it can work for people whose support needs are straightforward and stable, but whether it can also do so for people with complex, unstable, unpredictable needs, and where their capacity to indicate preferences may be limited.
- 3 It was to explore these issues in greater depth that CSCI commissioned this special study. A shorter version of the report forms a chapter in the annual report *The state of social care in England 2007-08* (the final such report from CSCI before its merger with the Healthcare Commission, to create the integrated Care Quality Commission). The full account of the findings of the study cannot be told in a single chapter, and for those who wish to explore the issues in greater depth and to understand their context, this report provides the analysis.
- 4 The study was undertaken in five anonymised councils in England. These five provided a range of geographical locations, authority types, socio-demographic characteristics and CSCI star-rating attainment, and different points of engagement with the personalisation agenda, from the cautious – and at times sceptical – to the enthusiastic, and all points in between.
- 5 Fieldwork was undertaken at three levels: of policy, operational and frontline staff, and at the individual level of people with experience of using services, either directly or as carers. In addition to analysis of policy and related documents, we undertook a total of 76 semi-structured interviews with policy, operational and frontline staff, and semi-structured interviews and focus group discussions with 35 people using services and carers. We addressed different aspects of complexity and focused on young people moving through

transition to adulthood, people of working age and people of pensionable age. We also focused on the different issues where the prime needs related variously to learning disabilities, mental health, physical and sensory disabilities, and older age.

- 6 In addition to the local fieldwork, the study also draws on wider research findings. At the time the research was undertaken, the report of the evaluation of the Individual Budgets pilot projects in 13 sites (produced by the Individual Budgets Evaluation Network – IBSEN) was still awaiting publication (and was published in October 2008). However, two members of the team had also been part of the IBSEN study, and access to the IBSEN data provided a further level of analysis. Comparisons between the five fieldwork sites and the 13 Individual Budget sites are made throughout the report. Additionally we have drawn liberally upon some of the most recent local CSCI inspections into the independence, wellbeing and choice agendas, as well as utilising a wide range of other published material.
- 7 The narrative that emerges in this report is one that underlines the difficulties councils face in responding to complex needs. Too often this results in poor solutions which seek to fit people within inappropriate service definitions and to offer standardised and unimaginative services. However, this story is illuminated by flashes of quite different experiences where highly individualised solutions have been devised to meet people's multiple and complex needs, maximise their opportunities for exercising control, and provide far superior quality of life.
- 8 It is evident that understanding of 'multiple and complex needs' is contested. Both in the research literature and in the experience of our fieldwork, there is a 'surplus of meaning' surrounding definition. 'Complexity' is typically defined in one of three ways. The dominant criterion focuses on the depth of a particular characteristic to identify complex cases. The most frequently occurring example is the use of IQ scores in determining the definition of learning disability. More often people define complexity by reference to both breadth and depth, and this reflects the interaction of multiple characteristics and needs. Finally, complexity is defined by situations and needs that pose a challenge to services. Not only are definitions contested, but they are also changing and in some respects becoming narrower. Some definitions have reinterpreted complexity to refer simply to what used to be referred to as challenging behaviour. Yet other definitions argued that complexity is less about specific health or care needs than it is indicative of 'chaotic lifestyles' where other variables including drugs and alcohol play a part.
- 9 Far from there being objective definitions of complexity, the variable and often subjective understandings all underline the difficulties that arise when people's needs fail to conform with traditional 'boxes' or identified client group differentiation.

- 10 The scope for responding flexibly and individually to people's needs is constrained by a number of interrelated factors. The study found that the key dimensions of this reflected inappropriate out-of-area residential provision, restricted choice and access, weak patterns of commissioning, limited use of personalisation, and the marginalisation of human rights. These themes are all well documented in the research literature and were echoed to a lesser or greater extent in the fieldwork.

Policy-level issues

- 11 Reliance on out-of-area residential placements, particularly for people with complex learning disabilities, was a concern in all the fieldwork sites. It was widely recognised not only that such placements are costly, but also that they do not always offer adequate quality or fit with the direction of policy that councils are trying to pursue around support for independent living and optimal choice. At the same time it was also recognised that the solution to the out-of-area difficulty was far from straightforward. Developing appropriate local alternatives was also demanding, and returning people from out of area on the basis of dogma rather than choice and quality was widely viewed as problematic.
- 12 It is self-evident that people with complex needs (however that is defined) will inevitably cross professional and organisational boundaries. Dealing with these boundaries in a way that allows needs to be addressed comprehensively creates significant difficulties at the level of both policy and practice. Three particularly key areas of interface were identified and explored in the study. These are the boundaries in the transition from adolescence to young adulthood, boundaries between adult social care and the NHS, and boundaries between different funding streams that may be involved in individual or personal budgets.
- 13 Transition appears to be an area of policy that has improved with the development of dedicated transition teams. Nonetheless it remains an area of difficulty and interfaces are problematic where different definitions of adulthood are adopted by health and social care services. Another major interface at transition is that with the Learning and Skills Council. Costs that used to be met by the LSC are increasingly the subject of dispute and negotiation, particularly around residential college placements.
- 14 The health and social care boundary in general is one that appears to be better managed than in the past. This has been assisted where there is coterminosity of council and primary care trust (PCT) boundaries. Disagreements which do occur are typically around funding and Continuing Healthcare, and this remains problematic despite reported improvements since the introduction of the national framework. Moreover, new problems are arising around Continuing Healthcare where the loss of jointly funded

support also jeopardises opportunities to achieve personalised solutions by means of Direct Payments.

- 15 The significance of different funding streams arises particularly in the Individual Budget pilot schemes. Evidence from IBSEN indicates that integration of different resource streams has been hard to achieve and the best that has been possible has been broad alignment. In our fieldwork sites the issue of different sources of support was identified most frequently in respect of the Independent Living Fund. Despite positive views of the role of ILF assessors, there was also widespread concern over apparently reducing flexibility, and incompatibility with personalisation objectives in the continuing restrictions on the use of ILF funding.
- 16 The personalisation agenda was being adopted in a range of ways across the councils. Three broad positions were identified which featured supporters, doubters and opponents. Opposition was rare among professionals and council officers, but consistently negative or sceptical positions were apparent on the part of elected members in four out of the five councils.
- 17 All the fieldwork sites were still finding their way through the technical requirements and practical implementation of self-assessment questionnaires (SAQ) and resource allocation systems (RAS). The risks of people underestimating their needs in the self-assessment process were widely recognised. The major challenges to the operation of RAS were identified in accommodating high cost cases associated with complex needs; problems arising from cost ceilings on support for older people relative to other care groups; and uncertainty over how best to reflect the contribution of carers.
- 18 Critical to the success of personalisation will be the engagement of providers, but it was notable that few external providers were being adequately engaged by commissioners and too often were marginalised from constructive dialogue.

Operational-level issues: independence, wellbeing and choice

- 19 Meeting the needs of people for personalised services has a number of components and the following dimensions were identified as particularly important: assessment and care management; promoting independence and choice; range of services; support and advocacy; and flexibility and accountability.
- 20 It is striking that much assessment and care planning remains deficit-based and focused on what people are unable to do rather than understanding individuals with a range of strengths and qualities. However, examples of good practice in person-centred planning were in evidence, albeit that the quality of practice was recognised as variable.

- 21 Self-assessment was widely viewed as a misleading term, and in practice self-assessment entailed intensive support from care managers working with people needing support to identify their needs and aspirations jointly. Where this worked well it was viewed as a superior outcome to that attained by conventional assessment; however, it was more demanding of staff time and skills than traditional professional assessment, and this is an important consideration in addressing the roll-out of personalisation.
- 22 The engagement of the councils with Direct Payments provides a basic indicator of their approach to choice and independence, although arguably this does not capture the full breadth and depth of engagement with personalisation. Independence and choice were widely supported as principles and values, but reservations were expressed about the applicability of the model either to people with so-called 'chaotic lifestyles', or to people with severe learning disabilities.
- 23 Across the councils people with complex needs were making use of Direct Payments in a variety of ways; from fine tuning conventional support packages to developing highly creative and individualised support. Restrictions on the use of Direct Payments were often viewed as unfair and inappropriate, particularly by people using services and their families who favoured greater flexibility to fit with the reality of their complex lives.
- 24 Some of the councils had moved ahead of national policy to find creative solutions to the limitations that restrict the availability of Direct Payments for people lacking capacity to consent. Creative solutions to legal impediments have enabled these councils to be well placed to make optimal use of the more permissive rules following the Health and Social Care Act 2008.
- 25 It is important to bear in mind that personalisation is not *just* about Direct Payments or personal budgets, and some sites were also addressing how choice and control could be enhanced in mainstream support, and for people living in residential settings. However, such approaches required particularly committed and enlightened staff determined to deliver better outcomes and quality of life for people with often highly complex needs.
- 26 The absence of a sufficient range of services to support choice and control was a major theme and in all the councils there were concerns over traditional approaches to commissioning resulting in limited, standard and insufficiently flexible services. In many instances this was compounded by conservative preferences for traditional and building-based services, expressed particularly by carers who were often anxious about people needing to be adequately 'looked after' throughout the day. The dilemma for councils very often is the need to double-fund new and traditional models of support in a transitional period.
- 27 A further limit on choice is that posed by the workforce. The difficulties of recruiting and retaining social care workers are legion and well documented.

Despite this it was also apparent that some people using Direct Payments are finding innovative solutions, particularly by recruiting PAs from non-traditional backgrounds and drawing on the social capital of local communities.

- 28 The balance between choice and control on the one hand and increased risk on the other was identified in all councils. Many staff expressed concern that personalisation would expose people to greater risk of exploitation and abuse. The implications for regulation are uncertain but the development of an unregulated market parallel to a regulated one creates particular pressures; in addition to the risks for individuals, this parallel development could exacerbate workforce challenges.
- 29 Advocacy and brokerage support is under-developed in many councils and particularly poor where there is no strong tradition of local user-led organisations.
- 30 The balance between flexibility and accountability was one that was debated in all the councils, and a range of differing views were in evidence. However, there appears to be increasing recognition that the most important criterion for judging appropriate use of public resources is the question of whether it meets assessed needs and delivers agreed outcomes, rather than a preoccupation with *how* such outcomes are achieved.

Conclusions

- 31 It is, perhaps, self-evident that people with complex needs frequently require correspondingly multiple and complex responses from a range of professions and agencies if those needs are to be properly met. Such responses are difficult and demanding and require sophisticated partnership working to ensure that the experience of the person using services is one of coherence and integration. Traditionally, services have often failed to rise to these challenges and have instead sought solutions which categorise people in a single category rather than recognising the multiplicity of their needs. Such examples still abound.
- 32 Where councils *are* achieving ambitious solutions and inspiring outcomes for people, they are doing so often *despite* rather than *because* of the systems in which they operate. The difficulties of managing multiple (and at times conflicting) administrative, financial, organisational and professional boundaries require both excellent partnership working and sustained commitment.
- 33 Personalisation offers a new way forward in which the emphasis is less upon the means of the joint arrangements than upon ends (outcomes), underpinned and supported by strong values. Some councils are deliberately focusing their energies on delivering personalisation for people with complex needs, but most are as yet more conservative in approach and indeed

concerned to achieve some 'easy wins' at the outset. All councils face major difficulties in moving from small-scale pilot developments to mainstream operating systems, and at the current rate of change it will take many years to realise ambitions.

- 34 The study provides a snapshot of development and engagement with the emerging personalisation paradigm. It tells a story in which there are glimmers of good news and innovative development, but set alongside the continued existence of the traditional service paradigm which takes little account of individual needs and circumstances. The challenge for councils is to move from one side of the spectrum to the other and to ensure that all those people who seek choice, flexibility and control over their lives are enabled to achieve it.
- 35 The findings from this study provide some inspirational glimpses of what can be achieved, and some cautionary tales of what to avoid. It tells some stories of indomitable human courage in the face of enormous adversity, and of professional support and commitment of the highest order. It also describes an 'operating system' that frustrates professionals and confuses people who use services and their carers. The new paradigm of personalisation could well offer a way through this impasse, but so far it has only marginally touched the lives of people with multiple and complex needs.

1: Introduction

Box 1:

The experience of a person with complex needs

Roy Jones is a young man in his mid-20s who has very high levels of need. He has cerebral palsy, learning disability and epilepsy and is reliant upon other people for meeting all of his needs. His communication consists of gestures and his preferences can only be discerned by people who know him very well indeed. After his schooling had ended, Roy was offered a place at a residential college but his parents were not convinced this would best meet his needs and opted for him to remain at home and attend the local day centre that adjoins the special school. Although the centre is not popular with his social worker, Roy's parents are appreciative of the specialist equipment and attention that Roy receives.

Although happy for Roy to remain living at home after the end of his education, Mr and Mrs Jones were keen for him to have a place of his own to live – “*like other young men*” – and this became the main goal in his care plan. In the meantime he accessed a Direct Payment for support in getting out of bed in the morning and having a shower before going out. Roy's parents were less than satisfied with the quality of support, especially the high staff turnover and the absence of training and preparation for understanding Roy as an individual.

In Roy's locality the council was introducing the *In Control* model, and he was assessed under the Resource Allocation System (RAS) for an 'indicative amount' of £50,000 per annum. Although this was insufficient to fund his own housing, Roy had two friends at the day centre whose parents were also looking at the possibility of supported living. The three young people and the families all knew each other and agreed to pool all of the available funding to secure suitable accommodation and support. The council's calculations assumed that support through the Independent Living Fund (ILF) would be available on top of the combined indicative budgets.

It proved difficult to find an accessible four-bedroom bungalow, but in the meantime tenders for providing the support element were invited. Four providers expressed an interest, and were invited to be interviewed by the three families themselves in their own homes, with a social worker in attendance. This process worked well and a provider was selected. Finding a housing provider proved to be more difficult but eventually (and after much complication) a specialist learning disability housing association agreed to undertake the task on the basis of a three-way

shared ownership arrangement. In total it took three years to make these arrangements.

Roy's story has aspects of almost all of the various services, supports and dilemmas that can be found in the cases of people with complex needs – the problem of transition from adolescence to young adulthood, the role of traditional day centres, the use of Direct Payments and access to appropriate supported living. In Roy's case he has been well supported by committed and loving parents, and an experienced and creative social worker.

Box 2: **A carer's story**

Marion is in her 60s and cares for her daughter Jane, who is 38. Marion's husband recently died. Jane has a severe learning disability and limited mobility; she has non-verbal communication and various behavioural issues. She also has uncontrolled and treatment-resistant epilepsy. Jane requires total assistance in all aspects of personal care and independent living, and has a high level of need due to her combination of physical, health and behavioural difficulties.

Marion needs regular periods of respite in order to continue caring and has found that social services have been responsive to her needs for more respite, particularly since her husband died. Margaret has asked for Jane to be added to the residential placement list for medium- to long-term planning.

Marion is hostile to the idea of *In Control* and personal budgets. She has found that everyone she talks to in adult services is trying to "*push it down your throat*" and she doesn't see this model as offering anything that will support her. As she explained: "*I'm 65, I've looked after my daughter for 38 years – I don't want to take on more responsibility.*" Marion finds the whole idea of a personal budget threatening and too demanding and doesn't want anything to do with it. She wants someone else to take over responsibility for Jane and she also fears that supported living would be too isolating and that Jane needs company. The only solution that she is happy with is for Jane to move into residential care. At the time of our visit Jane was going along to the care home for introductory tea visits and was about to try out some overnight stays to see if it would suit her. Marion was adamant that both she and the care home would have the best interests of Jane at heart.

Marion has devoted her life to supporting her daughter and is exhausted by it. Losing her husband has been another blow and she feels she just

needs someone to remove the demands she has faced for nearly 40 years. She is not approaching the issue of residential care lightly but can see no alternative for Jane. Marion is trying to be responsible in making the best arrangements that will ensure Jane is cared for when Marion is no longer around to do so. Her resistance to personalised support suggests that she has only a partial understanding of what might be possible, and that it might not have been explained to her as well as it could have been. Her energy is diminishing and she feels unable to cope with any new challenges. She does not want to investigate whether Jane could be supported to live more independently and what alternatives might be open to her.

- 1.1 What is the response of councils and other agencies to people who are deemed to have 'complex needs'? Are these needs properly addressed, or do people risk falling between the boundaries of groups defined in terms of age, diagnosis or client group characteristics? Do local agencies work in partnership to ensure that complex needs that cross traditional organisational boundaries are met holistically? Moreover, what does the new personalisation agenda have to offer to people with complex needs? Many personal budget success stories have revolved around people who are articulate, well able to communicate their needs and specify their preferences, but what happens in the case of people who may have none of these abilities? Support for people with complex needs *can* be high quality and can offer a personalised response, as the first case study we have presented above indicates.¹ However, this is by no means the experience of everyone, and too often people with the most complex needs risk having the least personalised support or being seen as too difficult to support in anything other than the most dependent of settings. It is also evident (as will be explored elsewhere in the report) that there can be tensions between the wishes of family carers and the best interests of the people they support, particularly where there are concerns that personalisation is either too risky or will place undue demands on the family.
- 1.2 In *The State of social care in England 2005-06* the Commission for Social Care Inspection (CSCI) raised concerns about people with complex needs, whose specialist needs in addition to their ordinary needs are not being met. As the Commission remarked, "*it is often these small numbers of people who are not offered the special packages of services that mean they can live their lives with dignity*".² This special study was undertaken to explore these issues in greater depth.

1 In order to preserve anonymity, the names used in all the case studies in this report are aliases and are not the real names of the people concerned.

2 Commission for Social Care Inspection (2006), *The state of social care in England 2005-06*, p5.

- 1.3 As we explore in Section 2, the definition of 'complex needs' is a matter of some debate, and we were concerned to define it for the fieldwork in terms of both breadth and depth. 'Breadth' refers to people having a range of different, often interrelated, needs and likely to require support from different services, while 'depth' refers to needs that are serious, intense, severe or profound. This definition includes people with multiple and complex needs who are in transition between children's and adult services, people of working age, and people of pensionable age. In the councils participating in the fieldwork we focused variously on people with complex needs where the prime need relates to learning disabilities, mental health, physical and sensory disabilities, and older age.

Introduction to the sites

- 1.4 In-depth fieldwork was undertaken in five English councils. These were selected to meet a range of standard criteria including:
- a geographical spread across England
 - a mix of urban and rural localities to capture a range of different local challenges
 - a mix of areas with relatively high and relatively low levels of deprivation and with diverse populations in terms of age profiles and ethnicity.
- 1.5 In addition, we selected sites that featured a range of CSCI star ratings, and that were at different points on a continuum in terms of their engagement with the personalisation agenda. Thus while some were enthusiastic and eager to embrace the challenges of 'total transformation' and were engaged with *In Control* for some or all of their client groups, others were still occupying a more cautious position and were following a more incremental approach to personalisation and the requirements of *Putting people first*.³
- 1.6 All of the sites were guaranteed anonymity. It is difficult to describe the sites without providing information which makes them identifiable, and throughout the report we avoid relating specific findings to particular sites for this reason. However, the sites are briefly described below.
- 1.7 One of two counties we visited is broadly located in the south of England. It covers a large area including many villages and small towns, and while it is generally viewed as an affluent area it conceals pockets of considerable deprivation. It has a largely white population and has experienced recent inward migration of workers from eastern Europe. The largest proportion of the population is middle aged (40–54), but the increases in numbers of older people are notable, with the population aged over 65 projected to rise from

3 HM Government (2007), *Putting people first: a shared vision and commitment to the transformation of adult social care*.

11.5% in 2010 to 13.5% by 2020, and the numbers of people aged at least 85 increasing by a third over the same period. The council has oscillated between two- and three-star status in recent years but has risen to three-star rating from CSCI in 2007 and is judged to have excellent capacity for improvement. A key strength of adult social care is the council's promotion of Direct Payments and Individual Budgets to maximise choice and control.

- 1.8 Our other county is located at the other end of the country and has a one-star rating from CSCI, providing adequate adult social care services, and is judged to have a promising potential for improvement. It has always been a one-star council but its prospects have improved from uncertain in the past. Take-up of Direct Payments has been promoted in an attempt to improve the choice and control on offer, but remains below that achieved in comparable authorities. Take-up for people with mental health needs is particularly poor. In response to this the council has opted to become an *In Control Total* site, and is moving rapidly towards offering a personal budget to all new clients and all existing clients on review.
- 1.9 The third council included in the fieldwork was an outer London borough with a two-star rating and good performance overall, but 'adequate' on improving choice and control. The council had achieved three-star rating which it lost in 2005, and has remained at two stars since. Its improvement prospects have dropped from excellent to promising and are now judged as uncertain. However, the council has improved progress on the use of Direct Payments and is promoting the use of Individual Budgets, and is aware of the need for further work. However, this takes place against a backdrop of financial pressure and a requirement to find £18m savings over four years. Any additional resources have been targeted on young people with a learning disability in transition. The population of the borough aged 65–84 is expected to fall over the next five years, while the numbers over 85 are projected to grow by 1.45% (considerably less than the average increased of 10.17% for all London boroughs over the same period). Twenty per cent of the population are from black and minority ethnic communities, and the borough includes some of the most affluent wards in London, as well as some with significant levels of deprivation.
- 1.10 Our fourth council is a metropolitan borough in the North West which contains some of the wealthiest as well as some of the poorest areas in the country; it is a highly diverse town with 11% of the population from minority ethnic communities. The council has a three-star CSCI rating (which it has maintained since 2003) and is judged excellent on increasing choice and control, and is seen to have excellent prospects for continued improvement. Take-up of Direct Payments has increased (and is higher than achieved by comparator councils) and should continue to develop. However in some respects the council is relatively conservative, with large and traditional in-

house provision for people with complex needs, and a cautious approach to personal budgets.

- 1.11 The final council included in the fieldwork is a unitary authority in the North East with a history of industrial decline, but which has been the focus of regeneration since the mid-1990s, and has reversed long-term population decline. It had held three-star rating from CSCI since 2002 but dropped to two stars in 2006, where it has remained. It is rated as good across all outcomes, and with promising capacity for further improvement. Improvements have been achieved in the take-up of Direct Payments and there is good provision of advocacy support. Pilot programmes on personal budgets have been undertaken for young people in transition and adults and the findings from the respective evaluations are under consideration. It is thought that the council will move towards a 'total transformation' approach to personal budgets.
- 1.12 The study examined support for people with complex needs at three levels: policy, operational and individual. The methodology comprised:
- analysis of all relevant national, local and academic documentation
 - analysis of CSCI service inspection reports on independence, wellbeing and choice
 - semi-structured interviews with executive members and senior managers at the policy level
 - semi-structured interviews with operational managers and care managers
 - individual interviews with people with complex needs and their carers, and wider consultation with people who use services and their carers through focus groups
 - analysis of case records of people with complex needs
 - visits to observe some services and consult with people using the support.
- 1.13 In total 76 semi-structured interviews took place with policy, operational and frontline staff; further semi-structured interviews and focus group discussions included 35 people using services and carers. We engaged with older people with complex needs, including some with dementia; adults of all ages with complex physical needs, learning disabilities or mental health problems. Fieldwork was undertaken between May and July 2008, and all interviews and discussions were digitally recorded and fully transcribed. We draw liberally on the interview transcripts throughout the report. There were some obvious limitations to our capacity to interview people with complex needs, particularly where this included a significant learning disability and communication difficulties. We took steps to maximise the participation of people (including engagement with one person who had no verbal ability but who was able to write her answers to questions), but we also relied on

speaking to carers and staff who knew a person best where it was not possible to engage with people directly.

- 1.14 Alongside the in-depth fieldwork in the five sites the study also incorporated a further level of analysis. Two members of the team were part of the independent evaluation of the 13 Individual Budget pilots, known as the Individual Budgets Evaluation Network (IBSEN). At the time of writing the full IBSEN report was still awaiting publication, although this was subsequently published in October 2008.⁴ However, access to the Individual Budget data enabled analysis to be undertaken across all 13 sites for the purpose of this study which provides a basis for comparison between the experience in the fieldwork sites and in the Individual Budget pilot sites. The data draw on interviews with Individual Budget project leads, funding stream lead officers and frontline staff. The Individual Budget data provide a wider context within which to locate the fieldwork findings and throughout the report we highlight similarities and differences in findings.
- 1.15 Throughout the report we refer variously to Direct Payments, Individual Budgets, personal budgets and self-directed support. It is important to understand from the outset what these terms mean since they are not all interchangeable.⁵ Direct Payments were introduced by the Community Care (Direct Payments) Act 1996 which gave councils powers to make cash payments, or a combination of cash and services, in lieu of local authority commissioned services to disabled people who were willing and able to take responsibility for their own care arrangements. Initially Direct Payments were only available to adults aged between 18 and 65 who were eligible for social care. Subsequently they were extended to people aged over 65 (2000), and to carers, parents of disabled children, and young people aged over 16 in 2001. Since 2003 regulations have changed the power to offer a Direct Payment to a *duty* to do so, and all councils are required to offer Direct Payments as an option to people eligible for social care.
- 1.16 The term 'Individual Budgets' refers specifically to 13 pilot initiatives that were developed during 2006 and were the focus of independent evaluation (the IBSEN study). Unlike Direct Payments, Individual Budgets potentially bring together a number of other streams of funding in addition to council social care monies (Supporting People, Access to Work, Disabled Facilities Grants, Integrated Community Equipment Services, and the Independent Living Funds). The idea of Individual Budgets is (where appropriate to individual circumstances) to bring together these various streams into a single

4 Glendinning, C, Challis, D, Fernandez, J L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M and Wilberforce, M (2008), *Evaluation of the Individual Budgets pilot programme final report*. Social Policy Research Unit, University of York; Personal Social Services Research Unit, Universities of Manchester, Kent, and London School of Economics; Social Care Workforce Research Unit, King's College, London.

5 Carr S (2008), *Personalisation: a rough guide*. Adults' Services Report 20. London: SCIE.

transparent sum that is allocated to people eligible for social care. People can then choose a range of deployment methods. They can take this money as cash (in a Direct Payment), or have the money managed on their behalf by a third party, or receive services to the value of the budget with the council acting on their behalf. The budget might be paid to a service provider allowing the individual to call off services as they need them against this budget, and it might be managed by a trust fund on behalf of a person. The Individual Budget model is more than simply bringing together different funding sources; it is also – and most importantly – about enhancing the choice and control for people using services, and this is epitomised in the central importance of self-assessment at the heart of the process.

- 1.17 The term 'personal budgets' is increasingly used interchangeably with 'Individual Budgets'. However, it should refer to a budget that uses only social care resources, rather than attempting to integrate other funding streams. Concepts of personalisation and self-directed support underlie all of these funding mechanisms. Whether or not people choose to receive a Direct Payment and manage their own care arrangements, their experience of social care support should be one in which they have maximum control (self-direction) and solutions are fine-tuned to their particular needs and preferences (personalisation). The emergence of these themes and emphases reflects the influence of the social model of disability and of the service user movement, and the acceleration of these ideas reflects, in particular, the influence of *In Control* which was established as a social enterprise organisation in 2003 and has popularised the concepts of self-directed support and the model of Individual Budgets.
- 1.18 In the next section of the report we explore the context to our study in terms of understandings of complex needs and the various meanings which this has in respect of different groups of people who use services.

2: The context of the study

- 2.1 In this section of the report we take the opportunity to consider the issue of people with multiple and complex needs in a broad context. Two strands will be explored – conceptual issues around the nature of multiple and complex needs and the consequences of these understandings; and an overview of the concerns that have been expressed about the quality of support that people with multiple and complex needs receive.

Conceptual issues

- 2.2 It is important not to assume that there is a conceptual consensus on what is meant by the notion of 'multiple and complex needs' or why this term should be favoured over others. A review of this field undertaken by Rosengard et al for the Scottish Government,⁶ for example, noted that "*a plethora of terms are linked with the concepts of 'complex' and 'multiple' needs, used by various disciplines, sometimes specifically and most often interchangeable*" (para 2.2). Examples of the terms used include multiple disadvantage, multiple disabilities, multiple impairment, dual diagnosis, high support needs and complex health needs, as well as 'multiple and complex needs' itself. Rosengard et al point out that other definitions adopted in the literature focus on particular client groups that have co-existing or additional needs (for example, people with mental health *and* substance misuse problems). It is in this context that Stalker et al⁷ conclude that there is no consensus of definition either within the literature or amongst professionals, but rather a 'surplus of meaning'.
- 2.3 Rankin and Regan⁸ similarly conceptualise 'complex needs' as an "*active framework for response*" rather than a description of an individual's characteristics. In doing so, they distinguish two dimensions of 'multiple and complex needs':
- *Breadth*: People are likely to have a range of different needs and to require support from several different services to meet these needs; and these needs will be interrelated or interconnected.
 - *Depth*: Needs will be above average, variously described as serious, intense, severe or profound. It will include people with severe and complex learning disabilities and non-verbal communication, people with

6 Rosengard, A et al (2007), *A literature review on multiple and complex needs*. The Scottish Government.

7 Stalker, K et al (2003), *Care and treatment? Supporting children with complex needs in health settings*. Brighton: Pavilion Publishing for the Rowntree Foundation.

8 Rankin, J and Regan, S (2004), *Meeting complex needs: the future of social care*. London: Turning Point/IPPR.

severe and lasting mental health problems, and people who are blind and have additional needs.

2.4 In addition to defining multiple and complex needs in terms of the breadth and depth of individuals' needs and their complex interaction, other definitions focus on the multiple problems that are presented to *services*, particularly when people have behaviour problems. In the UK the notion of 'challenging behaviour' is frequently adopted as a means of describing people whose behaviour presents a significant challenge to services, whatever the presumed cause of the problem. The definition, coined over 20 years ago by Emerson et al,⁹ is still used today:

"Severely challenging behaviour refers to behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to seriously limit or delay access to, and use of, ordinary community facilities."

2.5 In the case of learning disability (the context in which this term is most frequently used), Mansell¹⁰ has suggested this covers a diverse group that includes people with all levels of learning disability, many different sensory or physical impairments, and presenting some quite different kinds of challenges. It includes, for example, people with mild or borderline learning disability who have been diagnosed as mentally ill and who enter the criminal justice system for crimes such as arson or sexual offences, as well as people with profound learning disability, often with sensory impairments and other physical health problems. It is also used to refer to people with more moderate learning disabilities in conjunction with an autistic spectrum disorder.

2.6 Mansell's conceptualisation is similar to that adopted by the joint inspectorates in their current investigation of the commissioning of services and support for people with learning disabilities and complex needs¹¹ where it is said difficulties will be experienced because of:

- the extent of their intellectual impairment
- having physical disabilities which severely affect the ability to be independent
- having sensory disabilities which severely affect the ability to be independent
- having a combination of physical and sensory disabilities

9 Emerson, E et al (1987), *Developing services for people with severe learning difficulties and challenging behaviours*. Canterbury: Institute of Social and Applied Psychology.

10 Mansell, J (2007), *Services for people with learning disabilities and challenging behaviour or mental health needs*. London: Department of Health.

11 CSCI, Healthcare Commission and Mental Health Act Commission (2008), *The commissioning of services and support for people with learning disabilities and complex needs: assessment framework*.

- any behaviour that can severely challenge services
- having a form of autistic spectrum disorder
- having complex health needs
- having a forensic history.

2.7 Other countries may use other terms but with similar meanings. The Government of Western Australia,¹² for example, uses the term 'people with exceptionally complex needs' and defines this as:

- people 18 years of age and older, who meet *two or more* of the following criteria:
 - a mental disorder as defined under the Mental Health Act 1996
 - an acquired brain injury
 - an intellectual disability
 - a significant substance abuse problem *and*
- pose a significant risk of harm to self and others, *and*
- require intensive support and would benefit from receiving coordinated services, *and*
- for whom the existing system is not working.

2.8 The final point on the Western Australian definition is important because it refocuses attention away from an *individual deficit* model towards a *service deficit* model. A service deficit could arise from many causes such as accommodation problems, poor planning and support, and professional and service fragmentation. Rosengard et al (*op cit*) note that "*a strong thread running through the literature is that service users identified as having multiple and complex needs are seen to be particularly poorly served by services*" (para 2.18). In the case of 'challenging behaviour', Mansell (*op cit*) has pointed to the way in which the original construction of a term can be corrupted over time to imply a different aetiology. He notes that when the term was introduced, it was intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics. He is critical of the drift in ensuing years to using it as a label for *people*, and he consistently uses the term in its original meaning in his own influential guidance commissioned by the Department of Health.

2.9 The typical diagnostic classifications and service structures adopted by service planners and providers tend to segregate people according to the reason for their impairments, as well as in relation to demographic factors such as age. Not only does this approach highlight differences between groups (rather than

12 Government of Western Australia (2007), *People with exceptionally complex needs project*. Phase 1 Report. Social Policy Unit, Policy Division.

similarities that are shared across boundaries), but it is poorly suited to supporting people whose needs fall into more than one category. In this report we are therefore using the term 'multiple and complex needs' as a favoured term for two main reasons:

- Because we are concerned with a wide range of people from young adults through to people of pensionable age, and we do not wish to use a term that is normally associated with a specific age or condition. As Clare and Cox¹³ argue, the advantage of 'complex needs' as a shorthand descriptor is that it does not reflect a diagnostic or classificatory approach, but at the same time it emphasises to service planners and providers that their focus should be on responding to need.
- Because we are exploring the use of a common policy and practice framework rooted in personalisation that is expected to be applied across all conditions and ages.

2.10 In the course of our fieldwork we took the opportunity to gauge views from the field on what terms they used and the consequences of using them. The responses echo many of the definitions explored above, with three clear positions emerging – the dominant criterion, multiple criteria, and the challenge to services.

The dominant criterion

2.11 Those taking this stance tended towards the view that the *depth* of one criterion was the critical factor in delineating complex cases from others. This applied especially where it was felt that a relatively precise measure of complexity could be derived from tests, and was most commonly applied to the use of IQ scores for people with a learning disability. Although academic and policy discourses have long since moved on from the use of intelligence testing, this still seems to be a key factor in determining learning disability 'classification' and hence access to specialist support. One manager of a physical disabilities team noted, perhaps ruefully, that:

"An IQ of less than 70 seems to be used as the passport into learning disability services, but it is very difficult for us to say we will only work with people with disability X or Y so we are less structured in who we will work with."

For an operations manager the key criterion was immobility:

"It can be quite complex where people don't have particularly high health needs but are very dependent and can't move anywhere, basically in a chair"

13 Clare, L and Cox, S (2003), 'Improving service approaches and outcomes for people with complex needs through consultation and involvement.' *Disability & Society*, 18(7), pp 935-53.

until somebody moves them. If you miss a call then they're going to get dehydrated or wet."

More simply for another respondent there was one clear criterion to determine the degree of complexity of any case – the cost of a funding package.

Multiple criteria

- 2.12 People in this group saw complexity in terms of *breadth* and not just depth, with definitions tending to identify a multiplicity of factors both for individuals and for services, for example:

"It's the multiple thing where their mobility is impaired, they might be sensory, have a learning disability and there might be behaviour contingent to that."

(Voluntary sector manager)

And

"There are those that have complex needs, either relating to forensic histories or issues relating to challenging behaviour, around autism, Asperger's...and the other end which is kind of the profound multiple needs around people with high physical care needs and having health issues."

(Area manager, learning disability)

- 2.13 Some interviewees described their service arrangements as constituting multiple responses to these multiple criteria. One manager in children's services, for example, referred to a 'high care needs system' for children with the most complex needs who challenge services across health, education and social care – between 20 and 30 children in the authority. And as one head of learning disability services put it, complex cases were "*about people crossing the conventional boundaries of client group classification*".

The challenge to services

- 2.14 People who challenge services can exhibit either a depth or a breadth of conditions and circumstances, or may even have ostensibly lower levels of need, yet still pose a significant service challenge:

"Someone might have needs that traditionally don't look complex but for a service they are hugely challenging, perhaps around criminal or sexual behaviour."

(Commissioning manager)

"It may be nothing to do with a health condition but particular circumstances like drug or alcohol abuse, or homelessness, that are difficult to deal with...We could be talking about serious self-harm."

(Principal manager)

- 2.15 Some interviewees indicated that terminology had changed and whereas in the past 'complex needs' was typically used to indicate that a person had a severe and enduring learning disability alongside multiple physical disabilities, while another group of people would be identified as those who challenged services, since the publication of *Valuing People*:

"...they have coined the [term] 'complex needs' for those people who we previously described as 'challenging'."

- 2.16 Other interviewees understood complexity to refer to a range of other circumstances, for example:

"...it may well be that they have complex needs not just because of a health condition but because of circumstances drugs, alcohol, homelessness. People that may well be living in quite neglected conditions."

(Manager, older people's services)

And

"...we call them maybe complex cases, but it is more that they have a chaotic lifestyle – usually because of drugs or alcohol."

(Social worker)

- 2.17 The ways in which people are defined and classified by service agencies is more than a question of semantics; it can determine access to any support at all and to the type of support received. In one of our localities, for example, people with a learning disability attending day care were classified according to a hierarchy of dependency – profound disability, high dependency needs behaviour and high dependency needs physical – with staff support levels linked to the classifications. Alternatively, a service definition of complexity can be used to determine who gets access to support from a specialist team or from mainstream care management, or 'signposted' into community services. More commonly in the case of multiple and complex need, classifications can be used to allocate individuals to one specialist team rather than another – fitting people into existing organisational arrangements. As one care manager put it:

"We look at the most appropriate team for the person – is it more of a physical or a learning disability?"

- 2.18 Overall, it is hard to disagree with the conclusion of Stalker et al that there is indeed a 'surplus of meaning' around multiple and complex need. Part of the problem here is that professionals and organisations have traditionally been structured around specific identifiable groupings. In the IBSEN study, for example, one Individual Budget lead commented that care managers are used to working with specific user groups (working in silos) and this can create difficulties when working with people with complex and/or multiple needs as such individuals tend not to fit into one box. A learning disability team manager in our fieldwork (perhaps unwittingly) encapsulated the dilemma:

"We don't actually have a definition of complex need but we do tick a box to say someone has complex needs. I hate putting people into boxes, but basically it's someone who doesn't fit into our usual boxes (...) I would consider a complex need is somebody that I would struggle to find a good solution for."

- 2.19 Given the lack of consensus on what is meant by multiple and complex needs, the estimation of prevalence is a difficult task, and such figures as *are* available do tend to be diagnostically classified, are made on the basis of different approaches, and are not consistent or comprehensive. There is a particular difficulty in tracing the 'care pathway' of people who have been in contact with several different services as a result of the complexity of their needs. Indeed, in their review, Rosengard et al (*op cit*) conclude that the one key finding from the literature is that there is *no* clear picture, at either service or strategic planning level, of users' contacts with different services. However, one study of shared populations of health and social care services in an English county by Keene and Li¹⁴ found that 22% of service users were in touch with at least two service 'clusters' defined as different delivery agencies.
- 2.20 Better information is available in the case of specific categories, especially where the problems are of long-standing. In the case of learning disability, for example, Emerson has estimated that over the whole country it is likely that about 24 adults with a learning disability per 100,000 total population present a serious challenge at any one time.¹⁵ If accurate, this would mean that there are over 12,000 people with learning disabilities in England whose behaviour presents a serious challenge. The position in relation to older people is harder to calculate, and the best estimates are probably those contained in the Wanless Report.¹⁶ In attempting to estimate current and future levels of need, the figures most relevant are for what Wanless calls 'Group 4' – people who are unable to perform two or more core activities of daily living (ADLs). Using a combination of data from different sources it is calculated that the numbers in this category will increase from 551,000 in 2002 to 631,000 in 2012 and then to 847,000 by 2026 – an increase over the whole period of 54%.
- 2.21 Complex and multiple needs across the older population are also likely to reflect additional problems associated with dementia or other cognitive impairment. The combination of cognitive impairment *and* ADL disability is particularly strongly associated with the move into permanent residential

14 Keene, J and Li, X (2005), 'A study of a total social services care population and its inter-agency shared care populations. *British Journal of Social Work*, 35: 1145-1161.

15 Emerson, E (2001), *Challenging behaviour: analysis and intervention in people with severe intellectual disabilities*. Cambridge: Cambridge University Press.

16 Wanless, D (2006), *Securing good care for older people*, p44. London: King's Fund.

care. Data cited by the Wanless inquiry suggested that as many as 85% of people with both ADL limitation and cognitive impairment live in institutional provision, compared with 25% with ADL limitation only, and 12% with cognitive impairment only.¹⁷ And in all cases, the numbers are being fuelled by improvements in medicine, increases in longevity, and higher expectations of both the standard and the location of service support.

Multiple and complex needs: quality of support

2.22 As we outlined in the previous section, in *The state of social care* report for 2005-06¹⁸ the Commission for Social Care Inspection raised concerns about people with complex needs whose specialist needs, in addition to their ordinary needs, were not always being met. It is possible to identify a wide range of interrelated dimensions that are creating difficulties, though these will not apply equally across all categories of need. This section will briefly explore the following:

- inappropriate out-of-area provision
- restricted choice and access
- weak patterns of commissioning
- limited use of personalisation
- marginalisation of human rights.

Inappropriate out-of-area provision

2.23 In its good practice guidance on specialist adult learning disability health services issued in 2007, the Department of Health¹⁹ refers critically to the highly variable services available across the country, noting that:

- there are still up to 3,000 NHS campus beds in use despite government policy stating that these should be closed and replaced with ordinary housing and support run and managed outside the NHS
- there is a growing use of independent sector hospitals and residential social care services that are often many miles from a person's home and community
- a significant proportion of NHS assessment and treatment centres are effectively 'blocked' as people have lived in them for years due to delayed discharge and a lack of investment in non-bed-based provision.

17 Ibid p166.

18 Commission for Social Care Inspection (2006), *The state of social care in England 2005-06*.

19 Department of Health (2007), *Commissioning specialist adult learning disability health services: good practice guidance*.

- 2.24 The Mansell report (*op cit*) estimates that there are over 11,000 people with complex needs related to their learning disability who are supported 'out of area' by their local authorities in England. This constitutes 31% of all people with learning disabilities supported by local authorities, and the increasing number of these placements has contributed to the dramatic rise in social services expenditure on such services. Moreover, there is evidence that the quality of support in these settings is often poor. The recent national audit by the Healthcare Commission,²⁰ for example, revealed several difficulties:
- being placed a long way from home presented some challenges for maintaining contact with families
 - education and recreation were often delivered on site
 - only half of people using services for adults with learning disabilities had received a visit from family or friends in the previous month, and many had never received a visit
 - very few people had friendships apart from those with paid staff.
- 2.25 The position in respect of children and young people is somewhat similar. Over 11,000 pupils with a statement of special educational needs are placed in out-of-authority schools, usually children with severe behavioural, emotional and social difficulties (BESD) and autistic spectrum disorders (ASD). Expenditure on these placements is high and has increased steeply in recent years.²¹ Mansell (*op cit*) further notes that these placements are often disruptive of ties with family and community, so that families face particular problems getting local services that can provide the level of support needed when responsibility passes from children's to adult services.
- 2.26 Many families attempt to continue providing support in the family home rather than suffer these disadvantages – it is estimated that 62% of people with learning disabilities aged over 16 still live with their families, though this percentage will be much lower for people with multiple and complex needs²². However, when families *do* choose to try to manage at home, then support is often insufficient. A survey by Mencap, for example, found that 60% of parents of children and adults with profound and multiple learning disabilities spent more than 10 hours a day on basic physical care; of these families, 78% received either no support at all or less than two hours per week.²³ This, in turn, is likely to fuel the demand for residential placement if family care breaks down, and further weaken ties to family and community.

20 Healthcare Commission (2007), *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*.

21 Audit Commission (2007), *Out-of-authority placements for special educational needs*.

22 Emerson, E, Malam, S, Davies, I and Spencer, K (2005), *Adults with learning difficulties in England 2003/4*. London: Department of Health.

23 Mencap (2001), *No ordinary life*.

Restricted choice and access

- 2.27 One of the key planks of government social policy is to extend choice and improve access to services and support, but there is concern that the position of people with multiple and complex needs may be marginalised. In its recent report on the human rights of adults with learning disabilities, for example, the Joint Committee on Human Rights²⁴ referred to evidence of inadequate access to further and continuing education, transport, healthcare, dentistry, welfare benefits and housing. Similar findings are evident in the Healthcare Commission audit of specialist inpatient healthcare services for people with learning disabilities (*op cit*) which explored the extent to which people were being supported to make everyday choices, and were being actively listened to in order to make them. The Commission reports only "*limited evidence*" that this is happening, with site visits frequently failing to support the claims made in questionnaires by providers.
- 2.28 In the specific case of access to healthcare, the recent Michael Report into healthcare for people with a learning disability²⁵ finds "*convincing evidence*" of higher levels of unmet need and less effective treatment. It concluded that:
- It is harder to access assessment and treatment for general health problems that have nothing directly to do with the disability.
 - There is insufficient attention given to making "*reasonable adjustments*" to support the delivery of equal treatment as required by the Disability Discrimination Act.
 - Parents and carers often find their opinions ignored by healthcare professionals.
 - Health service staff have very little knowledge about learning disability and fail to understand that a right to equal treatment does not mean treatment should be the same.
 - Partnership working is poor, especially for those with complex needs.
- The Inquiry discovered "*some appalling examples of discrimination, abuse and neglect*".

- 2.29 Where there is limited choice and access to services and support, little progress on personalisation can be expected, regardless of the sophistication of a person-centred planning process. Robertson et al,²⁶ in a recently reported study of barriers to the implementation of person-centred planning,

24 Joint Committee on Human Rights (2008), *A life like any other? Human rights of adults with learning disabilities*. Seventh Report of Session 2007-8. HL Paper 40-1. HC 73-1.

25 The Michael Report (2008), *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

26 Robertson, J et al (2007), 'Reported barriers to the implementation of person-centred planning for people with intellectual disabilities in the UK.' *Journal of Applied Research in Intellectual Disabilities*, 20, pp 297-307.

for example, found that once a plan had been developed, the limited choice and availability of services was identified as a highly ranked barrier. This was found to be especially the case with day services, housing and community activities.

Weak patterns of commissioning

2.30 The dominant mode of commissioning hitherto has been one of strategic macro-commissioning by statutory agencies, but there is considerable and growing evidence that this has been ineffective. The recent review of commissioning for people with learning disabilities by the Social Care Institute for Excellence²⁷ concluded that *“far too many localities appeared to be characterised by underdeveloped systems”* for:

- mapping current and future needs, especially at the point of transition
- evaluating the costs and outcomes of placements, especially out-of-area placements
- developing joint protocols, service specifications and other mechanisms for delivering more sophisticated commissioning.

2.31 The weakness – or indeed the total absence – of a commissioning strategy is also a recurring theme in some recent CSCI inspection reports, as the following extracts indicate:

“Neither a strategy nor an action plan to guide learning disability priorities and deployment of resources existed for 2007/8.”

“Commissioning activity was relatively under-developed – only approximately 50% of people estimated to have a severe learning disability were known to the council.”

“The joint commissioning strategy had no analyses of changing demographics, resources or risks on which to base commissioning for the coming three years.”

“The lack of a proper commissioning strategy meant that principled commitments to altered patterns of service were unsecured by clear plans.”

2.32 The Healthcare Commission investigation (*op cit*) also reported *“limited evidence”* of robust involvement by councils and PCTs in the commissioning process, describing this as *“a missed opportunity to influence the safety, quality and cost-effectiveness of service provision”*. In these circumstances there can be little assurance about standards of service provision for senior managers, board members or elected members.

27 Emerson, E and Robertson, J (2008), *Commissioning person-centred, cost-effective, local support for people with learning disabilities*. London: Social Care Institute for Excellence.

The limited use of personalised approaches

- 2.33 Again much of the evidence is from the field of learning disability, with the most recent data contained in the report of the Healthcare Commission (2007 *op cit*). It is clear from this investigation that although the rhetoric of a personalised approach to support is now widespread, there are some routine failings in much practice. The report revealed that:
- most adolescent services had not adopted a formal person-centred approach to care planning
 - there was little evidence that plans for the care of adults were carried out with their full involvement
 - in just over half of all services, people did not have a copy of their care plan that was accessible
 - there was little evidence that care plans were audited regularly or kept up to date
 - the majority of services did not provide independent advocacy.
- 2.34 In a different field, a study from the Commission for Social Care Inspection on the experience of people with dementia living in care homes used a new observational process – the Short Observational Framework for Inspection (SOFI) – to look at the experience of 424 people with a diagnosis of moderate to advanced dementia. Key questions relating to people’s dignity and respect were addressed:
- Are my wishes respected and my views taken into account?
 - How am I treated and do staff communicate with me?
 - Do I have opportunities to relate to other people that are important to me?²⁸
- 2.35 Earlier inspection work by CSCI has found that people with dementia do not always receive good person-centred care, while other research has also documented the poor quality of life for some people with dementia living in care homes,^{29 30} and inadequate services for all people with dementia.³¹ Improving the quality of care for people with dementia is one of the three key themes of the draft National Dementia Strategy issued for consultation in June 2008.³² The consultation document acknowledges that there is room for

28 CSCI (2008), *See me, not just the dementia: understanding people's experiences of living in a care home*, London: CSCI.

29 Help the Aged, National Care Forum and National Care Homes Research and Development Forum (2007), *My home life. Quality of life in care homes. A review of the literature*. London: Help the Aged.

30 Alzheimer's Society (2007), *Home from home. A report highlighting opportunities for improving standards of dementia care in care homes*. London: Alzheimer's Society.

31 National Audit Office (2007), *Improving services and support for people with dementia*. London: The Stationery Office.

improvement *"in almost every area from diagnosis to the end of life"*, and identifies four areas where the greatest need has been identified to date: general hospital care, home care, intermediate care and care homes.

- 2.36 The CSCI report found that over one-third of homes inspected failed to meet statutory requirements on the quality of their care planning, and staff were sometimes not involved in the process and would have *"little background information on which to judge what someone's wishes or preferences might be"*. While 22% of people were observed to spend time in a withdrawn state when people around them were engaged in activities, and while it was acknowledged that some of this may have reflected long-standing mental health problems, the fact that this withdrawn behaviour was 'clustered' across 15 of the 100 homes *"suggests that additional environmental factors, such as a poor culture of care, may have been at work here"*.³³ The report also documented some poor practices around communication and observed that *"the quality of staff communications has a great bearing on how people with dementia feel"*.
- 2.37 Recent work between the Centre for Policy on Ageing and the Older People's Programme to explore older people's experiences of living with high support needs, focusing on those moving to and living in care homes and using other kinds of supported accommodation, has highlighted the lack of a voice for these older people. This means that people cannot exercise choice and control over their support or any aspect of their life. The project identifies the need for significant cultural and structural changes, taking an approach that is *"based on citizenship and a focus on personal identity, self expression, individual aspirations and fundamental human rights"*.³⁴

The marginalisation of human rights

- 2.38 The Mansell Report (*op cit*) adopts a clear moral premise:

"People whose behaviour challenges have the same needs as anyone else, in addition to special needs for help to overcome the problems their behaviour presents. They do not surrender their needs for personal relationships, for growth and development, or for anything else because their behaviour presents a challenge to services. They have the same human and civil rights as anyone else."

(para 12)

32 Department of Health (2008), *Transforming the quality of dementia care: consultation on a national dementia strategy*.

33 CSCI (2008), *Op Cit*, p25.

34 CPA briefings (2008) *Older people's vision for long term care*
http://www.cpa.org.uk/policy/briefings/older_peoples_vision_long_term_care.pdf

- 2.39 Evidence of the marginalisation (or even denial) of human rights to people with multiple and complex needs is the most fundamental problem of all, for if these are denied then there can be no improvement in people's lives on any other dimension. There is considerable evidence that guarantees of such basic rights are not routinely in place. The Mencap Report, *Death by indifference*,³⁵ highlighted six tragic examples of institutional discrimination against people with a learning disability, and drew attention to a number of contributory factors. One common factor across all of the cases was that the individuals had severe or profound learning disabilities, with little or no verbal communication. Subsequent investigations in Cornwall³⁶ and Sutton and Merton³⁷ NHS trusts also highlighted a correlation between increased levels of impairment and abusive practices, including sexual abuse, physical abuse, deprivation of liberty and institutional practices.
- 2.40 Again, the Healthcare Commission investigation into specialist inpatient services for people with learning disabilities (*op cit*) went as far as suggesting that the routinisation of abuse was so entrenched that it was often unrecognised as abusive and therefore went unreported. Wider research also consistently draws the same conclusion that adults who have the most severe learning disabilities will also be the most at risk of having their human rights ignored or denied³⁸ as also are older people³⁹ being treated for healthcare. All of this raises substantive issues about the compatibility of such treatment with human rights and equality law under the Human Rights Act 1998, the Disability Discrimination Act 1995 (as amended), the European Convention on Human Rights and other international legal standards.

Conclusion

- 2.41 All of the issues from wider literature and reports identified in this section have been prominent themes in our own fieldwork for this report, and will be more fully explored in subsequent sections. The main conclusion to be drawn from this contextual review, however, is that there is a gap between the rhetoric of inclusion for people with multiple and complex needs and the reality of their circumstances. The dominant framework has been a disease-based model that focuses on individual pathology, and although there are

35 Mencap (2007), *Death by indifference*.

36 Commission for Social Care Inspection/Healthcare Commission (2006), *Joint investigation into services for people with learning disabilities at Cornwall Partnership NHS Trust*.

37 Healthcare Commission (2007), *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*.

38 Carnaby, S (1999), 'Individual programme planning: where is the individual?' *Tizard Learning Disability Review*, 4(3), pp 4–9.

39 Joint Committee on Human Rights (2007), *The human rights of older people in healthcare*. Eighteenth Report of Session 2006–7. HL Paper 156–1. HC 378–1.

many situations where medical skills and knowledge are invaluable, this model does not always provide the best foundation for responding to longer-term, non-acute conditions or for promoting social inclusion.

- 2.42 It is in this context that personalisation is seen as a way of introducing choice, control and flexibility into the lives of all people who use services, including those with multiple and complex needs. Individualised services may be achieved in a range of ways – well-coordinated services that transcend traditional boundaries, person-centred planning, Direct Payments, the *In Control* model, Individual Budgets, personal budgets and others. Although initially these ideas – particularly Direct Payments – have been developed in the context of support for adults with physical and sensory impairments, and have emerged from the disabled people’s movement, they have been applied more recently in relation to people with learning disabilities, particularly through the work of *In Control* in developing self-directed support. However, the model of personalisation is increasingly seen as equally appropriate for the whole age range and the spread of conditions that could be covered by the term ‘multiple and complex needs’. A key aim of this report is to examine the factors that might promote or impede such developments.

3: Policy-level issues

- 3.1 In this section we identify key policy themes and consider these in the light of current local experiences. The themes are:
- the role of out-of-area provision
 - working in partnership
 - developing personalisation policies
 - monitoring, inspection and performance assessment.

The role of out-of-area provision

- 3.2 The placement of people with multiple and complex needs 'out of area' tends to primarily concern people with learning disabilities and, as noted earlier, around 11,000 people aged 18 to 64 with a learning disability were estimated to be living out of area in 2006. However, this data is limited to people supported by councils with social services responsibilities – those people in some supported living arrangements or funded by the NHS are not included in these figures. The main groups of people most likely to be placed out of area are those with challenging behaviour, autism, mental health needs, complex health needs and forensic needs; the individuals concerned are usually relatively young – with placement often occurring at the transition to adult services – and will require support for the foreseeable future.
- 3.3 In their analysis of the data, Emerson and Robertson (*op cit*) show that the most striking finding is the extent of local variation – at one end Greenwich externally places around 90% of its supported residents and at the other Durham externally places only about 5%. In general the London Boroughs are big 'exporters', whilst the North East and Yorkshire & Humber come in low. None of the councils in our study was a high out-of-area placer in Emerson and Robertson's local council breakdown table (p5/6), and none appeared to be high 'receiving' areas. The policy dilemma in relation to the accommodation and support arrangements for people with multiple and complex needs has been concisely summarised in the Mansell Guidance⁴⁰ (para 95):

"Developing good local services will not be cheaper, overall, than institutional care, but it will be more efficient because it will achieve more. If local services are not developed, then a trickle of expensive out-of-area placements will become a rush as more people are excluded from mainstream community

40 Mansell, J (2007), *Services for people with learning disabilities and challenging behaviour or mental health needs*. London: Department of Health.

services by being defined as unmanageable in the community. Large amounts of money will be tied up in buying less good services. The policy of community care will be said to have failed."

- 3.4 Government policy on increasing the availability of appropriate local provision for people with multiple and complex needs is well established and was certainly clearly understood in all of the fieldwork sites in our study. This was the case both with adults and with children and young people. In the latter case, there is now a legislative basis to the policy following the passage of the Children and Young Persons Act 2008. Initially the Bill simply included a clause that placed a ban on councils making unnecessary out-of-area placements, but this was challenged on the grounds that it was insufficient to ensure councils made local provision. In response the Government tabled an amendment that has placed a duty on councils to *"take steps to secure sufficient accommodation that is appropriate for the needs of children they look after within their area"*, though it is probable that the restrictions will not be used to prevent children with multiple and complex needs being placed in external settings that are considered appropriate for meeting their needs.
- 3.5 Adult care has not been the subject of similar legislation, but the recommendations of practice guidance and performance management expectations are having a similar effect. Over 30 councils have subscribed to the *Getting to grips* initiative, which arose from the October 2005 report by the then Association of Directors of Social Services on spending pressures in learning disability services.⁴¹ Since 2006, the Care Standards Improvement Partnership (CSIP) has been working to help councils and the NHS to respond to this challenge, and the work programme has been developed in partnership with *In Control* and the former Regional Centres of Excellence.
- 3.6 One output of this work has been the Care Funding Calculator, launched in July 2008, to assist councils to assess a fair price for residential care and supported living arrangements; another has been a focus upon regional commissioning by councils and regional gatherings of portfolio holders.
- 3.7 The research review by Emerson and Robertson (*op cit*) suggests that out-of-area placements are made for predominantly negative reasons such as placement breakdown and dissatisfaction with local services. Most such placements are in the independent sector, often in large settings, and tend to disrupt relationships with family and friends, as well as having other disadvantages for the people using these services. From the point of view of commissioners, an equally important problem was the cost of funding the placements, which were seen as unduly expensive and diverting resources that could be used to develop local services. Such issues were replicated in

41 Association of Directors of Social Services (2005), *Spending pressures in learning disability services*.

all the councils in the study, as one of our elected member interviewees stated:

"We can't make any straightforward calculations about our budget. All we need is someone to come out of hospital needing a massive care package and that would hit us really hard."

- 3.8 Reducing dependence upon such costly placements can become a major local policy imperative, and was a significant concern in all the fieldwork councils, both because of the associated high costs, but also because it was recognised that out-of-area placements were often low quality and resulted in poor outcomes for the people concerned.
- 3.9 Data from the IBSEN study shows that Individual Budget leads in the pilot sites were anticipating that cost savings made with particular user groups (typically people with learning disabilities who were brought back into the authority from expensive out-of-area placements) could be used to offset the higher costs of introducing Individual Budgets among other user groups (typically older people), although it was too early to determine whether this proved to be the general experience of implementation. However, others expressed concern that any savings made in the short term would be cancelled out by the impact of demographic changes, in particular the ageing population and the increase in older people with more complex needs requiring more complex and costly support.
- 3.10 Concerns about the *quality* of out-of-area provision were also prominent in the minds of many of our interviewees. A particular concern related to specialist residential colleges for young people. One manager in adult care services found it difficult to comprehend the reasoning behind some such placements by children's services suggesting poor strategic coherence between children's and adult service agendas despite the greater emphasis on improved transition:

"It feels like there is a disjuncture in culture between us and children's services in terms of out-of-area placements. They are not placements we would have. It has almost set up a culture that is counter to the culture we want to develop."

- 3.11 Other interviewees similarly highlighted the difficulties associated with out-of-area placements:

"They disappear off to residential college for two or three years and have a wonderful time and then they have got to be moved back. In theory, they are supposed to be getting prepared for supported independent living but the reality is quite different. They are learning a set of skills that aren't easily transferable."

(Transitions coordinator)

And as the following comments illustrate, there were major concerns about the quality of the care provided at a distance and about the disparity between the claims made by some providers and the reality of experience:

"The school would say he has to learn to go to Tesco's, he has to learn to sit in assembly, and I would say 'he can't...it's like saying to someone with no legs they have to walk'. This went on and on, and as he got bigger, they used more and more people to manage his behaviour. We found out that he had been locked in cupboards, wrapped in parachutes, had his nose squeezed and held down."

(Mother of a severely autistic child living at home but attending a specialist college)

"Lots of places sell themselves saying they do A, B and C and then say 'oh we have difficulties, we have a staff shortage'. It's just one thing after another."

(Transitions coordinator)

"Certainly one place that we went to [look at] – the fabric of the place was fantastic (...) I met the manager, I talked to the staff, and it was (...) you know people are seduced by what they saw but not what they got (...) in this particular environment, the young people, one of whom has a disability the same as [my son], their needs are appallingly met. And yet, ostensibly, you walk through the door and you think 'wow, this looks very smart'."

(Mother of a young man with learning disabilities)

3.12 Some similar concerns were expressed about adult placements:

"Many of these specialist services out of county would claim to be doing a person-centred approach but the reality is that it's containment...they haven't been delivering."

(Area manager, learning disability)

"Once they have got them at 19 they think they have got them for life. There is a complacent attitude of 'we are wonderful at what we do'. They might be good at some things like keeping the person safe, but how much do they access the community? I wouldn't want to be watching Fireman Sam DVDs back to back."

(Transitions coordinator)

However, the out-of-area issue was far from clear-cut. Several complicating issues emerged from the fieldwork:

The proximity of neighbouring areas

3.13 One problem raised by both commissioners and providers was the narrow definition of what constitutes 'out of area', with provision in an adjoining council area deemed to fall foul of government expectations. A senior manager in children's services responsible for a team of specialist foster

carers was concerned about the impact of a strict interpretation on the viability of the service:

“Our local authority is a small geographical area and there would be an issue in terms of recruitment. A number of our foster carers are two or three miles down the road in another authority. So what is the actual boundary?”

“One thing that concerns me is that we get a black mark when we place a child in a neighbouring authority, which is just ridiculous because it’s virtually a street away. There has to be some reality to all of this.”

(Elected member)

The limitations of local provision

3.14 The emphasis upon local provision may obscure the possibility that this may not be the most appropriate setting for some individuals – partly because of the specific needs of these individuals, and partly because local provision may not be sufficiently well developed (a particular challenge in smaller councils). An acknowledgement that local provision may not necessarily be in the best interests of the service users was a prominent theme in our fieldwork, as the following comments illustrate:

“A lot of our business comes from people being moved out of hospital into badly supported settings. People are being moved, but not for the right reasons.”

(Specialist independent provider)

“Bringing people home is a later piece of work. The first, and more difficult, piece of work is to improve the local choice for local people now so that it doesn’t have to happen again. Very few people are doing that.”

(Independent provider)

“You can’t do it for everybody. Why would some people want to come back here? They have no links or networks.”

(Transitions coordinator)

“Every authority can’t have provision for every possible type of complex need. Some people’s needs will inevitably be better served with a placement that is not in this area.”

(Senior manager)

“It’s been undertaken with a dogma that is really quite unsettling where people are being moved against their will into a local area that they don’t wish to move to and have no interest in moving to. We have had a number of examples of this. If any of us were moved to where we grew up without involvement from ourselves it would be a national scandal.”

(Independent provider)

"It's a directive that comes out and everybody has to follow it. The poor individual for whom it is meant to improve things is not considered in a lot of cases. It's a big frustration for us."

(Independent provider)

Working in partnership

- 3.15 People with multiple and complex needs will inevitably require support that crosses established professional and organisational boundaries, and these boundaries will be traversed in complicated and sometimes rapidly changing ways. Social care often lies at the centre of a complex web of relationships, and policy makers, managers and practitioners have the task of pulling together these diverse strands. Developing an effective 'whole-system' or 'whole-person' approach to support people with multiple and complex needs proved to be very challenging across all of the sites in this study. Several key boundaries were identified:
- boundaries at the transition from adolescence to young adulthood
 - boundaries between adult social care and the NHS
 - boundaries between Individual Budget income streams.

Transition from adolescence to young adulthood

- 3.16 Transition from adolescence to young adulthood is characterised by a plethora of guidance developed at national level, and many localities now seem to have appointed transition coordinators or created transition teams to address the issue. This was certainly the case in the councils that comprised this study where arrangements included: a multi-disciplinary transition service that begins work with young people well before school-leaving, in one case from age 14 to 25; dedicated transition workers, sometimes jointly funded and based in either children's services or in adult social care; and a joint transitions group bringing together children's and adult services and the Learning and Skills Council, and which feeds into the children's strategic partnership.
- 3.17 There was a widespread view that initiatives such as these had greatly improved the transition process in recent years, with localities now much more confident about the quality of their information on the number of young people coming through the system, and the nature of their needs. In some cases, the transition period had also been used to pilot personal budgets and prepare the ground for the changes taking place in adult social care. In one council, several families had been through the resource allocation system (RAS) process and had received indicative allocations of between £11,000 and £16,000. But despite these efforts, the transition process continues to be affected by boundary issues of various types. These findings echo those of

other work undertaken by CSCI which found, despite examples of good practice, there remains inadequate commissioning, poor coordination of services and a failure to plan with young people and their families.⁴²

Standardised definitions of adulthood

- 3.18 There is no consensus across the various agencies as to when adolescence ends and young adulthood begins. If the crucial task for the adolescent is to move from the protected life of a child to the autonomous and independent life of an adult (or as close to that as possible), then individuals are unlikely to reach the same milestones at the same time. Nowhere is this more the case than with young people with multiple and complex needs, where readiness may be significantly delayed and service responses will need to be personalised.
- 3.19 Some of the key agencies seem to take an inflexible approach, much to the frustration of some of our interviewees working in the transition field. Different agencies define transition variously at age 16, 18 or 19 with different criteria followed by different parts of the health, education and social care system. Health services were seen in the fieldwork councils as the most rigid. In one council, for example, children in specialist educational provision continued to receive an input from the health team until leaving school at 18 or 19, whereas those who were supported in a mainstream school lost support at 16. Moreover, these young people were then deemed ineligible for support from adult services until the age of 18, leaving them effectively adrift for two years with no therapeutic input from the NHS. Similarly, the medical transition from paediatrics to adult medical care takes place at 16 regardless of individual needs and circumstances. As one transitions coordinator noted:

“The problematic area is getting the involvement and commitment from health colleagues around anyone moving from children’s services into adult services. They have different criteria that I’m still not clear about. It just all works so differently.”

These difficulties could potentially be addressed through the use of personal budgets and in future through their extension to aspects of NHS provision.

The children’s–adult social care division

- 3.20 Most local councils have now established separate children’s services authorities with responsibility for the education and social care of children and young people. The transition to young adulthood was not handled particularly well even in the time of unified social services departments, and there is concern that the new organisational division will only exacerbate the

42 Commission for Social Care Inspection (2007), *Growing up matters: better transition planning for young people with complex needs*.

difficulties. It has not been possible in this study to investigate this possibility rigorously, though the creation of so many transition teams suggests a commitment to minimise such a risk. Indeed, for one interviewee the division had prompted an *improvement* upon the previous situation.

“Once we split into two organisations we couldn’t take anything for granted anymore, so we had to work harder at actually gathering the information. It soon became noticeable what we didn’t have so we started to make links into children’s services that we never did when we were part of the same department.”

(Adult care manager)

Learning and Skills Councils

- 3.21 The Learning and Skills Council (LSC) has a specific duty to have regard to the education and training needs of learners with disabilities, and is aided by the local LSCs that have been established in England, each of which will have a designated contact person for disabilities and must consult local councils on their policies and priorities. A common view expressed in this study is that relations between councils and LSCs have become more difficult in recent years as costs have come under greater scrutiny, and new rules are being applied. The councils in this study reported that costs that were previously met by the LSC are now the subject of dispute and negotiation, most commonly in the case of residential college placements.

“There is now an expectation that we will contribute. The standard formula is 30% from social care and 20% from health if the person has a significant health need. We pay but some authorities don’t.”

(Transition worker)

“There’s argument all the time. They are trying not to fund anyone in residential colleges and tell us to encourage people to stay locally. We have to produce lots of reports to show that local provision isn’t appropriate. If we manage that they will then ask for a contribution from social care for the care parts and health for the health costs.”

(Transitions coordinator)

A similar approach was said to be taking place with local colleges:

“We have got young people on an entry programme who may have support workers to take them to the toilet and help them get their lunch, and this is not counted as education so LSC want to recover the costs. It comes out of people’s individual budgets.”

(Transitions coordinator)

- 3.22 One of the reasons for this behaviour by LSCs was said to be the ways in which funding bids by specialist colleges invariably requested the highest

banding regardless of individual circumstances – the highest Band is H which (at £68,829 pa) is over £20,000 pa more than Band G. One transitions coordinator felt this was difficult to defend:

“They cut and paste with the reports just to get the funding – sometimes they forget to change people’s names. We know they have done it. I think their days are numbered, I thought that a year or two ago.”

- 3.23 Again, a potential solution to this issue is the development of personal budgets based upon an explicitly calculated RAS, and this does seem to be something the LSC nationally wishes to develop. In 2006 it committed to:

“...examine the development of individualised budgets and the interaction with LSC funding...this represents an exciting opportunity to empower people with learning difficulties and other disabilities to personalise services.”⁴³

- 3.24 Despite this apparent commitment, it is notable that two years on these issues remain unresolved and an increasing obstacle to achieving personalisation for people using educational support.

Earlier entry into adult social care

- 3.25 Additional issues were identified with LSC funding which relate to the restrictions on access to courses. Moving from school to college (out-of-area or local) at the age of 18 or 19 is no longer something that can be taken for granted by young people with complex needs. Part of the problem here is the LSC requirement that people in educational settings must be able to demonstrate evidence of ‘progression’ – something that can be difficult or impossible to achieve in the cases of some young people with multiple and complex needs. This in turn has a significant knock-on effect for adult social care (identified across all the fieldwork councils), with young people entering adult social care services rather than accessing educational support, as this service manager explained:

“Colleges are saying ‘we can’t hit our targets with these people’ so they now come to us at 18. They are the only people we actually support in day services – we have not taken any new referral from any other source for three years, only young people with complex needs because we can’t support them elsewhere.”

- 3.26 The unexpected and unplanned funding implications for adult social care can be significant during this period, with attendance at a day centre plus some home support and respite costing around £40,000 pa. Taken in combination with other demand-side pressures, some managers were in despair:

43 Learning and Skills Council (2006), *Learning for living and work*.

“If each year there is a general transition of young people with more and more complex needs, and you can’t take it off the other end, and there is no growth in the adult social care pot, then how do we manage that within a finite resource?”

(Senior manager, adult social care)

- 3.27 All of these boundary disputes can result in a game of budgetary ‘pass the parcel’ in which the people whose interests should be at the forefront find themselves marginalised as agencies argue over who will foot the bill. A transitions coordinator summed up the consequences:

“We are at the frontline trying to support and advise parents and their families and it’s really hard. The despair of some of these families – and you can’t really blame them. It’s really, really difficult.”

The issues around restricted access to educational opportunities for people with learning disabilities are part of a wider debate about adult learning. An increased emphasis on courses that lead to skills and qualifications for people of working age raises issues about access to informal adult learning where qualifications are incidental to learning opportunities. These matters have been the focus of consultation by the Department of Innovation, Universities and Skills. Responses to the consultation highlighted concerns about the expense and decline of local courses and questioned the commitment to informal learning given the emphasis on adult vocational skills.⁴⁴

Boundaries between adult social care and the NHS

- 3.28 People with multiple and complex needs will almost certainly require support from both the NHS and social care, and the policy landscape of the past 20 years has been littered with attempts to create closer working relationships between these two agencies, with varying degrees of success. There is wider evidence that relationships have improved in many respects,^{45 46} and this was confirmed in some of the sites in our study, especially in those localities with coterminous boundaries between the council and the PCT. Sometimes this positive relationship was couched in terms of genuinely shared endeavour:

“We have to solve the problem between us. We take a joint commissioning approach which is ‘this is the money we have got between us, there is no point in saying “you don’t; we don’t”’. At the end of the day we have to

44 Department of Innovation, Universities and Skills (2008), *Informal adult learning – shaping the way ahead. Consultation response analysis*. Central Office of Information.

45 Henwood, M (2006), ‘Effective partnership working: a case study of hospital discharge’, *Health and Social Care in the Community* 14 (5), 400-407.

46 House of Commons Health Committee (2005), *NHS continuing care*, Sixth Report of Session 2004-05.

resolve problems and it's how we do it with the money we have got available."

(Senior manager)

- 3.29 At other times a good relationship was seen as resting in organisational self-interest:

"There's nothing like payment by results to focus the PCTs mind. They've invested in our services because they know we've been strapped for cash, and if they want things to happen then they have to give us money to deliver on it."

(Senior manager)

- 3.30 In some cases, this had also resulted in the PCT accepting that (via a pooled arrangement) their portion of shared support could be used as part of a Direct Payment to sustain a complex package of personalised support. The message from evidence such as this is that where council–PCT relationships are robust then it is certainly feasible to deliver coordinated and even personalised support. However, where relationships are less good – and this can be the case for a wide variety of reasons – then the outcomes for people who use services and their carers can be problematic. In our study we also found evidence of weak council–PCT relations, typically because of a history of financial pressure creating mutual mistrust:

"PCT officers turn up at the scrutiny panel but we have yet to have a meeting round the table with them – I have expressed concerns about the lack of communication."

(Elected member)

"From our politicians there's not a lot of love lost with Health. To get them to buy into a pooled budget would be quite difficult – they think they are going to be shafted."

(Senior manager)

"Let's be honest, the health guys have got more money than we ever knew existed. If people are in hospital it's costing us nothing, if they come out the cost gets pushed onto social care. It's a bad scenario, push and shove all the time really."

(Elected member)

- 3.31 Given the high cost of supporting people with multiple and complex needs, it is unsurprising that where disagreements arose they tended to be about funding. In some cases this involved alleged withdrawal from established agreements or perceived misuse of specific funding allocations. In one case, for example, the council and PCT were still arguing – many years on – about interpretations of the 'dowry system' for resettling people from long-stay hospitals, whilst in some parts of the country CSCI has reported inappropriate use of the Learning Disability Development Fund by PCTs.

3.32 In *Valuing people now*⁴⁷ the Department of Health has proposed to transfer the learning disability budgets and commissioning responsibilities of PCTs to local authorities – the only exceptions to this transfer will be mainstream healthcare and forensic/offender services. Councils and PCTs will be required to agree an appropriate amount for transfer which will then be allocated by the Department of Health based upon spend in 2007/08 with a view to allocation in 2009/10. In one site this situation was given as an explanation for withdrawal of the PCT from joint funded arrangements for learning disability services:

“Last year without any consultation the PCT took half a million pounds out of our Section 28A agreement – if you were being cynical that’s quite a clever move for when all of the commissioning comes to the local authority. If this amount is removed from their learning disability budget then they will be minimising the amount they have to hand over.”

(Senior manager)

3.33 By far the biggest reported area of contention, however, is Continuing Healthcare, though here too there was some limited evidence of fairly good working relationships in our study. One council, for example, could boast there were no formal disputes over Continuing Healthcare funding, but also acknowledged that it had a lower level of fully health funded cases compared with the national average. More typically, Continuing Healthcare was reported as an area of ongoing contention:

“There is a real steer coming from the SHA saying that people with learning disabilities probably generally won’t be eligible under Continuing Healthcare. I find that bizarre and we will be resisting that manfully.”

(Senior manager)

“Psychiatrists are saying they will not discharge some people from hospital unless they have 2:1 or even 3:1 staffing, then the PCT turns round and says because there is high staffing we are predictably managing unpredictable behaviour therefore there is no need for Continuing Healthcare. But if we reduced the staffing the person would soon become distressed and may end back in hospital – and then it’s not our problem.”

(Learning disability manager)

3.34 The introduction of the National Framework for Continuing Healthcare in October 2007⁴⁸ was generally believed to have led to some improvements (and this is consistent with wider trends nationally⁴⁹), but some basic problems remained:

47 Department of Health (2008), *Valuing people now: from progress to transformation*.

48 Department of Health (2007), *National Framework for NHS Continuing Healthcare*.

49 Parliamentary and Health Service Ombudsman (2008), *Annual Report 2007-08. Bringing wider public benefit from individual complaints*. London: The Stationery Office.

"Thankfully we now have a little more consistency since the National Framework was introduced. Prior to that it was a nightmare, an absolute nightmare. But a lot depends on each nurse assessor team. You can have very different types of people, sometimes leading to very different types of working relationships and different decisions."

(Team manager, physical disabilities)

"It has changed the balance – it was so narrow before. In terms of people with challenging behaviour we are getting more confident about putting an application in. We are getting a feel for it."

(Senior manager)

"We've got criteria but in a way you can interpret them how you like. The PCT is good on obvious ones like high health needs, rapid deterioration and unstable conditions, but I don't think they understand intensity and complexity."

(Area manager, adult services)

- 3.35 In addition to all of these issues around *access* to Continuing Healthcare and ensuring that criteria are based on need and not diagnosis, there is now an additional difficulty in the context of the personalisation agenda – the potential *consequences* of accessing Continuing Healthcare. Two sorts of interrelated issues were identified in our fieldwork – the consequences for jointly funded care packages, and the consequences for personalised support.

Jointly funded care packages

- 3.36 The emerging issue here is that where people with multiple and complex needs are in receipt of jointly funded care packages (from the council and PCT), there is reported to be a demand from auditors for evidence and assurances that health money is only spent on healthcare, and social care money on social care. Arrangements such as a general 50/50 split on complex cases may be judged as *ultra vires*. This situation is then rolled into the Continuing Healthcare framework and individuals are judged to be *either* a health or a social responsibility, but seemingly cannot be a *shared* responsibility:

"We have got an agreement around the screening tool – it used to be 50/50 but now it's either/or. All our multi-disciplinary team assessments go to a Continuing Healthcare panel which is joint between the council and the PCT and it's either agreed if it's health or it isn't. If it's health they put 100% in."

(Senior council manager)

- 3.37 However, some localities *are* still working on the basis of a general formula for cost sharing. In one council there was an agreement that young people with challenging needs are approved on 50/50 funding – "*a little local agreement*" as a transitions coordinator described it. And in another council, it was

reported that flexible agreements around jointly funded packages were now becoming *more* common than in the past:

"It used to be all or nothing funding but it's opening up a bit now. We can say you could do 20 and we could do 80, or just 50/50. Those discussions are opening up now."

(Council continuing healthcare manager)

- 3.38 The position on flexible joint funding of support packages for people with multiple and complex needs therefore appears to be highly variable across the country, and in some cases the introduction of the National Framework for Continuing Healthcare seems to have resulted in the unintended consequence of reduced scope for sharing costs.

Continuing Healthcare and personalised support

- 3.39 The importance of the funding source is not simply a matter of the impact upon the budgets of the respective agencies; it also has consequences for the type of support people receive and the costs they may have to bear. The main concern being expressed in this study – by professionals and people using services alike – is the potential loss of personalised support. Once Continuing Healthcare funding has been agreed for an individual then the general understanding of the legal position is that Direct Payments and support from the ILF are no longer possible, and this is likely to mean that existing personalised support arrangements will cease. Certainly this was the common experience across the sites in this study:

"At the moment there appears to be little flexibility. If someone is coming through transition with direct payments and ILF and are then Continuing Healthcare funded they will lose the flexibility in their support."

(Learning disability team manager)

"People who are Continuing Healthcare funded gain financially but lose in terms of choice and control. The NHS is a very patriarchal, clinical-led organisation in which the professionals know best and people are 'done to' rather than being part of person-centred planning. These individuals are at risk of losing a package of support that works for them."

(Team manager, physical disabilities)

- 3.40 As this manager described, this has led to perverse incentives *not* to seek fully funded continuing care:

"And it always used to be, 'let's hope this person gets 100% continuing care funding.' Now it tends to be, 'well, let's hope they get 95% or 90%' because then there's ability to commission and pay for that social care bit (...) at the moment it's very rigid. If somebody has 100% continuing care we have experienced difficulties in how you commission those (...) flexible services."

(Learning disability, team manager)

- 3.41 As another manager described, the consequences of becoming eligible for Continuing Healthcare were creating *“the biggest barrier”* to supporting personalisation objectives:

“Continuing care are not allowed to do anything through Direct Payments currently, and that’s a real issue because if we’ve encouraged people onto Direct Payments and they’re happy with it, and their health needs continue to deteriorate, and they get so their health needs are paramount, then there is complete dislocation because they can’t continue with their Direct Payments. And this is becoming quite an issue because the more people that you offer (at the complexity we are talking about) you get them onto Direct Payments and then they have to lose them again.”

(Area manager, elderly and physical disability services)

- 3.42 For some people with complex support arrangements founded upon long-serving and trusted PAs (many of whom are regarded as friends rather than employees) the transition to fully funded Continuing Healthcare was viewed as a potential disaster rather than a financial gain – and in some cases had led to a refusal to leave council-funded care. One service user facing the prospect of becoming eligible for continuing care (Mrs Keane, who is profiled elsewhere in this study) said:

“The social worker tries his best for me. I tell him what I need and he organises it. But once I go on this NHS care he won’t be part of it and I don’t know where I will go. Jean (PA) has got to stay with me. She has practically lived with us for four years, she’s here every day.”

- 3.43 Although the transfer to continuing healthcare still left social care with the potential to support carers, the general view across the fieldwork councils was that different lines of funding and accountability had failed to consider the best interests of the individuals in need of support – not so much a question of the volume of resources, but the way they are delivered. The vulnerability of these individuals was even more exposed in those cases where continuing healthcare was awarded for a short period (usually three months) after which it would be reviewed – an approach that could leave individuals bereft of previous funding sources, especially ILF funding, only to have to reapply when eligibility for continuing healthcare changed:

“Getting back into ILF again is a stinker. I have actually resisted accepting Continuing Healthcare simply because the individual would lose the ILF money and there is uncertainty about the duration of the Continuing Healthcare entitlement. We could end up with all sorts of disruption for the individual.”

(Manager, physical disabilities)

- 3.44 Overall, although there is some evidence of good PCT–council relationships and of positive practice with individuals, there are still some major fault-lines. Funding pressures too easily result in unilateral actions that are perceived as a betrayal of trust, and this in turn bedevils future partnering. Attempts to

clarify responsibilities have helped to some extent but have also resulted in some perverse consequences for the support of vulnerable individuals. The possibility of including Continuing Healthcare funding within Direct Payments through NHS personal budgets was one that was seen by most interviewees as logical and welcome, and we will explore this in greater detail below.

Boundaries between Individual Budget income streams

3.45 The idea behind Individual Budgets is to enable people needing social care and associated services to design that support and to give them the power to decide the nature of the services they need. In our next section we examine the issue of personalisation for people with multiple and complex needs more fully, but here we explore some specific boundary issues relating to the income streams of different agencies. This analysis comes from the experience of the Individual Budget pilot projects and is also included in the full report of the evaluation.⁵⁰ One of the key features of Individual Budgets is the proposed bringing together of a variety of streams of support and/or funding, from more than one agency. In the case of people with multiple and complex needs the main streams (in addition to council-provided social care services) are:

- Disabled Facilities Grant
- Integrated Community Equipment Services
- Supporting People
- Independent Living Fund.

Disabled Facilities Grant (DFGs)

3.46 DFGs are used to finance adaptations to the properties of older and disabled people to enable them to have easier access within their house and to facilitate them remaining in their own homes rather than moving into institutional care. DFGs may therefore be particularly important for people with very complex physical and other impairments. Findings from the IBSEN study show that sites that had included DFGs within the Individual Budget pilot had only managed to *align*, not *integrate*, assessment processes. This had been achieved via the inclusion of a trigger question relating to DFGs within the main Individual Budget assessment and through 'passporting' some of the service user's details to the DFG team. Recipients of DFGs remained separately accountable to the DFG team for how their grant was used.

50 Glendinning, C, Challis, D, Fernandez, J L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M, Wilberforce, M (2008), *Evaluation of the Individual Budgets pilot programme final report*. Social Policy Research Unit, University of York; Personal Social Services Research Unit, Universities of Manchester, Kent, and London School of Economics; Social Care Workforce Research Unit, King's College, London. Chapter 8 'Integrating funding streams with adult social care.'

- 3.47 Some Individual Budget lead officers in the IBSEN study were initially optimistic that the inclusion of DFGs within Individual Budgets could speed up assessments and ultimately the installation of adaptations. There were also potential gains to be made to the adult social care budget as the earlier installation of adaptations could reduce some ongoing adult social care support costs or prevent an individual from moving into residential care. In practice, however, the IBSEN study discovered that several sorts of barriers impeded progress:
- 3.48 *Legislative barriers:* Several Individual Budget leads commented on a perceived lack of commitment at national level, arguing that it was not possible to integrate DFGs into Individual Budgets without a change in primary legislation, and expressing frustration that this had not occurred prior to the Individual Budget pilot projects. Indeed, this perceived lack of commitment to supporting the integration or alignment of DFGs within Individual Budgets had led some sites to abandon local efforts with this funding stream altogether.
- 3.49 *Specialist assessment:* Individual Budget leads in some sites argued that the complexity of assessments for DFGs meant that it would be difficult, if not impossible, to integrate these with Individual Budget assessments as care managers would not have the necessary skills to undertake the assessments or act upon the results.
- 3.50 *Inability to 'personalise' adaptations:* Several Individual Budget leads commented that they could not see how including a DFG within an Individual Budget could benefit people using services. It was argued that there are very few flexibilities within DFGs, as the money can only be used to pay for an agreed adaptation. Integration would therefore mean DFG monies being ring-fenced within an Individual Budget for a particular adaptation, with little opportunity for flexibility, choice and control – precisely the opposite of what an Individual Budget is intended to achieve.
- 3.51 *Stresses of managing a DFG:* Some Individual Budget and DFG lead officers could not understand why an older person or someone who was physically or mentally frail would want to take responsibility for tendering for builders and project managing the construction of, for example, a ground floor extension. If DFGs remained outwith the Individual Budget system, responsibility for this would generally be managed by a third party on their behalf.
- 3.52 Since the Individual Budget pilots, and in response to Bristol University's evaluation of the DFG, the Department for Communities and Local Government has amended some of the regulations around the DFG⁵¹ which

51 Department for Communities and Local Government (February 2008), *Disabled Facilities Grant – the package of changes to modernise the programme*.

ought to make it easier for DFGs to be included within Individual Budgets. In particular:

- Removing the ring-fence around DFGs and broadening the scope of what DFGs can be used for will enable DFGs to be pooled with other funding streams, such as adult social care, tele-care and equipment services more broadly (this is being piloted in sites over an 18-month period from April 2008).
- Removing the need for individuals in receipt of certain social security benefits to undergo further financial assessments will reduce duplication and potentially speed up the processing of applications for DFGs.
- The increase in the global DFG budget and the increase in the amount available to an individual from £25,000 to £30,000 may speed up the rate at which DFGs are granted.

Integrated Community Equipment Services (ICES)

- 3.53 Local ICES are resourced from baseline social care and NHS PCT budgets and as such do not strictly constitute a separate 'funding stream'. ICES provides health and social care equipment to people with short- or long-term needs to enable them to remain living in the community⁵². Examples include hoists and raised toilet seats. In principle, the inclusion of community equipment within Individual Budgets was thought to offer older and disabled people and their families the opportunity to consider more flexible solutions to assessed needs and to choose from a greater range of equipment than was traditionally available from health or social services' equipment stores.
- 3.54 In practice, the experience of the IBSEN study again reveals implementation problems. Most of the Individual Budget sites that had included ICES in their local pilots argued that, although ICES was one of the easier budgets to work with, integration would have few benefits for service users typically because of the time and effort involved in sourcing one's own equipment. Moreover it was argued that integrating ICES assessments within Individual Budget assessments undermined OTs' specialist skills and risked users receiving no, or inappropriate, advice. And finally, ICES teams were able to bulk purchase standard pieces of equipment at very low cost and both Individual Budget and ICES managers argued that people managing their own ICES as part of an Individual Budget would not be able to buy individual items from suppliers at such low prices. Indeed, costly individualised purchasing was seen as having the potential to undermine the cost neutrality of Individual Budgets.

52 Care Services Improvement Partnership (2006), *Provision of equipment via an Individual Budget resource allocation system*.

Supporting People

- 3.55 Housing provision is a critical component of local support for people with multiple and complex needs, and Supporting People is only one of the dimensions of activity. Supported living is now a clear platform of government policy and the Mansell Report (*op cit*) is adamant that the best model of residential service is likely to be support to enable people with challenging behaviours to live in ordinary housing. There is growing interest in, and support for, accommodation arrangements based upon 'clusters' or 'networks' of tenants, whereby people can benefit from the friendship and safety of having one another as co-tenants or neighbours whilst retaining the privacy and independence of their own individual living accommodation.
- 3.56 Some form of supported housing model was widely seen across our sites as the most appropriate approach, though turning it into practice was proving to be difficult. One of the advantages for adult social care is that part of the funding will come from other sources such as housing benefit, social security benefits and the Supporting People budget, but accessing these is not without difficulty. At national level this includes a ruling by the Social Security Commissioners that it is illegal to charge supported living residents a rent above the local market rate – a common practice by providers as a means of covering the cost of overheads and conversion. Alongside this, there have been important rulings by care standards tribunals that require evidence of significant changes before permitting a change of status from a care home to supported living.
- 3.57 Supporting People (SP) has pulled together housing benefit, the Housing Corporation Grant and Home Improvement Agency grants into a single fund to encourage individuals to move into supported living in the community. Nationally there is around £1.5 billion in the SP budget and the likelihood is that a large slice of this has been used to support people with multiple and complex needs. The SP budget was capped nationally at £1.7 billion in 2007/08 and from 2008/09 will no longer be ring-fenced, raising concerns that it may no longer be devoted to supported living. Across the sites in this study, the use of SP funding to support people with multiple and complex needs seemed to be getting increasingly difficult. Some interviewees took a phlegmatic view:

"Every year we have a withdrawal of Supporting People money. You win some and lose some don't you? It was all new money anyway. We took advantage of it when it was there and now it's coming home to roost."

(Senior manager)

- 3.58 Others saw the budgetary implications as being much more significant. A learning disability manager described the loss to her budget of the Supporting People funding:

“When the first tranche of Supporting People was taken out it was about a million and a half and I had to replace it. Everyone’s funding was cut by 20% on a spreadsheet – and half the figures weren’t right. We had to go to corporate finance and ask for growth money.”

- 3.59 In the context of Individual Budgets, the usefulness of Supporting People funding is also diminished by the fact that commissioning focuses upon *schemes* rather than individuals, with provider organisations leading their development. Overall, the provision of supported housing for people with multiple and complex needs is proving to be a complex matter, as highlighted in the vignette of Roy Jones at the beginning of this study. Achieving progress will probably involve partnering skills of a very high order – one local CSCI inspection report in 2007 for example noted that 10 agencies and carers were involved in a project for people with high needs.
- 3.60 Nonetheless, the IBSEN evaluation found that of all the funding streams, the 13 pilot sites had most success in integrating Supporting People funding and associated assessment, resource allocation and review processes into Individual Budgets.⁵³

Independent Living Fund (ILF)

- 3.61 The Independent Living Fund long pre-dates the emergence of Individual Budgets, having been in existence since 1988, and unlike the other Individual Budget funding streams it consists solely of social care monies and might therefore be expected to dovetail closely with council adult social care funds. There was often praise across our sites for the role of the ILF assessors, who were sometimes favourably compared with local authority care managers. One service user receiving funding from both sources commented, for example:

“I find the ILF system easier in some ways. Their social workers know the principles of independence and empowerment, whereas with local authority social workers I never see the same one because as a Direct Payment user my case is de-allocated.”

- 3.62 There was also a view that the ILF has been willing to be more flexible in how the money is put to use:

“As far as the ILF is concerned I sign the form to say this is what I am spending it on – PAs and what have you – and they are quite happy with that.”

(Service user)

53 Glendinning et al (2008), Op Cit, p117.

"I find ILF very flexible in terms of looking at things like respite and holidays...they are often very willing to consider flexible and creative packages."

(Local authority care manager)

"They have got a list of rules but I have never had a situation where they have gone through what people are allowed or not allowed to spend their money on."

(Team manager, physical disabilities)

- 3.63 However, although frontline ILF assessors were generally well regarded, there was also a widespread view that ILF was problematic in two respects – a tightening up on the permitted extent of flexibility and (more fundamentally) a structural incongruence with the personalisation agenda.

Tightening of flexibility

- 3.64 There was a common view across the fieldwork councils that the flexible approach of ILF assessors was coming to an end as the ILF looked to tighten up its own expenditure.

"ILF traditionally gave people the ability to move outside of social care tasks and functions and take a broader perspective, but it now says 'we need to know what tasks and functions are going to be undertaken with ILF'. It has moved into assessment care management land too far, right down to absolute detail."

(Head of service, adult care)

"ILF is getting more difficult to apply for. They used to be fairly flexible but now look at what every penny is going on."

(Team leader, learning disability)

"ILF is definitely tightening up. Years ago people were not asked to do returns in the same way as with Direct Payments but things have got much more rigid."

(Team manager, physical disabilities)

Structural incongruence

- 3.65 Essentially the ILF is an ad hoc, non-governmental body dispensing a large tranche of social care funding in a similar way and for similar purposes to local councils. The need for such parallel (and duplicative) activity, especially in the light of the emergence of Individual Budgets, was frequently questioned in the IBSEN evaluation and in our own study. The IBSEN evaluation found that the constraints of the ILF Trust Deeds meant that integration with social care funding during the duration of the pilot was not possible. Instead, the ILF and the pilot sites attempted to align and fast-track some of their processes, but

Individual Budget leads remained frustrated at the time taken for an ILF application to be turned around.

- 3.66 Most Individual Budget leads in the IBSEN study reported feeling deeply frustrated at the restrictions surrounding ILF funding, in particular that:
- Only that portion of adult social care monies spent on personal care counts towards the £200 per week threshold for the ILF (indeed this has become more difficult with the increase in the threshold to £320 a week since April 2008).
 - ILF monies have to be spent wholly on personal care and domestic assistance and cannot, for example, be used towards purchasing pieces of equipment or support for social inclusion (eg leisure activities). Such restrictions significantly reduced the flexibility of how an Individual Budget could be used in more creative ways.
- 3.67 Not only does the ILF operate a minimum eligibility threshold of £320 a week local authority spending on social care, but it also operates a maximum ceiling on the amount it will contribute to care. The ILF will fund a maximum of £455 per week on top of the social services contribution, subject to the combined social services and ILF contribution not exceeding £785 per week. As the independent review of the ILF remarked, “the people whom ILF might have been most expected to help – people needing very high levels of support – are effectively excluded from even applying.”⁵⁴
- 3.68 None of the Individual Budget pilot sites had managed to include ILF resources in its RAS, even on a recharge basis, as there was no way of guaranteeing that the ILF would make a contribution to an Individual Budget or what the level of that contribution might be. Lead officers in several sites reported ‘second-guessing’ what the outcome of an ILF application might be when calculating an indicative Individual Budget allocation, but sites differed as to how far they were willing to honour an indicative budget that included a predicted ILF contribution that might fail to materialise. Most lead officers and senior managers argued that if the Individual Budget assessment had identified a need then the local authority had a duty to meet that need, although this did not necessarily involve funding the entire ILF shortfall. However, the lack of certainty about the ILF contribution was considered incompatible with the transparency at the heart of the Individual Budget process. Indeed, in some sites service users were asked to devise two support plans, one that included a ‘guesstimate’ of a potential ILF contribution and one that did not.
- 3.69 The ILF itself reported difficulties in working with different RAS models across the pilot sites and has advocated a consistent national approach to resource

54 Henwood and Hudson (2007), Op Cit, para 2.19.

allocation should Individual Budgets be mainstreamed⁵⁵. This is in line with the recommendation made in the independent review of the ILF that was undertaken for the Department for Work and Pensions,⁵⁶ and it offers a way of integrating ILF and council funds into a national framework that provides consistency and portability. Indeed, in such a scenario there would be no need to retain the ILF as an ad hoc commissioner of social care or a separate administrative organisation.

- 3.70 In a Written Statement to the House of Commons (March 15 2007), the Minister for Disabled People, Anne McGuire, welcomed the *“thorough review”* and noted the recommendation that there should be a smooth transition towards full integration within a system of personalised budgets. In a subsequent Written Statement (July 23 2007) she further said:

“A full response to all the recommendations will be published once we have considered the lessons from the individual budget pilots and the timescale required to ensure they become a mainstream part of the support system.”

- 3.71 At the time of writing, no decision on the future of the ILF has yet been taken. The evidence from the present study and the IBSEN evaluation, alongside the planned roll-out of personal budgets following the publication of *Putting people first*, suggests that the need for fundamental reform is more critical than ever. Taken together, the problems of integrating income streams outlined in this section seem to pose major question marks over the notion of multi-stream Individual Budgets, as opposed to single-stream personal budgets consisting solely of council adult social care monies. One interviewee felt the idea of Individual Budgets as such was disappearing:

“To bring that evangelical vision to reality will take more than social care, but I think it’s defaulting to social care. ILF have changed their criteria and are running away at a pace. We can’t get Access to Work into town, and nobody has yet told us how we can turn DFGs into revenue rather than capital.”

(Senior manager)

Developing personalisation policies

- 3.72 Developing personalisation policies is currently the biggest single challenge facing adult social care, and was certainly an issue that preoccupied all of the sites in this study. This part of the report examines some of the key *policy* issues that councils were having to address – in the next section we explore

55 Independent Living Funds (2006), *Pilot Protocol Version 1*. Nottingham: Strategic Policy Directorate, Independent Living Funds.

56 Henwood, M and Hudson, B (2007), *Review of the Independent Living Funds*. London: Department for Work and Pensions.

some of the *operational* consequences arising from these policy decisions. Here we look at four key policy dimensions:

- conceptualising the system
- establishing the system
- supporting the system
- embedding the system.

Conceptualising the system

- 3.73 The development of a concept of personalisation has two dimensions – the understandings developed *nationally* (from a variety of sources) and formulated in central government policy, and the understandings developed *locally* during the process of implementation. It cannot be assumed that the latter will simply reflect the former. The reality is that both are important and that they interact in complex ways.
- 3.74 The concordat, *Putting people first*, published in December 2007, set out a vision and commitment to the transformation of adult social care.⁵⁷ Person-centred planning and self-directed support are to “*become mainstream and define individually tailored support packages*”. Personal budgets will become available for everyone eligible for publicly funded adult social care support (other than in circumstances where emergency response is required). Moreover, the report from Lord Darzi on the NHS next stage review has also signalled the intention to “*explore the potential of personal budgets to give individual patients greater control over the services they receive and the providers from which they receive services*”.⁵⁸ A pilot programme is to be developed in early 2009 and is likely to be focused on patients with “*fairly stable and predictable conditions, well placed to make informed choices about their treatment*”, which immediately raises questions about the applicability of the model to many people with multiple and complex needs.
- 3.75 Confusingly, the Darzi report states that personal health budgets could work “*for some of those in receipt of continuing care*”. While this would be welcome news given the difficulties we have previously described, it seems unlikely that people qualifying for Continuing Healthcare would also meet the conditions for personal health budgets. Eligibility for Continuing Healthcare is determined by reference to the “*frequency and intensity of need, unpredictability, deterioration and any instability*”,⁵⁹ which is the exact opposite of the situation apparently envisaged by the pilots for people with stable and predictable conditions.

57 HM Government (2007), *Putting people first: a shared vision and commitment to the transformation of adult social care*.

58 Lord Darzi (2008), *High quality care for all: NHS next stage review final report*, CM 7432. London: The Stationery Office, para 42.

59 Department of Health (2007), *Decision support tool for NHS Continuing Healthcare*.

- 3.76 Centrally shaped policy is not simply and automatically implemented across the country in a consistent way; rather it has to pass through a number of local 'filters' – political, professional, organisational and personal – which in turn can reshape the policy itself and how it is understood and applied. This certainly seems to be the case with personalisation policy in the sites that comprised this study, where a wide variety of local reactions co-existed. Three broad positions are identifiable along a continuum of supporters, doubters and opponents.

Supporters

- 3.77 Supporters acknowledged the need for change, accepted the personalisation model as a viable framework and understood the transformational implications of implementation. Supporters could be found in most of the councils in the study:

"I think the status quo is more challenging than actually doing what people want, which is why we have signed up to the personalisation agenda. Providing services that people don't want is the historic way of doing things."
(Senior manager)

"We are moving into another world and it's time for something different. The process has become far too bureaucratic because it was about living with cash limitations."
(Senior manager)

- 3.78 Supporters of personalisation were unlikely to underestimate the required scale of organisational change:

"It's fascinating, challenging and quite scary all of this...it's going to test us all."
(Senior manager)

"I look at the size of the task and it's a long-term vision. It's not fiddling around at the edges; it's not Valuing People with knobs on. It's something far more radical than that."
(Service manager)

- 3.79 In one of our councils, this had resulted in a commitment to becoming an *In Control* Total Transformation site. Strategic documents explained what was understood by this commitment:

"This means we are seeking to totally transform the way we work. People will be given their own individual budgets accompanied by individual personal support plans that focus on the outcomes people wish to achieve. By giving control to people we expect services to become far more responsive and flexible, tailored to meet individuals' unique requirements."

3.80 In this council there was stated to be a threefold strategy for creating greater choice and variety:

- telling people how much money there is to spend on their support – the resource allocation
- changing the system so that people can choose what, when and how they spend their time, and who supports them – self-directed support
- being clear about how providers will support people, particularly those who need support all of the time.

Doubters

3.81 Doubters understood – and even accepted – the case for change, but had reservations about the scale and pace of this change rather than about the direction of policy travel. This stance was particularly likely to be found in children's services:

"There will be a place for Individual Budgets in children's services but it's different to adults. Adults are saying Individual Budgets are the way forward but I wouldn't be saying that. I will be saying there is a place for Individual Budgets."

(Children's services manager)

"There is a whole agenda about safeguarding that would need to be developed before I felt confident about Individual Budgets. And we need to listen to what parents are telling us, and they are saying 'it's not for us'."

(Children's services manager)

3.82 However, doubters were also well represented in adult care services. One service manager felt the problem was one of changing professional culture:

"Direct Payments are being used primarily for people dissatisfied with the mainstream – it's always been an add-on rather than the automatic position. We have to bring it to the front of care managers' thinking rather than it being 'if you don't like what we have on offer there is always this'."

"Staff don't feel especially ready for personalisation yet so it is difficult to know what to tell the service users."

(Team manager)

"We are going to take this steady. We are not rushing into this because it's too big and too dramatic."

(Senior manager)

Opponents

3.83 Opponents expressed open scepticism about the feasibility of personalisation policies, though again usually on issues of practicability rather than principle. Sometimes this came from people outside of adult social care altogether. One

team manager in the learning disability field related a meeting held with PCT colleagues:

"We had a meeting with a senior PCT person who was horrified at the prospect of vulnerable people having a live-in support worker through KeyRing. I was taken aback by the ferocity of the language – 'how can you possibly do this, are you mad?' They hadn't got their heads round why this is a step forward for people."

- 3.84 Another opposing constituency was reported to be the finance staff of local councils, especially where they had not been properly engaged in the decision-making process:

"The financial controller hated it because it was a loss of control of finances. He couldn't see how it would work or what was happening to the public purse."

(Service manager)

"We have set up a change management team but it's specifically for the social work side of things. It doesn't include our administration and finance people. I'm beginning to feel we haven't got the systems in place to back it up."

(Team manager)

Others suspected there were unspoken threats posed by personalisation policies:

"There is a danger of the Emperor's New Clothes around some of this because it's a big idea with no evaluation. In my darker moments I think 'are we being set up here?' You read articles saying social care money could just go into the benefits system."

(Senior manager)

- 3.85 Perhaps the most consistent constituency of opposition (in all but one council) – regardless of political party – was that of elected members:

"The politicians were very resistant to Direct Payments. They have a real problem with the inequity of it and the impact on the workforce – that it could be the end of the in-house provider. They felt that if you got money through a Direct Payment then you could choose something that people without a Direct Payment couldn't choose, therefore nobody should get the choice."

(Service manager)

"The political view is that the buck stops with us, the liability stops with us, the negative media attention stops with us. So you can't ignore that."

(Senior manager)

"The whole idea is to get the best package for them rather than them having the money and thinking 'I'll go and buy a sofa' – not that anybody ever has. But it's got to be clear what they can use it for and how they can use it."

(Executive member, adult care)

- 3.86 Another elected member, who felt he had drawn "*the short straw*" in becoming lead member for adult services, felt the policy had no financial reality:

"At what point do you want to start printing money? Forgive my cynicism but we are in the real world and having to make £22m of budget reductions over four years."

- 3.87 Elsewhere there was concern about practicability and the application to people with multiple and complex needs:

"The officers were quite happy with Direct Payments but we were concerned that we don't have enough people to monitor that this money is being spent correctly. It's been abused, people owe us loads of money. I have never been comfortable with Direct Payments."

(Lead member, adult care)

"It's not about control; I just want them to have the best care. And if they can't actually make their own decisions then how is it going to work?"

(Lead member, adult care)

- 3.88 This all adds up to a significant spread of scepticism and even opposition at local level, and whilst the picture for officers and professionals is mixed, the almost entirely negative stance taken by politicians is something that cannot be ignored if personalisation policies are to thrive. In none of our fieldwork sites were politicians driving the debate or advancing the case for personalisation. In one council where there *was* a more positive stance on the part of the executive member for adult care, this was expressed only in terms of generalised support for the concept of personal budgets, rather than through a specific vision for transformation. Officers were pursuing the personalisation agenda with varying degrees of enthusiasm in the face of conditional support, indifference and outright resistance from members.

Establishing the system

- 3.89 Assuming that steps are being taken to implement *Putting people first*, then several measures need to be taken to establish what is often termed a 'new operating system', notably the development of a resource allocation system (RAS). In the next section of the report we explore how assessment and care management were being handled at operational levels, while we focus here on the new systems that were being established and how these relate to people with multiple and complex needs. All of the councils were still at an early

stage of development in this respect, though some had progressed much further than others. The first step has been to choose (or develop) one of the self-assessment questionnaires (SAQ) that have been developed by *In Control*, and to then use this as the initial basis of the RAS. Both of these tasks were preoccupying our sites.

The self-assessment questionnaire

3.90 None of the councils had a settled approach to the SAQ, and most expressed reservations about the accuracy of such assessments. One council had undertaken a small *In Control* pilot in 2006/07 (therefore using a very early version of SAQ) and concluded that the exercise had failed to generate a clear understanding of needs. Specifically, the evaluation of this pilot found that the SAQ:

- did not provide enough information about the person, leading to difficulties in reconciling the SAQ with Fair Access to Care Services (FACS) criteria
- did not provide enough information to understand potential risks, thereby compromising the 'duty to care'
- focused on the 'here and now' without giving context and background.

3.91 Others seemed to be still struggling with more recent versions of SAQ:

"I'm not happy with the assessment form. It's lifted from the learning disability field so there's a lot of stuff around supervision, monitoring, safety issues and questions around that. There aren't actually that many questions around other things."

(Person using services)

3.92 Generally, the reservations expressed about the SAQ came from professionals who often compared it unfavourably with their own professionally led procedures. A particular concern was that people using services would underestimate the nature and complexity of their needs.

"If you ask older people to self-assess, 90% of them will underestimate their needs because they feel it is their duty to do what they can. If we simply went with a self-assessment we would end up with a lot of inaccurate data."

(Team manager, older people)

3.93 Moreover, these risks were not restricted to older people, as these other comments indicate:

"I did it the way I thought it should be done really, which was with the young person, and actually their opinion of their abilities was absolutely far greater than the reality. Which was really interesting. His mum was there. She sat in on it and didn't contribute to it, but afterwards I met with mum and she

said 'well actually we need to go through it', because things that X was saying to me weren't actually accurate."

(Care manager, Transitions)

"People think users will want loads of money and tick all the high boxes but my experience is the opposite. A lot of people underplay things rather than overplay them."

(Team manager, physical disability)

"Self-assessment could be self-defeating for some people. That's where a good social worker could be quite good because they will tease that information out of you."

(Person using services)

3.94 To some extent these views are consistent with the conclusions drawn in the IBSEN study, where a number of the pilot sites had experienced older people and people with mental health problems in particular under-assessing their own needs. In part this was believed to be a consequence of older people having low expectations, and of people with mental health problems being in denial about their needs, or not perceiving their actions or behaviours to be anything unusual. In contrast, people with physical disabilities, sensory impairments or learning disabilities were more likely to over-assess their needs. The IBSEN analysis believed this may reflect the influence of a longer history of campaigning for greater rights, choice and control, particularly among physically disabled people, or the success of person-centred planning in learning disabilities.⁶⁰

3.95 Other interviewees in the councils thought the main problem was the simplicity of the SAQ, especially in responding to people with more complex needs:

"Some people can just fill in the SAQ and we can add up the points, but when you get into the complex packages it's going to take a long time. You really have to get to know the person."

(Senior manager)

"We decided to use In Control's assessment and everybody who read it went 'My goodness, am I assessing people's money on this?'"

(Team manager, learning disability)

3.96 The most frequent way in which these concerns about SAQ were being addressed was to look upon it as a joint enterprise between user and professional – normally the local authority care manager. The *In Control* Total locality, for example, had tried to align the domains in its professional assessment tool (the common assessment tool) with those in the SAQ to

60 Glendinning et al (2008), Op Cit, p149.

enable comparisons to be made between the two in order to adjust for 'over' or 'under' estimations. This approach has its own risks, as this person observed:

"What it doesn't do of course is grasp the issue of social workers over-egging the pudding as far as need is concerned."

- 3.97 Indeed one person using services thought this was simply an inescapable measure, at least in the short-term:

"It will take five or six years. The first step will be care management by another name because a lot of people will say 'Oh I'm happy with the way you are doing it'. But gradually it will change."

(Person using services)

The resource allocation system

- 3.98 The RAS is the mechanism through which the local authority sets Individual Budget levels and enables people to find out how much money they will have available for their support. The initial basis for making this calculation will be some form of SAQ or joint assessment between the person using services and a professional which will generate a score. This score is then used to identify the maximum amount of funding that can be allocated, and this may be linked to a range of funding bands. The sites in this study were all grappling with some of the practicalities of refining their RAS so that it generated indicative personal budgets that were affordable to the authority. Some localities approached the issue by working out their finances 'backwards' – estimating their budget, putting some of it aside for overheads and contingency, and then dividing the remainder up between the service user population. The evaluation of a pilot scheme in one of our sites highlighted the potentially perverse consequences of RAS bandings:

"The banding structure produced a distortion where one point's difference can dramatically alter the individual's RAS. It produces an incentive in the assessment to tip the balance to achieve a greater resource."

"The exercise didn't differentiate between the person whom we considered to be the least disabled and the person with the highest level of need."

(Independent advocate)

- 3.99 Whatever approach is adopted there is no escaping the need to articulate a rationale for allocating resources between competing priorities, and across the councils the potential effect of the transparency of the RAS was a major preoccupation of politicians and officers in this respect. This dilemma will be heightened where it is decided to have one RAS across a council for all groups of people using social care services – an option that commanded widespread support in principle:

"If you are implementing this with a view to making budgets more manageable and equitable then it doesn't make sense to have different disciplines each with their own RAS, and each arguing that their points should score more pounds than the others."

(Team manager, older people)

"In the end you have got to be seen to be fair to everybody, and it's about time everything was brought out into the open. If you don't make people aware of the problem it will come back to bite you later on. That's a politician's view."

(Cabinet member)

- 3.100 Putting these convictions into practice, however, was proving to be no simple matter. Three particular dilemmas were identified – the costliness of people with multiple and complex needs, the ceiling on support for older people, and the position of carers.

The costliness of people with multiple and complex needs

- 3.101 One of the virtues of the RAS widely identified in the councils was the fact that it did introduce the notion of a ceiling on costs – something felt by some interviewees to be lacking in previous arrangements:

"Obviously the RAS has got a ceiling, and that's the safeguard to alert us to the fact that this now maybe needs to be looked at in a different way. I think sometimes the fact that, particularly in learning disabilities, the assumption was that there wasn't much of a ceiling, so people weren't terribly robust sometimes about their costing. Whereas now, you can see very clearly where the cut-off is."

(Individual Budget project lead, IBSEN evaluation)

- 3.102 At the same time there was concern that the imposition of a RAS ceiling would lead to a lowering of support levels for people with multiple and complex needs in order to spread the limited resource around:

"My real worry is that everybody will be put down to the lower level – to elderly services levels."

(Independent advocate)

"It's a difficult situation. As an active person who does have quite a lot of needs, then if they say we have got to be fair to other people then I think 'Oh goodness, what am I going to do?'"

(Person with complex physical disabilities)

The ceiling on support for older people

- 3.103 The converse of uncapped support for some adults of working age has been the imposition of a ceiling on the levels of support that are offered to older

people – “*the elephant in the room*” as one interviewee described it. It was an issue that has been hotly debated in our study sites:

“You have got this massive issue that there are no ceilings in learning disability services. You could have an older person with dementia who really wants to stay in their own home but the package is going to be absolutely massive so they can’t have it. But you could have an older person with dementia and learning disability and they will be supported massively to stay at home. We have arguments all the time.”

(Service manager, learning disability)

3.104 For one senior manager, exposing the ‘hidden’ nature of the older person’s ‘ceiling’ was a source of concern as well as bafflement:

“It will fundamentally begin to challenge everything, but you can’t hide it away. I’m amazed someone hasn’t taken it to court.”

3.105 A more immediate concern was the impact of a transparent RAS on the cost of residential care for older people:

“Are we saying that providing 24-hour care at home will equate with the current residential fee? None of us are going to say it’s more than that because then every residential care home owner is going to be asking for more money and there’s millions gone.”

(Senior manager)

“What we won’t do is pay significantly more to keep an older person at home than it would cost in residential care. I do have some problems with that but if we say we will pay whatever it takes to keep you at home it would just be unaffordable. Saying yes or no to people who want to stay at home is difficult because we do not have a list of the rules of the game.”

(Senior manager)

We explore some of the wider issues around equity between different people using services in the next section of this report.

The position of carers

3.106 Councils often seemed uncertain about the position of carers in relation to the SAQ and the RAS, with some people concerned that they took the carer contribution for granted and others worried that they took the carer role into account:

“When we piloted the RAS it added scores for the role of carers to the users’ points total giving a RAS that was greater the more care that was provided by carers. This would have broken the bank so we had to experiment with different questions.”

(Team manager)

3.107 In another authority the RAS explicitly took account of the carer's contribution and this led to the opposite concern that it potentially discriminated against carers. With the SAQ some people self-assessed their needs by including the contribution of a carer whilst others excluded this contribution, and in one council the role of the care manager was to go through the completed SAQ returns and disentangle these inconsistencies.

3.108 In the face of all of these problems with the transparency of the RAS, those councils that had reached the point of decision had tended to look for ways of protecting people's current status rather than apply a new equitable formula.

"We offer protected status for all existing clients and assess new clients according to the RAS. That has already been determined as necessary."

(Team manager, older people)

3.109 In the specific case of people with multiple and complex needs with high costs, one council felt the only feasible strategy was to totally exclude them from the RAS because their inclusion would skew the global RAS calculations. Whilst this may make financial sense it leaves open the possibility that these individuals would then be excluded from the benefits of being part of the RAS – a transparent sum of money under the control of the user and potentially able to be used in flexible and innovative ways.

Supporting the system

3.110 Innovation and transformation are not characterised by spontaneous growth or self-perpetuation; rather they need an infrastructure to ensure they are promoted and supported. This is certainly the case with personalisation policy where – as has already been observed – there is not yet a consensus of support across all of the key stakeholders. Interviewees in the councils in the study identified two main anticipated sources of organisational learning and support – from official and 'semi-official' bodies such as CSIP and *In Control*, and from other councils that seemed to be making the greatest practical progress.

3.111 Those who strongly supported the notion of personalisation had sometimes had their ideas shaped by inspirational encounters at *In Control* events or elsewhere. Some of the councils in this study had subscribed to *In Control* membership, whilst others were making use of the support materials coming from CSIP and the Department of Health. There is no doubt at all that these sources of support were valued and heavily used, especially in the development of the SAQ and RAS. It was common for staff to be sent electronic updates and links to the websites of support agencies, though further exploration often appeared to be a matter for individual action. For some interviewees this was the main source of their understanding:

"I think our team is coming round to the idea but there has been a lot of misunderstanding. Everybody looked on the In Control website and said 'Oh God! Somebody has gone on holiday with the social care money' or whatever it was. We thought the floodgates will open, what a nightmare. But I think people missed the support planning stage in all of that."

(Team manager, physical disabilities)

3.112 Others had attended national 'showcasing' events, but often seemed unconvinced of the viability of the messages being given out, particularly in respect of supporting people with multiple and complex needs:

"Everyone is convinced of the Individual Budget DVDs and the 12 cases that you can share with people, but would that work for 12,000 people?"

(Senior manager)

"The people in the videos have one need rather than complex. I wonder how it would work with complex needs – it might work really well, it might not."

(Social worker)

"We've had presentations but it was a fairly straightforward need, not a complex package. We were all thinking yes that's very good, but what about my client with mental health problems, autism and whatever?"

(Multi-disciplinary team leader)

3.113 The other main source of learning was from those councils that had acquired a national profile either because of their apparent rapid progress on the personalisation agenda, or through their participation in the Individual Budget pilot evaluation. In general, neither source was well regarded. In the case of the Individual Budget pilot evaluation there was commonly expressed puzzlement and frustration at the absence of publication and the lack of messages coming through to support local development. Localities were keen to understand how the many practical problems that they were encountering had actually been addressed, but there was some scepticism about the extent to which some well-known 'trailblazing' localities were delivering genuine change:

"My frustration is that it feels like reinventing the wheel locally. It's that tension between doing the journey yourself and therefore understanding it, but not actually falling into the same bear traps as everyone else."

(Head of service, older people)

"There is so much going on but there isn't enough coming out of those places that have been there and found 'x'. Well, why not? Behind the scenes it just hasn't been worked through and that worries me."

(Senior manager)

"We're not completely sure what they've done. I approach it with scepticism because you hear things and you think 'well they can't have addressed that', and if they have then tell us how they've done it."

(Senior manager)

3.114 The danger here is that this may spill over into a general scepticism or even cynicism about the entire personalisation mission, and some interviewees almost seemed to be in this position:

"When you go to the launch of things there is still a sense of nobody telling you the truth. It's still 'this is fantastic, everybody would want this' but nobody is telling you about the huge long list of problems. That just seems an absolute madness for us."

(Senior manager)

"There are some big issues that somebody needs to articulate...let's at least get some of these things on the table. I've raised issues and been told 'oh it will be fine' and I think 'no it won't'. I'm not an idiot; it will all come out in the next 12 to 18 months."

(Senior manager)

"There are some big holes in the evidence. The studies we have got are based on incredibly small and untypical samples."

(Head of service)

"There are a lot of problems around and it seems like the Government hasn't got any answers to these either. It's like 'suck it and see' and tell us how you get on."

(Multi-disciplinary team leader)

3.115 These concerns around 'supporting the system' are important because they have the capacity to slow down or even undermine the personalisation imperative: supporters of the policy may be thrown back onto issues of principle, doubters will worry about the absence of clear answers, and opponents will be given destructive ammunition. The messages then getting through to the most important people – people who use services and carers – may fail to carry conviction.

"The difficulty for social workers in our team is that they have not felt able to put the idea forward properly because they cannot answer all of the questions."

(Team manager, health and disability)

"How do we have a decent dialogue with people to explain what this could be when actually we don't even know the answers to many of the questions?"

(Senior manager)

Embedding the system

- 3.116 On the assumption that a personalisation system has been conceptualised, developed and supported, there is a further stage that is essential – ensuring that the holders of personal budgets have a sufficient variety of provision available to allow the exercise of choice and the promotion of flexibility. Without this the system will fail to embed and will probably revert to the current default position. Providers – in-house, private and not-for-profit – all contributed to this study, and it is clear that embedding flexibility and choice of provider is a complex undertaking.
- 3.117 The dilemma facing councils is how to reconcile robust strategic planning and market development with the anticipated preferences of a multiplicity of service users holding some form of personal budget. In principle it should be feasible for commissioners to encourage providers to offer and deliver services specified in the joint strategic needs assessments that are (or should be) based upon information about current and future need gleaned from person-centred plans, and which then form part of local area agreements. In practice it is likely to be difficult to put in place effective strategies for people with multiple and complex needs when the need is often immediate, yet the necessary planning can take a considerable time. Certainly there is evidence from CSCI inspections that frontline staff are unclear about the interface between local person-centred commissioning and wider service-level commissioning.
- 3.118 The clear message coming from official literature is that local authority commissioners need to engage in a constructive dialogue with local providers (and potential providers) about the changing market conditions implied by personalisation. The *Commissioning framework for health and wellbeing*,⁶¹ for example, states that local commissioners should:
- engage the provider community constructively and transparently about priorities and issues for market-shaping and development; all commissioners should establish a local provider forum to support this
 - develop better market intelligence and greater understanding of the role of all providers
 - following needs assessment, systematically review the range of providers available to meet the needs of the community, and consider how best to incentivise providers to improve their services or meet gaps in provision.
- 3.119 The 2007 CSCI study on social care investment⁶² warns that by not talking to the independent sector, councils risk pushing private providers into a more specialised market niche. Providers are said to be constrained by councils'

61 Department of Health (2007), *Commissioning framework for health and wellbeing*.

62 Commission for Social Care Inspection (2007), *Safe as houses? What drives investment in social care?*

annual budget setting (which inhibits longer-term signalling) and by a risk-averse approach on the part of councils who appear more concerned with costs than with quality and innovation. The study concluded that:

“In developing a model for the 21st century, councils will need to get better and more confident at strategic commissioning, tracking individuals’ preferences and working with partners in housing and health services to signal people’s future requirements to investors and providers.”

(p24)

3.120 In our study there seemed to be very few opportunities for external providers – whether independent or not-for-profit – to have a seat at the table with commissioners in order to discuss issues such as those raised in this section (and indeed other sections) of the report. Although it was usual for some sort of provider forum to be found locally, these were not normally events where commissioning intentions were specified and discussed. The providers we spoke to generally resented their marginalised position and saw this as a missed opportunity for constructive dialogue.

3.121 Although there was some recognition that certain providers (typically small not-for-profit organisations) needed support to develop, the general view of local authority commissioners was that providers simply had to adapt or die:

“What we are trying to say to the independent organisations we work with is that you will die unless you move your services in this direction and become more flexible.”

(Commissioning manager)

3.122 Providers, on the other hand, tended to feel bereft of clear commissioning signals and were even subjected to last-minute changes to ostensibly settled agreements:

“What we need is somebody to say to us ‘No we won’t buy this, yes we will buy that’. That helps to bring about change within the organisation.”

(Independent provider)

“You have got to insist on getting a contract first but it’s very hard like a Rubik’s Cube. You are recruiting staff, try to set up a service, plan your timeline, do CRB checks, induct staff – imagine all the time, effort and money that costs. And then the council turn round and say ‘oh well we were going to give you so many hours but it’s been to panel and turned it down’.”

(Not-for-profit provider)

3.123 Although unclear about their specific position in a world of personal budgets, external providers were very aware of the changing policy imperative and expressed general concerns about the possible impact upon their activities. The most common of these was the shift from block contracts and service level agreements to a situation in which a multiplicity of individual

agreements had to be negotiated with Individual Budget holders or their advocates and care managers.

- 3.124 In facing up to a future of uncertainty, these external providers frequently compared their position unfavourably to that of in-house providers. The councils in this study varied in the extent to which they had in-house provision, though one council had retained a very substantial role, including provision for people with multiple and complex needs. If the use of personal budgets is (at least in the short term) heavily influenced by the judgements of care managers, then this could easily marginalise external providers who will probably have a more distant relationship with care managers. This is something that has already been highlighted in some recent CSCI inspection reports, for example:

“In-house provider staff felt well-connected to care managers and able to make approaches where they knew they would be involved...External providers did not feel valued.”

- 3.125 The chief executive of one relatively small not-for-profit provider specialising in services for people with learning disability and complex needs expressed his frustration:

“The philosophy of the council is we will keep it in-house and we will tell people what to do. One minute they say they are purchasers and the next minute they have got a provider hat on. In a nutshell, they are very controlling. My biggest grumble is our competitor head of in-house provision sits on our contract review meeting and has access to all our budget data.”

- 3.126 Overall the findings from this study suggest that external providers, both independent and not-for-profit, are very aware of the personalisation agenda but do not feel engaged in local developments and are uncertain of the impact upon their activities.

Contract monitoring, inspection and performance assessment

- 3.127 Earlier in this report we drew attention to the concerns about quality of support for people with multiple and complex needs, and some of the policy consequences that have arisen in the light of exposure of bad practice. Three levels of quality assurance can be identified and each of these arose in the course of this study – contract monitoring, service inspection and performance assessment.

Contract monitoring

- 3.128 Given the very high use of external providers in the provision of services for people with multiple and complex needs (especially in the case of people living out of area), it is important for commissioners to specify the terms of

their contracts carefully and ensure that providers fulfil these terms. This task may fall to dedicated contracts teams or to individual care managers, but the evidence from this study suggests that contracts can be loosely shaped and poorly monitored. One commissioner of learning disability services acknowledged that procedures needed to be tighter:

“The weakness is how we guide providers to get the right outcomes for people. Global statements like ‘we want you to support social inclusion’ mean nothing to some people – people say ‘oh I took them to the pub once’. We could get better, stronger and smarter with our objectives, and that would lead to us having more effective reviewing.”

3.129 For their part, providers reported highly variable experiences of contact and contract monitoring on the part of different commissioners. One independent provider with a large number of out-of-area placements said:

“It goes from one end of the spectrum to the other. We have some who are very involved, have very clear outcomes and have regular contact with the resident. At the other end we have had someone for 15 years and we can’t get a social worker or commissioner to attend or even take a phone call.”

3.130 In some cases even where there is some regular contract monitoring, providers sometimes felt it focused on the wrong issues:

“The difficult relationships are those commissioners who are looking entirely in terms of inputs – an occupational therapy report, a speech and language therapy report and so on – regardless of whether these are meaningful or helpful to the individual, and certainly regardless of whether they lead to a positive outcome for the individual. It’s a very poor use of clinical time and makes everything too expensive. One of the main reasons why placements are so highly costed is the unnecessary work being done by clinicians.”

(Independent provider)

Service inspection and performance assessment

3.131 Our study included providers subject to inspection and regulation by different statutory bodies, notably CSCI and the Healthcare Commission, including instances of separate inspection by both bodies. Interviewees drew attention to the difficulty of responding to two bodies, and different statutory inspectors with – on occasions – apparently very different cultures and requirements.

3.132 The final layer of quality assurance is the assessment of commissioners themselves by central government. The creation of the Care Quality Commission, along with the emergence of robust local area agreements, may offer a way of helping to bring health and social care agendas together around a common set of outcomes and performance drivers. However, the evidence from this study is that current quality assurance approaches are too often characterised by weak contracting, inadequate contract monitoring, and

different and at times conflicting service inspection and performance assessment.

Conclusions

3.133 In this section of the report we have highlighted the complexity of addressing the two key policy dimensions of partnership working and personalisation, and we have specifically noted problems relating to out-of-area provision and the ways in which services and agencies are monitored, inspected and performance managed. It is unarguable that these complexities are formidable and that they require a skilled and sophisticated response from policy makers and practitioners. Failure to rise to these challenges will mean failures in the lives of people with the greatest and most complex needs. In the next section we explore more fully the ways in which these complexities work out at operational level, and the impact upon people's lives. We finish this section by reviewing the key findings thus far.

Out-of-area provision

- Government policy on increasing the availability of appropriate local provision for people with multiple and complex needs is well established and was clearly understood in all of the fieldwork sites in our study. This was the case both with adults and with children and young people.
- Out-of-area placements are made for predominantly negative reasons such as placement breakdown and dissatisfaction with local services.
- The cost of funding external placements was seen as unduly expensive and diverting resources that could be used to develop local services. There are frequently expressed concerns about the quality and cost-effectiveness of out-of-area provision.
- Both commissioners and providers are concerned to avoid an unduly narrow definition of what constitutes 'out of area', with provision in an adjoining council area considered to be acceptable.
- The emphasis upon local provision might not be the most appropriate solution for some individuals – partly because of the specific needs of these individuals, and partly because local provision may not be well suited to meeting these needs.
- There seemed to be very few opportunities for external providers – whether independent or not-for-profit – to have a seat at the table with commissioners in order to discuss the development of local provision, but in-house provider arms tended to be given greater opportunity for dialogue.

Transition to adult services

- Many localities now seem to have appointed transition coordinators or created transition teams. There is a widespread view that such initiatives have greatly improved the transition process in recent years, with localities now much more confident about the number of young people coming through the system, and the nature of their needs.
- Some of the key agencies take a very rigid approach to defining adulthood, much to the frustration of some of our interviewees working in the transition field. Health services are seen as the most inflexible.
- Relations between councils and LSCs have become more difficult in recent years as costs have come under greater scrutiny. Councils are finding that costs that used to be met by the LSC are now the subject of dispute and negotiation, most commonly in the case of residential college placements.
- Moving from school to college (out of area or local) at the age of 18 or 19 is no longer something that can be taken for granted by young people with complex needs. This in turn has a significant knock-on effect for adult social care.
- There is a danger that boundary disputes can result in a game of budgetary 'pass the parcel' in which young people and their families find themselves marginalised as agencies argue over who will foot the bill.

The health–social care interface

- There is wider evidence that relationships between health and social care have improved in many respects, and this was confirmed in some of the councils in our study, especially in those localities where the council and the PCT have coterminous boundaries.
- Where council–PCT relationships are robust then it is feasible to deliver coordinated and even personalised support, but where relationships are less good the outcomes for users and carers can be problematic.
- Where disagreements arose they tended to be about funding. In some cases this involved alleged withdrawal from established agreements or perceived misuse of specific funding allocations.
- The biggest reported area of contention is Continuing Healthcare. The introduction of the National Framework had generally been felt to have led to some improvements, but basic problems of access remained.
- There is now an additional difficulty in the context of the personalisation agenda – the potential *consequences* of accessing Continuing Healthcare. Two sorts of interrelated issues were identified – the potential loss of jointly funded care packages, and of any opportunity to achieve personalised support that would otherwise be facilitated by means of a Direct Payment.

The boundaries between individual budget income streams

- Disabled Facilities Grants may be particularly important for people with very complex physical and other impairments, but findings from the IBSEN study show that sites that had included DFGs within the Individual Budget pilot had only managed to *align*, not integrate, assessment processes.
- In principle, the inclusion of community equipment within Individual Budgets was thought by the Individual Budget pilot sites to offer older and disabled people and their families the opportunity to consider more flexible solutions to assessed needs, but implementation was proving to be problematic.
- Some form of supported housing model was widely seen across the Individual Budget sites as the most appropriate approach, though turning it into practice was proving to be difficult.
- Across the councils in this study the use of Supporting People funding to support people with multiple and complex needs seemed to be increasingly difficult, and developing appropriate accommodation arrangements required partnering skills of a very high order.
- There was often praise across our sites for the role of the ILF assessors, who were sometimes favourably compared with local authority care managers, but there was a widespread view that the flexible approach of the ILF was coming to an end as it looked to tighten up its own expenditure.
- The ILF is an ad hoc body dispensing a large tranche of social care funding in a similar way and for similar purposes to local councils. It has not been possible to integrate the ILF within Individual Budget pilots and the need for such parallel activity if personal budgets are to be rolled out was frequently questioned in the course of our study.

The policy dimension of personalisation

- Centrally shaped policy is not simply and automatically implemented across the country in a consistent way. A range of local reactions co-existed: supporters, doubters and opponents.
- There is some scepticism and even opposition at local level, and whilst the picture for officers and professionals is mixed, the almost entirely negative stance taken by politicians is worrying.
- None of the sites had a settled approach to the self-assessment questionnaire, and most expressed reservations about the accuracy of such assessments. Generally, the reservations expressed about the SAQ came from professionals who often compared it unfavourably with their own professionally led procedures. A particular concern was that service users would underestimate the nature and complexity of their needs.

- The councils in this study were all grappling with some of the practicalities of refining their resource allocation system so that it resulted in indicative personal budgets that were affordable to the authority.
- The potential effect of the transparency of the RAS was a major preoccupation of politicians and officers. Three particular dilemmas were identified – the costliness of people with multiple and complex needs, the ceiling on support for older people, and the position of carers.
- Interviewees identified two main anticipated sources of learning and support – from official and ‘semi-official’ bodies like CSIP and *In Control*, and from localities that seemed to be making the greatest practical progress with personalisation. Views on the effectiveness of these supports were mixed.
- Embedding flexibility and choice of provider is a complex undertaking, but there seemed to be few opportunities for external providers – whether independent or not-for-profit – to have a seat at the table with commissioners. Providers generally resented their marginalised position and saw this as a missed opportunity for constructive dialogue.
- External providers frequently compared their position unfavourably to that of in-house providers.

Monitoring, inspection and performance assessment

- Given the very high use of external providers in the provision of services for people with multiple and complex, needs it is important for commissioners to specify the terms of their contracts carefully and ensure that providers fulfil these terms. The evidence from this study suggests that contracts are often loosely constructed and poorly monitored.
- Providers reported highly variable experiences of contact and contract monitoring on the part of different commissioners.
- Our study included providers with experience of both CSCI and Healthcare Commission regulation, and interviewees drew attention to the difficulty at times of responding to two bodies with apparently very different cultures and requirements. There is an opportunity for closer alignment with the establishment of the Care Quality Commission from April 2009.

4: Operational-level issues

Independence, wellbeing and choice

- 4.1 The Commission for Social Care Inspection carried out a number of inspections during 2007/08 under the independence, wellbeing and choice agenda. These inspections variously addressed how well councils were safeguarding adults and meeting the needs of people for personalised services, delivering preventative services and support, involving people, ensuring equality, and working in partnership. This framework has obvious relevance to the current study, and while our investigation was *not* an inspection, we examined many of these same dimensions. We will draw on the wider context of CSCI inspection reports throughout this section.
- 4.2 In the previous section we examined a number of policy issues which were being addressed across the councils and in the IBSEN study. We have analysed the ways in which sites were developing policies in respect of support for people with complex needs and the personalisation agenda, and their understandings of national policy drivers and requirements. We turn now to address what difference this was making in practice, and to explore the experience of people using services.

Delivering personalised services

- 4.3 Delivering personalised services for people with complex needs – whatever the nature or origin of those needs – has a number of components. Below we identify the key components in terms of:
- assessment and care management
 - promoting independence and choice
 - range of services
 - support and advocacy
 - flexibility and accountability.

Assessment and care management

- 4.4 CSCI inspections of assessment and care plans (under the independence, wellbeing and choice agenda) have explored the quality of many care plans, particularly in specifying outcomes or person-centred aspirations. Although in principle the assessment and care management process has the potential to be highly person-centred, inspections have consistently identified shortcomings, as the following anonymous extracts illustrate:

"[Care planning] was often unambitious and lacked a focus on outcomes and improvement. Some care plans were task focused and missed opportunities to be creative."

"Assessment systems and practice were service rather than needs led and there was little flexibility for care managers to develop innovative packages of care. The council was tied into block contracts for key services in residential and home care, and people were assessed for their eligibility for these."

"With some exceptions, care plans were largely task focused and did not always fully reflect the views of people using services including their desired outcomes."

"Assessments focused well on older people's immediate physical and care needs [but] had a reduced focus on social and psychological needs. Greater attention to the strengths and aspirations of service users would lead more clearly to an outcomes-focused assessment and care plan."

"Assessments we saw concentrated on information collection, but too often they lacked analysis, resulting in limited consideration of choices on how needs could be met...Providers reported a lack of depth in assessment material they received, requiring them to do their own assessments once people joined the service."

"Assessment and care plans were not holistic and did not adequately consider previous history and the strengths and aspirations of people who use services. None of the people who use services or carers who we met with had received a copy of their care plan."

- 4.5 Across our fieldwork sites we sampled the quality of assessment and care planning by examining samples of case files, and through our interviews both with care managers and with people using services (and their carers). The quality of files was variable. While some sites had moved over to entirely electronic systems for managing case files, others were still using paper-based systems and for some people this could mean a number of files containing hundreds of pages going back many years. In many cases the files provided a good sense of who a person was and their personal preferences. However, this was not always the case, and CSCI inspections record similar difficulties:

"The copying forward of some recording from one assessment period to the next, with new information being added rather than replacing the original assessment, made it difficult to track people's pathway through services...The assessment continued to reflect the original presenting difficulty and gave the impression that current interventions were being made against an out-of-date initial assessment."

- 4.6 What is also apparent is that the deficit focus of much assessment fails to recognise a person's strengths and qualities, and indeed the system rewards

negative self-portrayal, as the case study of Craig in Box 3 below exemplifies. Craig was a middle-aged adult with complex physical disabilities who was highly critical of the deficit approach of assessment:

"There is a feeling and you have to fight against it, but the only way that you are going to get the help us not by emphasising the positive points; you have to emphasise your negative points (...) it's not a question of saying 'I can do this but I need help to do it.' It's always – I can't do something."

- 4.7 Not only did this approach fail to recognise the richness and complexity of people's lives, but it failed to support or promote independence.
- 4.8 Some interviewees drew a distinction between person-centred planning and traditional assessment approaches. In the case of the latter these were seen to be less about a person's aspirations or preferences and more about *"deficit-based assessment tools"*. Such an approach focuses on what a person cannot do and the help that they need to do it. This assessment can also differ from genuine person-centred models to the extent that it is also concerned with *"gate keeping and how we manage resources"*. This transition worker described his frustration at such an approach to planning:

"...and so every young person at 16+ – before they are 18 – is going to need an assessment. So we concentrate on doing an assessment rather than actually start and think about how we plan with young people about what they want to see and the families want to see in the future really. So we do a deficit. Because they are still deficit-based assessment tools. It's not really about young people's hopes and ambition is it?"

- 4.9 While good workers would do their utmost in such a situation and would draw out the important features for each person, this was *despite* the assessment approach rather than because of it. Other evidence from CSCI inspections also points to the ways in which traditional assessment templates can undermine attempts by professionals to work in person-centred ways:

"The assessment template...did not lend itself to assessing needs holistically. It did not include prompts on issues to address such as hobbies, interests and lifestyle of the person being assessed."

- 4.10 As with the terminology of complex needs, the language of 'person-centred planning' is also better embedded in learning disability services. In the context of the new personalisation agenda the preferred term is now 'self-assessment'. In our five councils both terms were in frequent use. The quality of practice, however, is variable, as the following comment illustrates:

"I think we have pockets of outstanding person-centred planning; and we have an amount of tokenistic person-centred planning if I was honest."

(Operations manager, independent provider)

- 4.11 This very honest admission was probably a fair description of the state of play across the councils, and is confirmed by the evidence from CSCI inspections. In some cases the problem was not only the absence of person-centred planning but also the limited evidence that it was having much effect even when undertaken:

“The number of person-centred plans had increased but it was not always clear what had changed in the person’s life as a result of having such a plan. The plans were seldom reviewed to see whether any goals had been achieved.”

“Person-centred planning had not been mainstreamed as part of developing a personalised approach in the assessment and care management process. A concerning high proportion of care plans failed to translate identified needs into bespoke individualised action plans.”

- 4.12 Interviewees in our study acknowledged that it is easy to pay lip service to person-centred planning and assessment, but much harder to do it well. As the case study in Box 5 illustrates, the failure to communicate with people appropriately (such as through the use of sign language) can mean a total inability to address the needs and preferences of people with complex needs. One of the tools employed in at least three of our councils was the development of ‘communication passports’. These documents provide the essential information which says ‘this is who I am.’ Staff described the value of these documents:

“This is what I like and this is how I am communicating and this is what I am telling you. So when I do this, this is what I mean (...) I think it takes a long time to develop some of that, to get some of that information about some of the people we work with.”

In one council a manager for the in-house service described how these documents are sampled as part of the internal quality assurance process. The manager actively encourages competition between different service units to produce excellent plans. The ‘pen picture’ provided aims to convey key points that anyone should know about a particular person, including information about things which if not done, or done incorrectly, could make the service user angry or unhappy.

- 4.13 Such accounts as the following extracts are typical of the content of these good quality plans or passports:

“My name is...I have Down’s syndrome. I’m allergic to penicillin; I’ve been diagnosed with dementia and paranoid schizophrenia. I may shout and cry, sometimes about things that I have imagined happened.”

And

"My dementia has had an effect on my eating habits (...) sometimes I will say 'ham' or 'sandwich' (...) this does not necessarily mean that I want these specific foods, just that I want something to eat (...) it is important that staff keep offering me drinks throughout the day, as I am unlikely to pick them up myself."

- 4.14 As a learning disability team manager observed, these books or service user plans are portable and should go with a person if they move to a new service, where they can provide a real sense of who a person *is* rather than simply describing what they can't do. As a service manager for in-house services observed, such documents are an indicator of:

"...greater effort to understand those individuals as people with histories before they ever came to our service; people with personalities and dreams and wishes that are like anybody else's."

- 4.15 Such aspirations are excellent but, as we note above, there may be a difference between having plans or summaries which describe a person's preferences and these being used as a basis for day-to-day practice. For this to be guaranteed there has to be a follow-up from managers and through quality monitoring processes. One such manager described her confidence that services measure up because not only are spot checks part of the routine practice, but these are also reinforced by inspection and monitoring processes from Supporting People and CSCI. Encouraging services to identify good practice was also a critical part of the culture in this council:

"We have an online system where my expectation is that every unit should be able to identify a piece of good practice once a month. And they struggle with it because they don't see it as good practice."

- 4.16 Across the councils there was general recognition that the quality of service planning and reviews had improved significantly in recent years and was much more individually focused. There are clearly instances of staff not only taking account of people's individual needs, but going out of their way to ensure that things important to a person are addressed. Creating an organisational culture which supports and develops staff to follow such an approach is clearly demanding, and necessitates managers leading by example, celebrating excellence and having zero tolerance for poor practice.
- 4.17 The review element of care management has been identified in inspection reports as a particular difficulty, with care managers typically having withdrawn from the case and service users and carers uncertain of whom to contact and frustrated at having to repeat information already given, for example:

"The care management teams were small, there was no dedicated review team and ongoing care management was not common. Many cases were closed when a 'stable' care plan was deemed to have been established. Service users and carers lamented the lack of a facility to contact a social worker. Providers felt they were often left to manage things as best they could."

"Too many annual reviews were held late or did not happen at all. We were concerned that some reviews of needs had been held by agencies which provided the care instead of a care manager."

"Individual reviewing staff had excessive workloads and priority had been given to 'crisis' reviews such as where registered homes were closing or where there were safeguarding issues. Between a half and two-thirds of people had not had scheduled reviews for the last few years. Some people with complex needs but in 'stable' and expensive placements had not been reviewed by the council for over 15 years."

- 4.18 In our study a learning disability team leader described how monitoring individual reviews led to the conclusion that more training was required to embed person-centred approaches into day-to-day working:

"Because it is no good being person-centred and reviewing and that doesn't continue. We cannot be person-centred for an hour and then walk out of the door and forget it all you know."

- 4.19 Working with people in this way can be very demanding; staff described, for example, what real person-centred planning can entail:

"Monitoring...how they respond to that development, and robust communication packages so we know what somebody is trying to tell us and then making sure you have got the right support around that person. So think about what people want and not just provide services based on assumptions of what we would want for that person, but really get to know the individual to see what they want."

- 4.20 Person-centred planning with people who have complex needs including communication needs or whose capacity is variable raises further issues. CSCI inspection reports have noted instances where people with learning disabilities are not routinely given documents that are about them in accessible forms. The IBSEN study further suggests that communication problems account for unexpected difficulties and delays in implementing Individual Budgets for people with learning disabilities. This was explained by a number of factors: the need to make information about Individual Budgets more accessible for people with learning disabilities; the additional time needed to develop self-assessment documentation that service users and their carers felt comfortable with; and the additional time required to help people with learning disabilities develop support plans (or to work with

advocates or voluntary organisations to help them support users' support planning).

- 4.21 An independent sector provider in our study described the approach of a service to engaging with people in such circumstances:

"We don't have anybody with the communication systems, the electronic ones, but they exist and some people can use those, so that would be one way. If people have other systems to communicate we would use those. But you tend to find, I mean – say the people with challenging behaviour, when they have capacity to make decisions you would do it then. You know, you would ask them the questions when they are in that kind of frame of mind. People with dementia would be similar when they were having a good day."

- 4.22 Ensuring person-centred approaches also means engaging with carers, families and other people who know a person well and can help in planning their support and assessing their preferences. This has implications for advocacy, and we explore these issues later in this section. In some situations there are tensions or differences of view between carers and the people they support. These were identified most frequently around support for people with learning disabilities, and we will examine this more fully when we consider safeguarding issues. However, this is also relevant to person-centred planning, as this comment from a learning disability team manager illustrates:

"I worked with a lady, I remember, quite intensively on a person-centred plan. We did a book and everything. But it only worked during the hours she was at the day service. We couldn't get her family on board. So families sometimes can be very reluctant for whatever reasons to take into account that their son or daughter has got a voice and wants to do things."

- 4.23 Many of the carers we spoke to described problems they had encountered with assessment and diagnosis. Parents, in particular recounted stories of knowing there was 'something wrong' with their child from an early stage but struggling to get this recognised by services (particularly health services). Both of these parents had a child who was deaf and had a learning disability:

"Well they won't do anything until nine months, so we went for the routine nine-month test which X failed. They said they would come and do the test in my home where [he] was supposedly more relaxed, and he failed that as well. So at this stage they suggested I went to see my GP who made an appointment for me to see the paediatrician, who said right from the word go – you are probably right with X's disability because Mums usually are."

And

"I kept going back to the doctor saying he's not quite right, he's doing this and there is something odd (...) and they said 'oh he's your first child, you are

not coping well, do you want some anti-depressants?' (...) this went on for quite a long time and then they said 'oh he's deaf'."

- 4.24 Person-centred approaches must extend to services commissioned by councils. A provider of residential services described how staff need to be competent at certain tasks but also have appropriate understanding and compassion:

"For instance, we've worked a lot over the years on – we know that the life history of a person with dementia is pivotal in making that care work. Because if we get dementia we'll all experience it differently, every single one of us (...) and we will exhibit behaviours as a result of our life experience, our work experience. Put that into context and it's perfectly normal; take it out of context and it seems bizarre."

- 4.25 Assessment and care planning issues arise in the transition between children's and adult services, and were described particularly for young people with learning disabilities and complex needs. At the point where people transfer from one service to another it is clearly of great importance that their needs are well understood and planning does not start all over again. However, even if data are robust there may still be issues about responding to need as shown in this CSCI service inspection:

"Waiting lists for allocation and assessment had been systemic across the learning difficulties teams – just under half had waited under three months but a few for over a year. Individuals' situations might change markedly whilst awaiting contact. We saw this particularly for some younger adults no longer attending college and without purposeful activity. This added to carers' stress and could result in unhelpful behaviour patterns of longer-term significance being established."

- 4.26 Across all of our sites there was good understanding of the numbers of young people who would be coming through transition in the course of a year. This was as true in large sites where the numbers could be significant as it was in small sites where it might be just a few cases each year. As this transition worker described:

"I look across all the teams, the hospital teams included, to find out which children and young people they have worked with. So I run a report of all the 13- to 19-year-olds every August. I do it in January again as well just to update in case we miss anyone. But we run it twice a year to see which young people are actually worked with, and then some of the young people I know really, really well."

- 4.27 The approach to care planning and assessment is part of a wider approach and organisational culture. The training, incentives, and leadership are all central in reinforcing a way of working and a set of core values about individual worth.

Self-assessment and RAS

4.28 As we have explored in the Section 3, self-assessment brings a new dimension to assessment and care planning and is at the heart of the personalisation agenda. Some care managers were embracing these new approaches with enthusiasm, welcomed the opportunities which could be offered to people, and found such work extremely rewarding. However, it is also apparent that self-assessment does not remove the need for professional support (indeed, quite the reverse) and that undertaking work of this nature can be very intensive, as this care manager described:

"...you have to have so many more meetings, an awful lot more consultations getting to know the young person. It is not like two interviews, set up a package of care, go to panel for funding and set something up. It is much more, and especially working the Individual Budgets. It's a very good way of working, but very time consuming for the care manager."

4.29 In many ways the term 'self-assessment' is a misnomer because a person would often need other support and contributions to that assessment in addition to their own. A transitions coordinator described the issue:

"It can be a self-assessment, but we have found that doesn't always work really. The young people at 16 don't really understand enough about what you are doing, so you have to involve other people to get a proper picture. So quite often I involve the children's social worker as well and ask questions from nurses, from the family as well as the young person. And I am building up an assessment picture all the time."

4.30 Approaches to assessment can be located as points on a continuum. A team manager for physical disabilities observed that the assessments undertaken in the service were done very much *"in partnership with service users and not done to them"*. While it was accepted that this may not be the same as self-assessment *per se*, *"a lot of person-centred planning goes into the work that we do"*, although this was not always captured in the way that documentation was presented.

4.31 Where personal budgets were being developed for some or all client groups, self-assessment questionnaires were being used as the basis for applying the resource allocation system (RAS):

"We have self-assessment questionnaires and the full In Control model, and we have obviously done our own RAS. What we do is we hope that the individual [and] the person closest to them will do the self-assessment questionnaire. That is then approved by a care manager, agreed by the care manager, so when the person comes to panel we will know what their notional allocation is."

4.32 The RAS calculation, and being clear about the notional budget that is available, occurs at an early stage and needs to be completed before detailed

support planning takes place. As observed in our previous section, councils had worked through various versions of RAS and built on the experience of other councils to find a model that worked best for them. The approach to self-assessment within this was described as being clear and logical and based on the central domains of the single assessment process. However, there *had* been some difficulties, notably around how equipment needs were addressed and how carers' needs were approached as part of the assessment and RAS allocation. The sites were at different stages of development in addressing self-assessment and RAS, and were still finding the optimal ways of working locally. While there was considerable sharing of experience and cases of people seeking to learn from what others were doing, this happened in a largely unstructured way that relied on contacts, word of mouth and participation in regional networks. Some interviewees had participated in CSIP events and reported that they understood that national models for self-assessment and RAS might be forthcoming. While this could have certain advantages, the timing of any such development was a matter of some frustration, as this person remarked:

"...which would have been good to know earlier, now we've got on with it!"

4.33 Approaches to assessment have changed over time. This interviewee described how in the past using old types of paperwork, people would undertake a comprehensive assessment *"but basically wrote in the assessment what they wanted to write, rather than filling in a form"*. A person could then read that assessment and get 'a feel' for the client. By contrast, they believed that more comprehensive documents were now being completed with *"no feel for the client"*. This was compounded by the accompanying care plan which would then be drawn up as if from a 'pick and mix' menu of a bit of this and a bit of that *"because they are the only services that are available"*. This particular person was optimistic that the move to self-assessment *would* be an improvement because it would direct staff to looking at things from the point of view of a person using services, and should allow people using services to think about what they wanted rather than having to rely on a small menu of typical services.

4.34 The evolution of different models of RAS was also a reflection of sites adapting an instrument which had originated in assessing the needs of people with learning disabilities, and needing to adjust it to ensure the domains are appropriate to a range of people. It is important, as people recognised, not to become distracted by processes and systems, and while it is vital to have a workable model of resource allocation in place and to have accurate tools for self-assessment, these are means to an end but not necessarily a guarantee in themselves of meeting that end, as this person remarked:

"You can have a RAS that works incredibly well and implement it, and not end up with anything that is awfully like self-directed support or personalisation (...) so we needed to sort the RAS, but we are increasingly kind of recognising

that actually there are other elements like support planning and so on that are as crucial to get right."

- 4.35 Not surprisingly, exactly these same issues arose in the 13 Individual Budget pilot sites. The IBSEN study found some local Individual Budget leads were adamant that care coordinators should *not* assist people to complete their self-assessments since this was not the intention, except where a person had no one else who might assist them. In other Individual Budget sites the leads were equally adamant that care coordinators were the people *best placed* to assist someone to assess their needs, since they could help in understanding the questions; they could protect the person from inappropriate influence from family members, and they could discuss issues of risk with the service user. Care coordinators were most likely to be involved in supporting people with learning disabilities through the self-assessment process.
- 4.36 It was evident across the Individual Budget sites, as within our fieldwork sites, that there was a range of practice and of different ideological positions on the interpretation of self-assessment. An Individual Budget lead referred to a 'default position' that *"people can do this for themselves"*, while recognising that particularly in older people's services:

"...there may need to be care manager involvement especially as increasingly families don't live near the older person, so there's thus nobody to help them; they're more isolated. Some older people prefer supported self-assessment. In mental health, people can self-assess but this can cause anxiety around paperwork and so the care coordinator follows it up to make sure they are okay with it."

(Individual Budget project lead)

Another care coordinator in an Individual Budget site observed that all sorts of options were possible:

"They could have a professional advocate or if they want to have a family member or carer do that [self-assessment], it's entirely up to them."

Promoting independence and choice

Direct Payments and Individual Budgets

- 4.37 How councils are promoting independence and choice for people with complex needs was a central focus of our study. The approach to Direct Payments is one indicator of how councils are handling this area. However, the move to personalisation means that Direct Payments of themselves do not capture the breadth and depth of activity since councils are at different stages in their engagement with the personalisation agenda and its various forms, including *In Control Total*, *Staying In Control* and *Dynamite*. Moreover, personalisation must also be much more than simply the mechanism for enabling people to

take control of money and for people who cannot or do not wish to manage their own resources, including people who live in residential settings, it is important to explore the meaning of independence and choice.

- 4.38 Annual performance assessment by CSCI judged our five fieldwork sites to range from adequate to excellent, with three of the councils rated as good. The council judged to be adequate was nonetheless recognised to have increased take-up of Direct Payments and Individual Budgets, and the council acknowledged the need for further work to increase the pace of progress. The council was dealing with challenging budget constraints and was trying to provide greater choice and flexibility for people while also retaining block contracts. CSCI underlined the need for practice monitoring to ensure that person-centred outcomes were achieved.
- 4.39 In one of the three councils judged to be providing good outcomes around choice and control CSCI noted that progress had been made in enabling people to use Individual Budgets and Direct Payments, but cautioned that targets across all client groups needed to be realistic. In another of these three councils, despite increased take-up of Direct Payments, levels were below those achieved in similar councils and remained an area for development. However, it was recognised that the council had demonstrated a commitment to self-directed support by successfully bidding to be a pilot area for *In Control Total*. In the third of these councils the number of people receiving Direct Payments has increased and is seen as a key strength. Finally, the one council judged by CSCI to be excellent in contributing to increased choice and control for people who use services had increased use of Direct Payments. CSCI observed that further improvements could be made in supporting people using Direct Payments and other forms of self-directed support.
- 4.40 Against this overall assessment of progress with promoting independence and choice, we turn now to examine developments across the councils in greater detail. As we have outlined previously, the idea of self-directed support and greater personalisation commanded virtually universal support, although not totally without reservation. As we will discuss later, there were some particular tensions between issues of maximising flexibility versus accountability. There were also differences of view about the applicability of the model to people with complex needs. For example, an independent sector provider of mental health services remarked on the challenges which personalisation represented particularly around issues of compliance:

"I am really interested in how we develop a model of Individual Budgets and person-centred planning. You know, do a map or a path – which has traditionally come from learning disability – it's a totally different ballgame to apply those principles and that philosophy to this group (...) I think there is a danger of saying it works here and make the assumption that it's going to work for multiple needs and chaotic lifestyles."

And

“How would you do that when someone has an acquired brain injury, is taking heroin, is homeless...is hearing voices that are disturbing them? (...) How would you do that at 10.00 at night down on the streets?”

“The issues are going to be people who are coming to us in crisis, sometimes against their will and sometimes looking at treatment plans and maybe these aren't what everybody wants. And how do you do that through a personalised budget? I really don't know how that bit is going to work yet.”

Box 3:
Experience of a person using a Direct Payment

Craig is 49 and was diagnosed with Muscular Dystrophy shortly after his 30th birthday. He is now confined to a wheelchair. Craig is divorced with two children who come to stay with him every week. He has always been employed, initially in hotel management and later in running his own restaurant. Eventually this became too demanding for him and he sought help through Access to Work, but was unhappy with their assumption that wheelchair users were only suited to desk-based positions. On the advice of a social worker (*“in the days when social workers were social workers not care managers”*), Craig took a trainers' course on disability issues and was subsequently invited to lecture part-time on the course. He continued doing this until taking up a voluntary sector development worker job for a local disability organisation. Finally, because he wanted to use a Direct Payment, he became a self-employed consultant on disability-related issues.

Currently Craig spends around a third of his Direct Payment on PA support from a care agency and the rest on his own PAs, and his care package currently includes support from the ILF and Access to Work. His experience is that the ILF social workers show a greater understanding of the principles of independence and empowerment than council staff, and that there is greater continuity of personnel. Both ILF and Access to Work allow him considerable flexibility and freedom in the use of his funding, but he has problems accounting for the use of his DP. Craig takes the view that as long as he achieves the outcomes agreed in his care plan then the nature of the inputs are his own business, whereas council finance staff require considerable detail on the nature and frequency of his PA support.

Craig has strong views on PA recruitment, preferring to arrange his own training for them as needed – indeed he strongly believes that the main need is for *service user* training on how to use PAs appropriately. He uses a mix of PAs, favouring agency staff to help him get up in the mornings

(where the crucial issue is certainty of attendance) and his privately recruited PAs for all other occasions. His own PAs are offered substantial regular slots of work and he believes this is why he has had no recruitment difficulties.

Craig is critical of the way the system rewards negative self-portrayal (*"the only way you are going to get the help is by not emphasising the positive points"*) and indeed his social care case file fails to mention his considerable achievements as a trainer and disability consultant. He is fully supportive of the self-directed support principles but thinks that it will be *"care management by another name"* for a few years. He has been involved with local self-directed support developments and is critical of the self-assessment questionnaire which he says has been inappropriately lifted from a learning disability context. Craig's story is one of successful use of existing flexibilities in the system, but often having to battle to exercise control over the multiple funding elements in his support.

- 4.41 The issues identified are important ones and raise a number of questions about choice and compulsion. Some service providers found it very difficult to see ways around these challenges in support for people with mental health needs, and one, for example, predicted a major reduction in the size of his own organisation as it no longer offered the services required. Rather than seeing this as an opportunity to diversify and develop new service models appropriate to the personalisation agenda, this provider took the curious position that it was time to accept that *"we have done our job"*.
- 4.42 The IBSEN study has much to say about attitudes towards certain groups of users such as those for whom an Individual Budget was thought to be difficult or inappropriate. Some lead officers argued that Individual Budgets should not be introduced to individuals in times of crisis, for example while an individual is in hospital. This was on the grounds that individuals would not be in a position to undertake self-assessments, support planning and think about arranging their own support, and that support needs are likely to change as individuals move out of the crisis situation and begin to stabilise. Nevertheless, six of the 13 Individual Budget sites decided to offer Individual Budgets to mental health service users. Some sites explicitly chose to work with mental health service users because they thought that if they could make Individual Budgets work for this user group – particularly mental health service users with complex and/or fluctuating mental health needs – then they could make them work with any and all other user groups, and it was important to demonstrate that Individual Budgets could work for the most challenging groups.⁶³

4.43 A further group identified as problematic in the IBSEN study was that of older people where it was argued that support needs tend to change much faster, therefore a support plan may be out of date within a couple of months. Older people are thus likely to need more frequent monitoring, and this may particularly be the case for older people with complex needs. However the study found that the most striking difference between Individual Budget sites was their different experiences of working with older people. Sites generally expected that older people would not want the aggravation of managing an Individual Budget and would thus opt for a care-managed account. However, some sites found that, contrary to expectation, a larger percentage of older people had opted to take their Individual Budget through a Direct Payment and thus to manage the money themselves. Lead officers in the Individual Budget sites believed that this development reflected a number of factors, but particularly the opportunity for people to use a Direct Payment without having to be an employer; and more active promotion of Direct Payments by care managers as they developed better understanding of the range of options available and the capacity to mix and match elements of Direct Payments with other support directly commissioned by a care manager.

4.44 Some interviewees in our study identified similar concerns about whether personal budgets could work for people with severe learning disabilities, or for people whose behaviour challenges services. Nonetheless, there *were* also examples of people who on face value might be described as having 'chaotic lifestyles' who *were* managing with a Direct Payment. As this account illustrates:

"Y had a very, very dense stroke about six years ago. She lives on her own, no family, nobody. No family. No friends. Neighbours okay. She is a very feisty lady is Y, and she is very clear about what she does and doesn't want. She constantly falls, so she has broken her arm about eight times from falling. Because she drinks. She is an alcoholic (...) and she employs help with her Direct Payment, I think we have just upped it to about 25 hours a week, and that is all she has actually, it's all Direct Payment. And she has a carer who she employs herself."

4.45 Personalisation is not just about allocating money in different ways but also about creating greater flexibilities and opportunities in the ways that people can use their financial allocation. Some interviewees raised doubts about whether this would signal a comprehensive transformation in the nature of service provision, but accepted that a more mix-and-match approach to commissioning and purchasing was likely. However, for some people with particularly complex needs there was a view that traditional services would still be required, as this day services manager remarked:

"I think the independent sector will struggle with the more severely disabled people to a point, because more severely disabled people really will have their needs met under a roof somewhere, with the sensory stuff or the

physiotherapy and all that sort of stuff, the hydro-therapy swimming pool, all those sort of opportunities that they want. I think at this very moment in time and probably into the future, I think that's where our expertise lies and we have the buildings and the history behind us to be able to do it."

4.46 Other managers took a rather different view and recognised that increasingly many people would choose to go to the pub, meet their friends and carry on with normal social discourse in preference to using a day centre. The implication of this would be the *"need to reduce our building-based day care"*, but potentially alongside developing new and different services including outreach models.

4.47 Across the five councils interviewees acknowledged that development with Direct Payments over the years had been variable. In part this was a reflection of the way in which staff had or had not encouraged take-up and supported people, as this comment from a team manager explains:

"I want people to be on Direct Payments. But my argument has always been that it is inadequate to send somebody a leaflet or to say to somebody at the point of first contact or the first point of assessment, 'do you fancy a Direct Payment?' 'What does that mean?' 'It means you get the money and you organise it all yourself.' 'Oh no, that sounds far too much like hard work for me, I'm not going to do it.' I think that potentially a lot of people are excluded from having Direct Payments, not because they shouldn't have them, but because of the manner in which it is portrayed to them and the manner in which it is explained."

4.48 Not everyone welcomes the idea of Direct Payments. CSCI inspections have identified reservations arising from the nature and amount of funding available:

"The impact of Direct Payment packages on promoting independence and giving control and flexibility of care to service users had been hindered in some cases by a limit on the allowance paid. Some service users had found that the amount did not allow them to secure their own flexible care so they had to return to using the in-house service."

"There were challenges in using Direct Payments more creatively as the funding package was based on the costs of block providers' services that did not account for the costs to an individual making similar arrangements in a market situation. Also, as block providers had not been used, costs were taken out of team care budgets, creating cost pressures and a disincentive to promote Direct Payments."

4.49 In two of our five councils some carers objected to having the idea of Direct Payments *"pushed down our throats"* and fearing that far from offering greater choice or flexibility this merely signalled more paperwork and difficulty, despite attempts to offer reassurance that other people could

manage the administration of Direct Payments on their behalf. As this person remarked:

"For heaven's sake, County can't do it, and they've got hordes of paid people to do it. How are they going to expect us to do it just with a grant you know? There's something wrong here, and that's a real worry."

- 4.50 If support for people using basic Direct Payments is crucial, it will be even more so in the context of personal budgets where arrangements could seem more complex. The implications for support, advocacy and brokerage are explored at a later stage.
- 4.51 Take-up of Direct Payments is a crude indicator of engagement with personalisation or improved choice and control, not least because Direct Payments cover a range of possibilities. People – with or without complex needs – might use them very creatively to change the nature of support they receive and to fine-tune arrangements to suit their lives, or – as the case study in Box 4 highlights – to make relatively modest demands which might appear to make little difference, but which may in practice be highly significant.
- 4.52 A similar experience was evident in another of the fieldwork sites where a couple aged 95 were also making use of a Direct Payment alongside support commissioned by the council, and where the husband had made his own employment arrangements with care workers. As his social worker described:
- "He has found the most amazing care workers – I don't know how he has done it but he has!"*
- 4.53 In fact this person had managed to find people by using networks he already had, including employing a person who had previously been his cleaner, and by involving a neighbour. The social worker commented on how the arrangements had been put in place and pointed out that for many older people, who it is often assumed will not be able to cope with Direct Payments or with recruiting and employing people to help them, this may simply not be the case:
- "You see, lots of our clients are already employing people. They are already employing cleaners and gardeners. So that's not unusual for them; they are used to employing people."*
- 4.54 As we described above, the five councils were at different stages of evolution in their approach to personalisation. Typically the move to Individual Budgets was approached on a limited or pilot basis in the first instance, most often for people with learning disabilities. In one of the councils, for example, young people in transition to adult services had been the focus of an *In Control* model for two years and this was increasingly viewed as the core system model. While the council was poised to move from this platform to *In Control*

Total, it was recognised by service managers that this transformation would be demanding:

“And the challenge has been how do we spread that across the whole directorate, across everybody rather than stick with transition? Because in a way it was the easiest group to work with because they are new people and often families and individuals are absolutely ready for an In Control type model.”

4.55 It was also recognised that it made little sense to invest in setting up new systems and processes for just a small group of clients. In some ways it is easier to change systems for everyone, albeit that the scale of change raises many challenges. What might work on a relatively small scale or for a particular group of people can run into problems when scaling up. In this council, which was trying to move from pilot development around transition to wider transformation, there was rapid realisation that the pilot approach offered *“a very crude model that really isn’t fit for delivery in that much broader context”*. Despite efforts to ‘tweak’ the model it was decided that further work was required, particularly around developing the assessment questionnaire for RAS and ensuring that the domains had a wider applicability. The new system was due to go live shortly after the fieldwork period so it was too soon to conclude what was happening in practice, but considerable energy was being directed into preparation and advance planning.

4.56 An important conclusion from this experience was also that local learning was extremely valuable and in this instance was seen as preferable to simply following a ‘national blueprint’. The new approach was being planned to apply to all new assessments and reviews, all of which would lead to an identified individual financial allocation. People would be able to choose to take the money as a Direct Payment or to have the budget care managed on their behalf. Despite preparation and fine-tuning it was acknowledged that there was an element of guesswork involved and that the system would need to be adjusted as it evolved. However, the council was *“erring on the side of safety”* in terms of its financial commitment, as this service manager explained:

“I think by ensuring that the (...) amount of money that somebody will qualify for would not be of the kind of upper limit (...) I don’t think it will be £50,000 or £60,000 care packages. It’s probably going to be at the lower end of things more the £25,000 to £30,000 kind of limit, and then down from there in terms of where people’s scores qualify them for. It may be that some people get less money than they are probably getting.”

4.57 Another of the councils had also started with a pilot scheme, and despite some initial concerns from finance managers anxious about controlling expenditure, there was now a commitment to *“go full steam ahead”* and

action was focusing on young people coming through transition who would be part of the Dynamite project. This group of young people is seen as particularly ready for a new approach because many of their parents and carers have expectations that their son or daughter will have a life, have experiences and opportunities and be supported to live more independently.

4.58 Moving from pilot projects to a more ambitious development of personalisation is by no means straightforward. While one of the councils was preparing for total transformation, another acknowledged that they had become a *"bit stuck"* with a pilot which had been running for more than two years and it was still unclear what foundation this would provide for wider development.

4.59 Having a vision of what the move to personalisation would mean was also something that varied enormously. While the majority of staff, at all levels, were committed to the underlying principles and values of personalisation, some struggled to understand how this would translate into practice, particularly for people with complex needs, as this care manager explained:

"I do also think that for some people with learning disabilities, they do actually need some social interaction with their peers, not just staff (...) I've got some reservations about them becoming isolated. I know that they're going towards going into the community with people, but it's still not the same as having people you can (...) your own peers to interact with."

4.60 There should be no inherent tension between individualised support for people and support that facilitates their social contact. However, for some people it is clear that their understanding of individualised support is one which sees that happening in an exclusively one-to-one context. Across all the sites some interviewees raised concerns or expressed scepticism about the scope for developing Individual Budgets for people with complex needs. Many expressed their frustration that the national IBSEN evaluation report had not yet been published (the fieldwork for this study was undertaken in summer 2008 and the evaluation report was published in late October), so they were unsure what had been possible within those pilots. However, what they had heard at CSIP events or in similar presentations seemed to describe situations where people did *not* have complex needs, for example:

"Everything that we have ever seen on personal budgets – you know in video or people who have come and spoken to us – they all seem people that are in control of their budgets and they are using them advantageously to meet all their needs (...). But I have never seen anybody with some complex needs like some people I know. I wonder how it would work."

And

"We were all thinking, oh yes, that's very good, but what about my client with all these mental health needs, autism or whatever?"

"It looks fine on paper and we are very committed to it and we will make it happen, but I'm not so sure it will have quite the (...) it will not be quite as revolutionary for the vast majority of people that we work with in the short to medium term."

- 4.61 Making the step change that is required in moving from Direct Payments to comprehensive self-directed support is more than simply a change of scale. As another interviewee remarked, Direct Payments have tended to be used for people dissatisfied with mainstream support, rather than being seen as the 'automatic position.'
- 4.62 In another of our sites (one which was also moving ahead with personalisation for all new referrals and reviews) a manager acknowledged that *"some staff are much better at it than others"* and was using a system of mentoring to encourage staff who were slightly more reluctant by showing them cases that had worked successfully. However, it was evident that reluctance was associated not just with lack of vision around the potential achievements of Direct Payments, but also with a desire to avoid getting involved with unnecessary paperwork.

Box 4: Experience of using Direct Payments

Miss Davis is in her 80s; she has cerebral palsy and has become more disabled in recent years. She is unable to mobilise and she uses an electric scooter/wheelchair inside the house. She lives at home in a ground floor flat which she owns and her nephew lives in the flat above (which she also owns). He provides her with some practical help and gets her shopping but is not involved in providing any personal care. Miss Davis has been using Direct Payments since March 2008 and is very happy with the arrangements.

Miss Davis had been having council-organised personal care for about 18 months but was dissatisfied with the service. Arrangements had been fine initially and Miss Davis enjoyed the visits from the home carers until with less than 24 hours' notice she was told that the staff would be changing and her support would be moved to another agency. Miss Davis was not happy with the agency staff, who she felt were always rushing in and out, she never knew what time to expect them, and they did not engage with her the way previous home care staff had done. Her nephew had also remarked on the change, as Miss Davis recalled *"he said I can tell, you know, it is so different, he said there is just silence down here whereas with the others you could hear laughter and people chattering away"*. Miss Davis heard about the Direct Payments scheme from her OT and looked into it.

Miss Davis embarked on Direct Payments on the assumption that *“anything would be better than the agency quite honestly”*, and has *“never looked back since; I have been so happy with that and I have got three very nice carers”*. Miss Davis advertised for carers and interviewed several people before deciding who she wanted to work with her. One carer visits twice a day (morning and evening) while the other two visit either morning or evening so there are always two carers present, which she needs for lifting and handling. She has established an excellent relationship with the staff and they go out of their way to do extra things for Miss Davis including bringing her home-cooked meals.

The arrangements with Direct Payments allow Miss Davis to have greater certainty about her care arrangements; she knows that carers will visit her at 8am and at 6.30 each evening. She did not want to make demands that would interfere too much with the lives of her carers and is happy to go to bed at that time and sit up in bed watching television until she is ready to sleep.

One of the carers combines her home care work with being a school dinner lady, but has offered during the school holidays to take Miss Davis out shopping during the day. Miss Davis thought this would make a nice change but she is not greatly concerned about being inside the house most of her time and says that she has always been someone who prefers a quiet life at home.

Miss Davis has help in running her Direct Payment, and the bookkeeping and pay roll are managed on her behalf. At the outset Miss Davis was alarmed that she might have *“bitten off more than I can chew”* but her experiences have been positive. Miss Davis's flat is not ideal for her needs and the doorframes have become damaged by her using the wheelchair indoors but she has no desire to move to other accommodation. Miss Davis could use her Direct Payment in other ways and someone else in her situation might want support to get out and about or to socialise, but her sole concern was with organising her personal care, and employing people to help her each day has been the solution she needed, and as she remarked: *“I just wanted everybody to know how pleased I am with Direct Payments.”*

- 4.63 How Direct Payments and Individual Budgets can be used was a matter of debate across all five councils. In many instances people acknowledged that uncertainty about rules meant that people were operating on the margins of legality. The rules governing how Direct Payments can and cannot be used, particularly in not normally being paid to relatives within the same household, could be especially restrictive. In a particular case (see Box 5) the council explained their pragmatic approach to allowing money to be used in this way

because it offered the best outcomes for the person concerned whose *“life has never been better than it is today”*.

- 4.64 Across all of the sites where people had experience of using Direct Payments or Individual Budgets, these were generally positive. Many people chose to move to Direct Payments because of their frustration with mainstream council-organised services which failed to meet their needs or respond to their preferences. Some people using Direct Payments identified concerns about managing paperwork, or what would happen if a care worker was off sick, and had opted to use agencies rather than to get involved in directly employing personal assistants. The benefits of controlling a budget were usually identified in terms of the flexibility to be able to get more help as and when it was needed, as this carer described:

“Just for instance, it was Monday night and the girl was really down just for three hours. But my wife had a bit of an accident, not accident, she soiled herself basically (...) so really the way it happened the girl had to stay an hour. I said don’t worry about it, it will be paid for you know. But if you didn’t have that she would probably go home now.”

- 4.65 Despite the advantages of being able to adapt payment to the requirements of a situation, people also commented on the negative impact of restrictions in the way that money could be used only for certain help. One carer who was looking after both his disabled wife and his adult son commented that it would be helpful to be able to use the payment to help with fuel costs:

“It would be useful to spend the Direct Payment on other things as well. Even things like towards the electric bill, because you have the fire on all the time (...) and things like that for my wife (...) it’s not your money sort of thing. You don’t get the money, it’s just in this pot and it’s just going nowhere really. You don’t get the benefit of it like that.”

- 4.66 Not everyone using a Direct Payment had flexibility to change the support they received. Another person who was disabled with multiple sclerosis was using Direct Payments and was also using an agency to provide PAs but described a situation in which she had little control over what time people put her to bed:

“If I want an evening out now, my children have to put me to bed, and that’s on the odd occasion if they are doing something (...) you cannot get care calls when you need them. I mean, I have got a life; I have got children and there is the odd occasion when they are doing something in the evening and they want me to watch them, but the companies don’t provide, you are in a routine and you can’t change from that routine.”

- 4.67 The experience of this person is presented in more detail in Box 6 below. Very often people could probably negotiate a more satisfactory arrangement directly with the carer who is supporting them but reported that agencies

create barriers to their staff working directly for people using Direct Payments.

- 4.68 Recruiting people to work as PAs is a recurrent concern and affects people using Direct Payments just as it does council services and care providers. This was a particular challenge for people with complex needs for whom the choice of staff would be especially critical. However, some of the people using Direct Payments in the fieldwork councils had found innovative solutions. One man who was very disabled with a form of muscular dystrophy explained how he had recruited two of his PAs from bar staff at his local pub:

"...it means that I can go and have a night at the pub and stay until closing time – I haven't done that for a long time. Now I hope that is the sort of thing that could happen in In Control Total. But the landlord might say 'yeah well so and so said she would come back and help you, but I will have to pay her an hour extra.' Right, invoice me then."

- 4.69 This person believed that part of the solution to finding PAs lay in looking in the right place, which is not necessarily in the care sector, but draws on the wider social capital of the community. In fact, such was the success of recruiting PAs from other backgrounds that this person and one of his carers had decided to establish a recruitment agency *"but trying to attract people from different walks of life, and not from care backgrounds"*. Even people who were confident in handling a Direct Payment and who had successfully recruited their own PAs often combined such support with care through an agency to give them the security of having someone who would definitely turn up and know that their needs would still be addressed if a specific carer was away on holiday or absent with sickness. For people with complex needs the reliability of personal support is paramount as without it they are typically unable to get out of bed or attend to their personal care needs.

- 4.70 Another interviewee – the parent of a young man with severe learning disabilities, non-verbal communication and some physical disabilities – explained her approach to recruiting a range of people who could make small inputs that would add up to all the support needed:

"The word is beginning to seep out, and the marketing that we're doing differently is beginning to generate a different interest (...) and my aim really is to have a bank of people, and that's beginning to happen (...) one woman may be coming in and cooking, she's keen on cooking, and filling up the freezer once a month. That's with them – it's doing it with them, not for them or to them. And that's been the difference; it really has."

(Mother of son with learning disabilities)

- 4.71 Not all experiences of using Direct Payments were good ones, and several people reported genuine concerns about the quality of support offered by some agencies. In some instances this was just a general 'feeling' that a care worker was not quite right or that an attitude was wrong, but in some cases

people reported totally inappropriate behaviour from care workers (including failing to get up in the night to a person with dementia who had become distressed, because she argued she was 'trying to train him' as you do with small children).

- 4.72 The regulations surrounding the use of Direct Payments have restricted some groups of people who could potentially benefit from them. In particular, the issue of 'consent' has been crucial. However, the Health and Social Care Act 2008 extends the availability of Direct Payments to people who lack the capacity to consent to their receipt. Guidance on new regulations was issued for consultation in August 2008, and is intended to ensure that as many people as possible benefit from Direct Payments, while also ensuring that people who lack capacity to consent are safeguarded from potential abuse.⁶⁴ Two of the councils had already pushed the boundaries in terms of interpreting guidance as permissively as possible in order to maximise the opportunities for people to make best use of Direct Payments. In addition to the exceptional situation where co-resident family members were being paid through a Direct Payment, other situations had led to the creation of a trust fund and appointing trustees to administer a Direct Payment on behalf of a person lacking capacity to consent. The story of one family is presented in Box 7.

Box 5:
Carers' experience of using Direct Payments

Mr and Mrs Gordon are in their mid-40s and have one child – Niall, aged 20. Niall is autistic and has been diagnosed with fragile X, the most common inherited form of learning disability. He exhibits high levels of anxiety and when anxious turns to 'fight' rather than 'flight'. He went through a variety of unsuccessful educational experiences, and as he got older and bigger these included substantial amounts of physical restraint which only came to light when his mother did some teacher training practice in one of his schools. Other educational placements were tried without success – in his mother's view because her entreaties on the need for structure and routine were ignored. Despite the poor experiences of schooling, Niall's behaviour is managed much more successfully at home where he has been taught sign language and is able to communicate his anxiety, but there has always been a problem getting support staff who can use sign language. His mother is firmly of the view that the problem is not Niall's behaviour but the way it has been mismanaged by educational and other agencies.

64 Department of Health (2008), *Consultation on direct payment regulations*.

After leaving school at 16 it was suggested Niall went into a hospital setting as an in-patient for six months but his parents were unhappy with this and felt he needed support in his home environment. Their request for home-based support from NHS psychology and psychiatry was rejected, with such support said to be conditional upon Niall becoming an in-patient. In response to this situation Mrs Gordon gave up her own career aspirations and stayed at home to look after Niall despite the financial problems this created. By this time his behaviour was very difficult even at home – *“He was just so anxious and angry, he used to trash our house from top to bottom. He would sit under the stairs and say he was sorry. I would say it’s alright. You just had to give him loads of love and then put all the things back”*.

A package of support commissioned by adult social care was offered to the family, but Niall’s parents worried that this was adversely affecting his behaviour. Both of his parents tracked his movements during the day and were horrified by what they saw – Niall was sitting alone, eating dirt and was subjected to verbal abuse from the support workers at the placement. At a subsequent meeting with the specialist behavioural analysis intervention team it was suggested that a Direct Payment be used and this has (unusually and creatively) been paid to Niall’s parents to support him during the day. Full accounts of what activities are undertaken and how the money is spent are provided by Mr and Mrs Gordon, and Niall’s behaviour has now improved beyond recognition.

This story reveals the enduring difficulty services so often seem to have in supporting people whose behaviour is regarded as challenging. The key to coping with the behaviour lay in listening carefully to what Niall was attempting to express and responding sensitively, but both the education and adult social care services found it hard to do this. In this case the answer lay in allowing the parents to access Direct Payments to pay themselves a wage – an effective solution but one that was on the borders of legality.

- 4.73 Another family in the same council had also been allocated a substantial Direct Payment through a trust fund for their son. In this situation the family had been angry and believed the services offered had never provided good enough support for their son, which in turn had involved them in multiple disputes with care providers and many carers refused to work with the family again. It was essential to find a solution that would work and be sustainable; the council had advised the family that *“although not impossible, this may be a trust type of case and it will not be quick to sort out”*. In fact the process had taken more than a year to negotiate and draft guidance was developed by the council to cover the arrangement of ‘user-controlled trusts’ which provided for the following circumstances:

“Setting up a user-controlled trust enables a person (...) to benefit from Direct Payments in terms of being able to have control and independence, whilst having the support of a small group of people to support them. These people are prepared to act on behalf of the user; they take on the responsibility of organising the care and managing the money. The user is crucial to any decision making and their wishes must always be consulted. If a user can only demonstrate their wishes through their behaviour for example, it is crucial that two of the trustees know the user very well. At least one of the trustees should be from outside the family connections to ensure there is some objectivity.”

- 4.74 In the councils that were attempting to move beyond Direct Payments and to develop more ambitious approaches to personalisation there were numerous challenges. The climate of uncertainty about what the future might look like and the implications for service providers and managers were part of this. Some people adopted a highly pragmatic response, for example:

“For me, it’s trying to work out as a manager, it’s trying to work out how we can respond to that. You know, what are the threats? What are the opportunities?”

- 4.75 As we explore in the previous section, the uncertainty for providers – both independent sector and in-house – is a major factor, with a sense that ‘nobody knows what’s happening.’ Some services were confident that they were of sufficient quality that the new market created by personal budgets would not have a negative impact, although others acknowledged the risks – *“we are pretty damn good, but we are expensive”*. In such circumstances, people with limited budgets may well seek better value for their money.
- 4.76 In all five councils, whatever the experience in developing new models of personalised budgets, it was clear that the approach was seen as a compromise or hybrid that stopped short of full Individual Budgets. This raised issues about the place of different funding streams and how funding through Supporting People, Access to Work and the ILF might be integrated, quite apart from wider issues around integrating health funding. Interviews with Individual Budget lead officers in the 13 IBSEN pilot sites identified the potential of integrating multiple funding streams into a single personalised budget as one of the distinctive features of Individual Budgets, which distinguished them from Direct Payments and from *In Control* (both of which only involve local authority adult social care expenditure).

Box 6: Using Direct Payments

Mrs Keane is in her late 40s; she was diagnosed with multiple sclerosis 14 years ago and within six years she was using a wheelchair. At that time she had three school-age daughters and a husband in full-time work. Subsequently her condition steadily deteriorated and she now has no movement below the neck. Two years ago her husband was diagnosed with motor neurone disease. The family house had to be sold and they were allocated a council house sufficiently large to be adapted for both of them. Within days of moving into this house Mr Keane died – *“So I lost my husband, my home, my neighbours, my friends. I lost everything”*. The only remaining family member – her brother – was killed in an accident a year later. Her youngest daughter received a Young Carers’ award for caring for her father and mother through these tragic times, but Mrs Keane constantly worries about the effects of this upon her daughter’s education.

Mrs Keane now receives a care package worth £3,000 per month funded through the council and ILF, with provider support coming mostly from an independent sector agency. This is a complex arrangement that involves 49 carers a week coming into her house, but the constant (and crucial) factor is her PA, Jean, who for several years has supported her Monday to Friday throughout the day. Whilst hugely appreciative of the support and friendship given by Jean, Mrs Keane is critical of the routines required from the other support staff – *“it would be nice if they could be a little bit more flexible... I never get a lie in, they expect you to live by a routine seven days a week”*. She is normally put to bed at 6.30pm and she dreads the prospects of lonely introspection: *“It’s a long time to sit and think about your worries. I keep my telly on all night because I couldn’t bear what my thoughts would do to me with all of what’s happened over the years.”*

Jean is employed by the agency and both she and Mrs Keane would like to have a private relationship to increase her time and hourly pay, but Jean worries about losing security of employment. Although the council runs a Direct Payment support unit, Mrs Keane says she was just told ‘you are in charge’. Currently she is experiencing difficulties on two fronts. Firstly with the ILF, whom she believes have failed to pay her backdated monies owing to her, and secondly with the proposed transfer of her funding to NHS Continuing Healthcare. Her main worry here is that she will not be allowed to retain the one constant source of support in her care – Jean.

Mrs Keane’s story is one of coping courageously in the face of huge adversity. She has taken on the responsibility of a complex care package but still finds herself insufficiently in control of her own circumstances, and now faces the prospect of losing the support she most values because of a change in funding arrangements.

Box 7:

Innovative use of a Direct Payment through a trust fund

Gary is 23 years old. He has complex learning disabilities and some physical disabilities; he has very limited verbal skills and has learned other ways of communicating. Gary attended a boarding school followed by a residential college and all his life he has been good friends with Max, another young man who attended the same school and college. The families also know each other and live near each other. Gary's parents had been investigating residential homes for his future; because he had lived away from home at college they felt strongly that he should not then come back to being dependent on them but should be helped to live in a supportive environment. Despite looking at various options the family were unable to find anything that met their requirements or offered appropriate support.

The council proposed an alternative approach that would involve supporting Gary and Max to live in a housing association property close to their families. For the council this was consistent with their pursuit of personalised care and an opportunity for them to develop an individualised solution. The families as well as staff were involved in training about *In Control* and how to write a support plan. Gary and his family contributed almost all the information required for his support plan. The support package was put out to tender and five providers responded. The tender was awarded to a local Mencap service which saw this as a great opportunity to change their services and embrace the emerging personalisation agenda. Gary and Max moved into the house in January 2008, following a period of transition where they had overnight stays. The house is within walking distance of the family home and Gary knows the neighbourhood well. His mother describes the arrangements as *"far superior to anything that we have been able to research or find as an alternative"*.

While the families remain involved with their sons they have been able to withdraw so that they are providing less direct care or support themselves. At the outset the families continued to provide a lot of the support while a team was being established, rather than delay the young men moving into the house until the perfect team could be assembled. They have gradually built up a bank of staff and carers who want to work with Gary and Max and who can bring a range of skills and interests to their lives. All of the staff have been newly recruited rather than transferring people who already worked in Mencap services. All prospective staff are observed interacting with Gary and Max and the young men have the final say on whether or not a person comes to support them. Recruiting staff has been difficult, partly because the

parents have refused to make use of agency staff. Gaps in staffing have been met in the interim by the parents of both young men providing hands-on support. Gary has a personal budget worked out using the RAS model; on the first calculation this produced an indicative budget of £45,000, and subsequent adjustments and weighting to take account of complexity produced a total budget of around £62,000 (and a similar figure for Max). There is a trust established to manage the money on his behalf and Gary has a 'Circle of Support' of people who are working in his best interests. Both the young men have settled into their new home and the community.

Gary's story is one which is being told frequently in this council. People are excited and touched by the achievements and can see the potential of the model in supporting other people in the community who would otherwise be in residential placements. It is still early days for Gary and Max in establishing their own home and living independent lives, but the success to date owes much to the combination of an enthusiastic council eager to push the boundaries of personalisation, and an ambitious and articulate parent unwilling to put up with residential containment for her son.

- 4.77 In Section 3 we explored how this integration did or did not occur in practice, and the legislative barriers to integration which remain. In our fieldwork the ILF was the funding stream most often identified as especially relevant to people with complex needs, and also the one that was most likely to be problematic for people trying to make flexible use of this funding to live their lives.
- 4.78 It is important to acknowledge that personalisation is not simply about Direct Payments or Individual Budgets. Services for everyone using social care support should be personalised, regardless of whether they choose to make use of a Direct Payment. This can be especially important in supporting people who do not have the capacity to consent to a Direct Payment, which has limited the scope for personalising their support and maximising choice and control. In the course of our fieldwork we found a few examples of practice where councils were providing excellent personalised support without using a Direct Payment. One such case is described in Box 8 below. Another example was identified by an independent sector provider of residential services for people with learning disabilities who described arrangements for maintaining contact between residents and their families:

"We actively encourage it and we always have. For instance, the distances involved; we'll help families get in touch with social services for funding to come. We will arrange for people to go home, more often we meet half way and have days out with families as much as we can. That works for the person and for the families. I suppose the best example is I had a lady when

I worked in one of the hospitals; her mother was in America, in Seattle. And I used to ring her at 2 in the morning to give her an update on a two weekly basis. I would work a night shift just to be able to do that and to maintain a consistency of approach (...) She moved elsewhere and we were looking at web cameras, video conferences, so she could have some face-to-face contact with mum which was very important to her."

- 4.79 Ensuring personalisation in residential environments is challenging, but another of our councils was working with 'The Eden Alternative'⁶⁵ to improve the quality of life for people in care homes. This model focuses on improving the environment of the home and changing the culture of care to eliminate loneliness, helplessness and boredom.

Equity between people using services

- 4.80 An important issue which was identified in all of the councils was the question of equity between different groups of people using services. Whether some people are supported to achieve greater independence and to exercise more choice than others raises some profound ethical issues. As the case study in Box 9 below epitomises, these questions arose most frequently in relation to support for older people.
- 4.81 For people who have used social care services as younger adults, reaching retirement age can signify a major shift and a transfer to a new team dealing with 'older people'. In addition to the disruption that this can entail (a transition which attracts much less attention than that of young people into adult services), it is also evident that there is often an expectation that 'independence' will have a different and more limited meaning, and that the resources available will be reduced accordingly.
- 4.82 Some older people using services were only too aware of the inequity of services and the potential implications for their own support. One such person who had experienced life-long complex physical disabilities and was now entering old age believed she had a 'reasonable package' of support and was a long-time user of Direct Payments, but was fearful of the future. Mary's experience is described in Box 9.
- 4.83 Mary had long experience of using a Direct Payment but viewed the future with trepidation, fearing that she would be unable to cope with the requirements of an Individual Budget. As she remarked:

"I get to the point now when I think I don't know if I want to see any great change because I don't think it could stand it, and I am not being dramatic. I just feel generally that it is interesting as you get older there are things you can tolerate less."

- 4.84 Mary was also aware that her needs are increasing as she gets older and was concerned about whether these would be met, as she described:

"I guess if I was getting a Direct Payment now I don't think I would be quite so lucky; I would be very worried (...) as a person who does have quite a lot of need I am a very active person; it is very hard then if they say well we have got to be fair and other people don't want to do a lot of those things (...) I think I could finish up with less."

Box 8:

Personalisation without a Direct Payment

Danny and Steve are identical twins of almost 20 years old. They both have profound and multiple physical disabilities and severe learning disabilities. The young men are non-verbal and have no other means of communication, beyond some basic noises, but for skilled carers who know them well they are able to indicate preferences and discomfort. Both young men need a high level of support 24 hours a day and have no independent mobility. For most of their lives Danny and Steve have been cared for at home by their father (a sole parent and carer) with a package of home care. The family lived in a local authority four-bedroom bungalow which has been adapted for their use.

Three years ago the father decided that when his sons left school at 19 they should be supported to live independently. This decision was partly based on wanting his sons to have the best life possible and looking to the long-term future, but he was also hoping that this would enable him to return to paid employment, since he had given up work to be a full time carer to his sons. It was agreed with the council that the father would vacate the family home and be re-housed nearby, leaving his sons living in a home they were familiar with and which had already been adapted for their needs.

The young men have different personalities and preferences. They respond to people being around them and enjoy the stimulation of activity and going out. They become distressed if they are separated or out of sight of each other for more than a short period. The young men have constant support from a team of care staff. The house (on an ordinary estate) has been refurbished throughout and provides a high quality environment. Ceiling tracks are provided throughout the bungalow to allow hoisting in and out of wheelchairs wherever necessary.

Since the care package has been taken over by the young adults team it is reported that Danny and Steve have become more engaged and healthier. It is believed they are benefiting from greater stimulation and attention from staff. Despite their lack of vocalisation, the care staff constantly talk

to Danny and Steve and involve them in everything that is happening. The young men left school in July 2008 and started a college programme in the autumn. In addition to personalised support at home they also have access to hydrotherapy and rebound exercise facilities.

Since they have left school, support for Danny and Steve is funded entirely through social services at an annual cost of almost £93,000 each (nearly £186,000 in total per annum). They do not qualify for support from the ILF because of the high costs of their support package. They do not have a Direct Payment and their support is through council-arranged services. Their needs are complex but largely stable and they have a quality of life which reflects not only the nature of the one-to-one support they receive but also the input of a highly committed and motivated staff team.

- 4.85 Because of the difficulties in reviewing her Direct Payment, Mary decided not to pursue this route. By contrast, her experience with a different funding stream (Access to Work) was far more positive. This financial support had lapsed two years previously on Mary's request because this too necessitated time-consuming form filling. However, Access to Work contacted her to renew her three-year contract at the same time her Direct Payment was being reviewed, and she decided to pursue Access to Work assistance. Mary was subsequently awarded more support than she requested from this budget and the decision was turned around very rapidly. Mary is taking a pragmatic approach and is ensuring that funding from Access to Work is used for her work-related support, which in turn reduces some of the demands on funding through her Direct Payment. This now means she can avoid subjecting herself to what she experiences as bureaucratic and painful processes associated with reviewing her Direct Payment. In the longer term this may not be a viable route if Mary is no longer able to work, but for the time being she feels that Access to Work "has given me a reprieve".
- 4.86 Other people who were not using Direct Payments also commented on the consequences of ageing. The carer of a 65-year-old man with a degenerative condition remarked that the four days a week of day care was likely to be reduced, and also would entail moving to a different day centre rather than remaining where he had been for the past several years.
- 4.87 Across the councils it was recognised that cost ceilings had a differential impact on different groups of people using services and mean that older people generally have fewer options than other people. As this person remarked:

"So you could have an older person in the early stages of dementia or whatever it might be, who really wants to stay in their own home, but their package is going to be absolutely massive and you have got a spend ceiling

for older people, so they can't have it. They have to go into residential care unless somebody tops them up, you know, their family. You could have a person with learning disability with dementia in their later stages of life being supported, and massively, to stay at home. Now that's the tension."

(Manager, learning disability services)

- 4.88 As we have explored in the previous section, these issues of equity are becoming more transparent under the RAS models whereby there may be varying price points for different service user groups.
- 4.89 The point at which people move into age-related services also arises at younger ages for some. In particular, people with learning disabilities – particularly Down's syndrome – are increasingly being recognised with dementia emerging at around 50 to 55. Where people with these needs should be supported is an important question; whether they should stay in a service they are familiar with, or whether their needs would be better met by looking at services which have typically been designed to support older people.

Box 9:

An older person's experience

Mary has been disabled since early childhood and is now in her 60s. She has complex physical needs and uses a powered wheelchair. Mary spent some years living in a residential home when she was younger because she could not find any alternative accommodation after leaving her parents' home. More than 30 years ago she left the care home (or "escaped" as she describes it) and moved into a housing association warden controlled flat where she has lived ever since. Despite this being a positive move, the experience of leaving residential care was a traumatic one.

Mary has a Direct Payment which covers almost 50 hours of support (plus one night) each week. She employs people to support her with personal care every morning and evening. She has flexibility within what she sees as a "fairly fluid care plan" to be able to call on people to provide more support if she is unwell. However, the overall level of support is beginning to be insufficient for her needs although she fears that demonstrating the case for more support may be very difficult. From a personal perspective Mary also worries that as she gets older her level of support will be reduced. She resisted being moved to the older people's team and was upset at having to lose contact with care managers she had known for a long time and start afresh with a new team. Despite needing considerable support, Mary leads a very busy life and has concerns that support to do this could be reduced in the future, particularly if there are issues about

fairness and equity between service users as she recognises that she receives considerably more support than many other people of her age. Her experience of seeking additional support from adult care is not a positive one. Although her care manager was helpful, Mary found the form-filling requirements and the need to justify her case for additional support laborious and stressful. Mary feels strongly that she has a right to some privacy and she resents the level of intrusion required by both personal and financial assessment (*“everybody knows everything about you”*). At the same time, Mary fully recognises the need for accountability in the use of public money and is rigorous about keeping records and receipts for her Direct Payment.

Mary has used a Direct Payment for a long time and is generally happy with the arrangements. She particularly values the commitment of both council and voluntary sector staff she comes into contact with. From the outset Mary has recruited her own PAs and has never used an agency to supply staff. However, she acknowledges that it has become much more difficult to recruit and retain staff in recent years, but she has been successful in keeping her PAs for long periods. She employs an agency to manage the payroll services on her behalf. Despite being a big fan of Direct Payments Mary is extremely cautious about the new agenda of Individual Budgets and personalisation and fears that it could all be a cloak for cost cutting. She also fears that people with complex needs will not be adequately supported to manage this new approach and are effectively “being set up to fail”. Mary is a highly articulate person who has long experience of using social care services generally and Direct Payments in particular but she feels unable to manage too much further change or disruption to her life. Mary has lived alone since leaving her family home and does not have informal carers, or family living close by, who could support her or stick up for her. While she has successfully assembled a budget by combining Direct Payments and Access to Work, this has been a cumbersome and time-consuming process requiring considerable initiative and effort on her part.

- 4.90 The issue of people being treated differently simply because of their age was also identified in relation to the ILF. People who are eligible for support from the ILF before they reach 65 are able to keep it beyond that age; however, people cannot apply to the ILF for the first time once they are 65 or older. The unfairness of this situation was not lost on this person:

“One of the things I have about ILF – and it doesn’t affect me because I qualified for it before I was 65 (...) is that I could be next door to someone with the same level of impairment. I was diagnosed and got ILF before 65, [but if] they didn’t apply – they have an existence; they get up in the morning and get fed, they get showered and they get put to bed again. But I can go

to the cinema, I can go shopping. Yet it is just because of an age – that one person can't have a life."

- 4.91 The overt age discrimination which many people identified was not the only issue of equity. There were also concerns that the new system of personalised budgets had some inherent flaws because of its origins in support for people with learning disabilities which could limit its applicability to people with other needs. In some of the councils this was an issue that had been identified through piloting of assessment tools, for example:

"Somebody that has got a lot of physical needs won't score very highly on that self-assessment form, because it was basically lifted from a form that was used for learning disabilities. And so there is a lot around supervision, monitoring, safety issues, and a lot of questions around that."

Range of services

- 4.92 Establishing new systems to enable people to use Direct Payments or personal budgets is only part of the essential superstructure to support people in achieving greater independence and choice. Another vital ingredient is the range of services available and the reconfiguration of traditional service patterns. The CSCI service inspections on independence, wellbeing and choice have highlighted the difficulties where services are limited, traditional and insufficiently flexible, where day services are traditional and predominantly based in buildings, and where block contracting arrangements limit the range of services on offer. These features were also identified in the councils taking part in this study. In Section 3 we addressed policy issues across the councils including the question of out-of-area provision. Clearly the lack of specialist provision which necessitated people being placed far away from their family and community networks could be a major constraint on choice and control.

- 4.93 A further factor that limited the personalisation of support for people with complex needs was a conservative tendency of many people using services, and more particularly of the parents and carers of people with learning disabilities who tended to emphasise traditional and familiar services. The following comments highlight the difficulties of providing personalised support to people with complex needs within the constraints of traditional services and were typical of many across the five councils:

"Parents like to see a building; they cannot really understand that, oh you can be here one day, you can be there one day. Who is looking after your son or daughter? They are really afraid of how much social interaction their sons and daughters can have."

"Some families are very up for it and some families aren't at all, and that's been very interesting (...) some want five days in the service and so many

days respite care, and that's all they want. They're not interested in employment, they're not even interested in what happens during the day, as long as they're picked up by transport and taken to a day service five days a week. They want it to look like school."

And

"For some people, and certainly carers, I think that one of the big dilemmas is that carers actually want – you know I was in a meeting last week with 12 carers and they were all saying: we don't want; we know about Individual Budgets and Direct Payments and we don't want it! We want this service. We want the more traditional type of service. We don't want our sons and daughters doing the all singing, all dancing things in the community, five, six and seven days a week."

"There is a strong majority who just want to know that the young person is cared for five days a week while they go to work."

"I have to be honest and realistically a lot of the carers look upon us as respite and couldn't cope if they had to support their son or daughter at home (...) and I think a lot of the difficulty that we do have is balancing carers' needs with the needs of the service user."

(Learning disability, team leader)

- 4.94 Some parents of young people with learning disabilities can struggle to accept that their son or daughter is an adult and should be supported to develop as an individual and to have their own rights and choices. Even if families accept a person's right to independence, supporting them to achieve that and to manage a personal budget can be extremely demanding, as this learning disability team manager acknowledged:

"Parents, for example, would be responsible for sorting a lot of the stuff out for individuals that aren't so able. They're like the rest of us; they're short of money, they need to work full time, they have all the same pressures that the rest of us are under. And then they've being asked to actually coordinate that as well."

- 4.95 In fact, this manager speculated that at present only around 20% of people in the caseload would be willing to consider moving to an Individual Budget:

"And there are an awful lot of people out there than don't want individualised budgets. This family in particular in transition said 'no way, José, thank you very much. We just want the services."

- 4.96 Resistance to changing models of service is not solely about preference for traditional building-based support. One carer dismissed the move towards outreach services as political correctness, but went on to explain how she believed this was also not in the best interests of her disabled son:

"...using his home as a base and taking him 'hither and yon'; I mean he has spent most of his life on the transport, which isn't particularly pleasant. It's hot [in summer] and it's cold in winter; he is clamped with a strap across his middle and he can't move. It's not very nice (...) it's not a life."

- 4.97 Social care staff fully recognised the difficulties for many parents, particularly if they had spent the past 18 years struggling with services and with the needs of a child or young person, and they have run out of energy to take on anything new. As this carer remarked:

"I don't want (...) I'm 65; I've looked after my daughter for 38 years. I don't want to take on more responsibility."

- 4.98 It was not only parent-carers who expressed concerns about changing services and new approaches of personalisation. An older person supporting her 65-year-old husband who had a degenerative condition was extremely hostile to the idea of Direct Payments and was adamant that structure and consistency were of the utmost importance:

"It sounds to me as if somebody has made that decision when they have no experience of disabled people at all, because you cannot say to a disabled person 'what would you like to do today, or where would you like to go?' They want to be told 'we are going on a theatre outing next Saturday', and it gives them something to look forward to, or the music room today, and a meeting at such and such a time, that sort of thing."

- 4.99 The case study of Mrs Bardsley in Box 10 below epitomises the experience of a parent-carer who has coped with the multiple needs of her son throughout his life but manages by sticking with a routine and has no interest in seeking any alternative to the package which they have been using for many years. The experience of the sites piloting Individual Budgets indicated that *most* people used their budgets for mainstream services or for employing PAs. However, for most people in the pilots it was very early days and it was expected that as confidence and experience increased more innovative approaches to care and support would be increasingly in evidence.⁶⁶

- 4.100 While parents could have a conservative influence on the choices available to people using services, in other situations parents were also – as we have noted previously – a driving force for change around young people in transition, as this head of learning disability services described:

"We have got the very traditional sort of services – the day centre – that has facilities for people with multiple disabilities, but obviously the age range is 18 to 65. And what this family and lots of other families who have young people going through transition are saying to us is that they want their kids to mix

66 Glendinning et al (2008), Op Cit, p62.

with young people (...) so they looked at the services we had and they were just not interested."

- 4.101 In this same site the council had difficulty in meeting specialised needs locally. The authority was geographically small and complex cases were few in number meaning that specialist provision sometimes did not exist locally or could not be easily developed cost effectively. It was hoped that this situation would change and in approaching needs on an individual basis and looking at options with personal budgets, different solutions were being explored. For example, planning had begun to develop supported living for three young people who would be coming through transition in about a year and a half. Previously it was likely that meeting needs in this way could only have been achieved through out-of-area placements.

Box 10:

A carer's experience of mainstream support

Mrs Bardsley is in her early 60s and has a son, James, who is 35 and has severe learning disabilities. James has many additional physical disabilities – he was born with a short jaw and tongue, he is blind, has missing bones and muscles in his legs and hands, a depressed chest bone, and has developed scoliosis of the spine. He can only swallow liquidised food and is unable to walk unaided. His communication is very limited, though Mrs Bardsley thinks he understands much more than he could ever communicate. Mrs Bardsley herself is now having health problems (including a major operation for a pelvic floor repair) and her husband has had a slight stroke and is diabetic.

For Mrs Bardsley, the key to sustainable caring is routine – *"we have a very tight routine and as long as we stick to it we manage"*. She does not take the view that caring has been a struggle, and is thankful for all of the help she has received over the years – help which she thinks is less accessible today. James stayed at school until he was 18 and, following three weeks' holiday, started at the local training centre where he has stayed since. Mrs Bardsley gets annoyed at suggestions that traditional day centres are no longer appropriate – she thinks it is just *"politically correct"* to take this view, and speaks appreciatively of the opportunities given to people to experience structured activities that *"give their lives a shape"*.

Mrs Bardsley's story is one of the perceived value of traditional directly provided support from the council. She has felt no need to consider a Direct Payment, and sees structure and routine (whether at home or in the day centre) as more important than choice and flexibility.

4.102 Councils were struggling to modernise their day services, and while outreach models *were* being developed this was often alongside building-based services which people fought to see continue. One day centre manager described the dilemma:

"...a large number of people who come to the centre are looking for some socialisation, some relief from social isolation and in some cases purely respite and a lot of those more traditional service users we are finding are moving with a great deal of reluctance into any new or different model of support."

4.103 Elsewhere it was acknowledged that the change to new models was something that had to be very gradual, *"meeting with users and carers throughout that process, way before it was ever started"*. The transition was not always smooth, but as this manager for learning disability services commented, the outcomes spoke for themselves:

"...over time it shows that things can work. There will always be (...) I'd be fibbing if I said it all went smoothly and everything was absolutely spot-on (...) [but] there's a lot more community access and staff are supporting people to do varying things (...) in terms of opportunities for people, I think that really has worked."

4.104 Developing high quality alternative services is vital, and as some interviewees observed, it is not enough to do things which are alternatives to building-based day services but offer little of quality. This team manager remarked that some of the comments made by carers who had withdrawn from services indicated that there were shortcomings:

"...and they say all they do is walk around the streets and get pushed around the streets in all weathers. And I think, you know, I think there has got to be a balance. And I think we can't meet everybody's needs."

4.105 For people who have very profound disabilities and little if any communication there is arguably still a need for some building-based provision. One such person was described:

"She is PEG-fed; she is doubly incontinent, and is moved everywhere by a sling, a hoist with two people; she has no verbal communication and even staff like me who have worked with her for a while and knew her when she was more able sometimes struggle to know whether or not we have got any kind of feedback with our communication, and we have to work in her best interests."

4.106 A day services manager described how many people were now using the day centre more as a base but spending much of their time away from the centre doing a range of other activities. Increasingly there is an attempt to access mainstream community facilities, and making those accessible to people with disabilities such as through providing appropriate changing facilities in leisure services, *"so that people can go there without having to go to the day centre*

and enjoy the leisure service like anyone else". Facilitating access to the community and linking people into natural support networks was recognised to be much more difficult for people with profound disabilities.

- 4.107 Other people using services were also often attached to using day centres which provided them with some *"sense of community"* that they could not find (or were fearful of not finding) in the wider community. One very clear reflection of this was in day centres where people called themselves 'members' of the centre and where the facilities were seen *"as a kind of club"*.
- 4.108 Councils were typically trying to manage the transition to newer models of support and not removing the option of using day centres. However, because investment was switching to the development of outreach and other alternatives, funding was being diverted elsewhere with the result that tired and under-resourced services were becoming shabbier and ever less attractive for people who continued to use them and could see no alternatives but to use them. In one council officers described their frustration at having to accept some people still wanted to use such a resource, and observed that *"we have got to manage it out of existence"*.
- 4.109 Some of the pressures on adult social care were a reflection of reduced service availability elsewhere. As we described in Section 3, a feature that was repeatedly identified across the fieldwork councils was the impact of changes to Learning and Skills Council funding on further education colleges. People with complex needs are increasingly unlikely to be able to access college-based support because of their inability to demonstrate progression or to follow employment-related courses. The difficulties that this situation creates were identified by this carer, for example:

"...this makes a joke of personalisation because X and Y have a 'Learning at Home' day where the college comes into their home. They're now saying that because [they] have had the Improving Choice money (...) that actually they're going to stop funding. That's it; end of story. So how do you continue that self-improvement, that continuous improvement if you have not got the LSC actually seeing that they are doing a valuable service? The easiest cuts are for the individuals who are deemed not to be worth it. Because that's what it feels like."

- 4.110 One of our councils was working closely with the colleges to find a way around this difficulty and had made joint funding bids:

"So we got fifty grand last year and we've put another fifty odd thousand in this year to pump prime the college courses that generally they wouldn't have put on because people wouldn't have achieved the milestones. So now we are asking them to do an audit this year of everybody that didn't get into college, why they didn't, what they would have wanted from college and then we'll put an ESF bid in next year."

- 4.111 As this person described, part of the motivation for working with the colleges was to avoid the situation in which people unable to access college *"automatically default to us"* and to day services.
- 4.112 Other difficulties with service availability concerned the need for specialised one-to-one support. Carers described the difficulties of trying to find people who could support their disabled child, and how this became more difficult as the young person reached adulthood, for example:
- "You couldn't find people who would actually be able to look after, or be a second mum, or any of that stuff. When they were tiny – different story, but come 16 or 17, and a hulking young man, well actually no. And (...) it's not something you pluck off a tree or out of an agency. They have to know people – you can't just say 'oh I'll send somebody in there for three hours', and they've never met them before. It's impossible to do that."*
- 4.113 This parent also described the difficulties of trying to work with a respite centre and provide an induction for staff so that they understood her son's complex needs (including alternative communication techniques), but the person identified as a one-to-one key worker was unavailable, *"it didn't actually happen (...) there was no concept of the need for continuity"*.
- 4.114 The lack of suitable services at transition can mean that a person's development and prospects for independent living are suddenly curtailed. A young man had gone to a residential college out of county after leaving school because of the inability of local colleges to meet his communication needs. While his parents were unhappy with him having to be placed away from home, they also acknowledged that there were some benefits for their son:
- "He achieved a huge amount by being out of our house (...) he has learnt, more or less, how to live without us, in a different sort of way (...) So he's come back with a much greater range of skills."*
- 4.115 As the case study in Box 7 describes, these achievements were jeopardised when the young man's future after college was being considered and the only option appeared to be placement in a residential home. In fact, the combination of determined parents and a council anxious to move ahead with personalisation created the preconditions for developing a far more ambitious solution in the form of supported living organised through a personal budget.
- 4.116 In seeking to develop community-based alternatives to traditional services, councils acknowledged the difficulties of achieving social inclusion. A service manager in learning disability services observed that *"a lot of our service users, particularly those with learning disabilities, are abused"*. This council had established an anti-bullying pack in conjunction with the police and had engaged in a variety of activity to challenge prejudice in the community. As another manager remarked, the implications of personalisation for community access are *"almost like a second phase resettlement"*. People who used to

live in long-stay hospitals have moved into the community; the challenge now is for people to be able to fully participate in that community:

"It will be a gradual thing; it's not going to happen overnight – but five, ten years down the road, it will be the norm."

(Area manager, community learning disability teams)

- 4.117 Despite frustrations with insufficient range of services from which to make choices, it was also clear across the sites that there were examples of successful personalisation and innovation in support for people with complex needs. These were bold stories of people creating new patterns of support to suit their ambitions, often with the support of exceptional caring families and visionary care staff. Some of the many stories had the following features:
- Using Direct Payments for support that traditionally adult social care would not pay for, such as a ticket to go to watch the football rather than to use traditional day services.
 - People living in supported tenancies where previously their only option would have been residential care.
 - Support to access the community in preference to using traditional day services.
 - People being brought back from out-of-area placements because new specialist services enable them to be supported locally.
 - Supporting people to live more independently and to have the confidence to participate in community life.

Safeguarding, support and advocacy

Risk

- 4.118 What support people need to use Direct Payments or personalised budgets, and the balance between choice, control and safety, were issues identified repeatedly across our sites. In all the fieldwork councils people drew attention to the risks that can arise when people using Direct Payments employ personal assistants who they may not know, who are currently unregulated, who may not have CRB checks, and who are accepted on face value. These issues arise for all people using Direct Payments, but they are amplified when people have complex needs. The following comments are typical of many that were made:

"I think vulnerable people do need protection; little ladies down the road could take advantage financially. Not just financially, you know it's practically – how well do they know them?"

(Registered manager)

"They need protection. I mean some people in an ideal world, your family do support you. But in the real world, they don't you know."

(Registered manager)

"I have a lot of concerns about it being open to abuse. There is an article I read (...) where those on personalised budgets have got a 20% chance of being abused by the people they are employing because CRB checks aren't being carried out."

(Operations manager, independent provider)

"I've got to say I have very real concerns about (...) rushing headlong into personalisation (...) I think it's a solution for some people but, in the case of people with complex needs, personalisation often means placing responsibility in the hands of another organisation or individuals who may or may not have the individual's best interests at heart, and what safeguards are there for that?"

(Independent advocate)

4.119 Some interviewees took an absolute position and believed there should be a rigid requirement that anyone using an Individual Budget must *only* employ people who have been CRB checked, while others recognised the risks but were less certain how to mitigate them, or how to balance positive risk taking, human rights and independence with issues of a duty of care and safeguarding considerations on the part of the local council.

4.120 The risks that people using Direct Payments or personal budgets might face were also contrasted with the experience of using council commissioned and regulated services. As the following comment highlights, the inconsistencies in the approach raise many difficulties:

"But there are some things that if it was going to be us that we would say we would always do CRBs on people (...) Everybody is used to that because through a period of whatever it is, the last 10 years, you know the amount of checks that people have done had gone up and up and up. And now they are asking us to employ Joe Bloggs down the road, or just to say 'can you take this person to the football match for an hour and he'll buy the ticket and that will be your payment.' You know, that kind of thing, which you know – it's a good idea. But do we really know that Joe Bloggs down the road won't go and sexually assault the guy behind the bus sheds on the way there?"

4.121 As the last comment indicates, there are particular concerns about the personalisation agenda for people with complex needs. One interviewee commented that:

"The people who are promoting that are very articulate, in control, forceful characters who wish to exert their choice – and good luck to them. But the people that I've been working with, many of them literally have no speech

never mind no real voice, but even those who can speak are not often listened to seriously. And I think there's a very, very great risk."

4.122 The sorts of risk that were identified across the councils were not only about paid carers, but also about family members. This is not solely around questions of opportunities for financial exploitation (although certainly that is part of the concern), but much more about questions of quality of life.

4.123 It was also recognised that there are positive aspects of risk, and that indeed it is inevitable that people are exposed to more risks when support is more personalised:

"I think we're allowing people to take more risks and make more mistakes, whereas I think previously we were very over-protective and were very concerned that if anything happened in our service it would be, you know, it would be our fault and we'd have to justify (...) Whereas now I think the staff and the service users are more understanding of – life's about risk, and the more risks, the more fun it is for most people."

4.124 Providers of social care had a range of responses to the development of personalisation as we have described previously. However, it was evident that there is concern that the expansion of people using PAs will exacerbate the staff recruitment and retention problems that many providers already face. If people can avoid what they perceive as the hassle of having to study for NVQs by working as an independent PA rather than for an agency or for the in-house service which requires that, many will choose the line of least resistance, as this comment highlights:

"CSCI demand certain levels from organisations where you have to put your resources and things in (...) I don't think it is best served for the staff or the service users. Whereas if you are a personal assistant for a person, it's alright to be a 'cannibody' (...) so I don't know many Mrs Cannibodys who want to come to work, have to do an NVQ, have to go through all of those hoops."

(In-house team manager)

4.125 The choice that some workers may make to work in a less regulated sector can also have more sinister aspects, and as some interviewees recognised, there are dangers of creating the conditions in which someone who is determined to seek out vulnerability will find opportunities. One interviewee observed:

"Of course there could be loads of people who are perfectly alright and are caring, but there are other people out there who get themselves into positions. It's like the analogy with the paedophile isn't it? They get themselves in a position to have access to children."

(Care manager for older people)

4.126 Although the issue of risk was widely articulated across the councils, there was little evidence that clear risk strategies designed to address the move towards personalisation were available or in the process of development. This is consistent with the findings in several CSCI inspections:

“Approaches to ensure appropriate consideration of additional risks associated with self-directed care were under-developed.”

“Not enough thought had been given to protecting people using self-directed support. CRB checks on potential employees were not offered automatically to each vulnerable person, but only if they specifically asked. There had been no strategic consideration of the council’s duty of care versus the less formal arrangements that self-directed support brings.”

Advocacy and support

4.127 Advocacy services were under-developed or in the process of developing in most of the councils. Independent advocates are typically involved where people with complex needs have no one to support their interests from their family, or if there has been a dispute between the local authority and family members and a neutral perspective is required, but there was a general recognition that more services are required to meet the range of people’s needs. The lack of adequate services was explained in one council:

“There’s absolutely no interest locally at all. We have no strong advocacy groups or user groups; we’re having to develop those all the time.”

4.128 Without a strong tradition of user-led organisations in this council there was nothing to build on and stimulate to develop advocacy or brokerage roles. It is also the case that there is considerable uncertainty about what these new roles actually entail, and particularly how they differ from care management or social work responsibilities. In councils where ‘robust organisations’ exist locally and have a long history, there is a greater range of models of support, including instructed and non-instructed advocacy,⁶⁷ professional advocacy and citizen advocacy (the latter model of support uses trained volunteers to support people). As this advocacy worker described, the volume of demands on the service was unmanageable:

“A huge issue (...) is the lack of capacity that we have to meet what feels like the tip of an iceberg of advocacy need (...) we spend too much of our time turning people away; trying to signpost people and not finding anywhere to signpost them.”

4.129 While there may be specialist services – for example, for people with learning disability – to which referrals might be made, this was rarely the case for

67 Non-instructed advocacy supports the interests of people who do not have the capacity to ‘instruct’ their advocate or cannot articulate their preferences.

advocacy for older people, or for people with physical disabilities. A lack (or misdirection) of advocacy support has also been found in some recent CSCI inspections:

“Advocacy support was not routinely available or offered other than for people with learning disabilities or those eligible under the IMCA service.”

“Advocacy capacity in general was somewhat limited. A relationship of trust and learning was lacking between some adult social care teams and advocacy agencies.”

“There was some evidence that independent advocacy services had been made available where necessary, although few people who use services were aware of advocacy services even in circumstances where they would have been appropriate. This was not consistent with the transformation agenda.”

“Significant investment had been made in one-to-one advocacy services and this had empowered service users in some situations. However, the service lacked strategic direction – it was not focused on those with most need or in the most vulnerable or unpredictable situations.”

- 4.130 People distinguished between advocacy that could be required around major decisions that might involve the IMCA service (Independent Mental Capacity Advocate) and more 'routine' or ongoing advocacy. Examples of the former might include decisions about whether a person should have particular medical treatment, or whether they should move into residential care. However, this is different from the situation where people might require ongoing support, for example:

“I think for a lot of people with complex needs who don't have close family members shouting their corner for them (...) you know, who is the consistent voice for those people?”

- 4.131 In another of the councils where a national advocacy group is very active concerns were also identified. While this person welcomed the opportunities around personalisation and recognised the capacity it had to change people's lives, there were nonetheless some worries:

“How people will be supported through that process now because in terms of advocacy, you can work with people when there's an issue, but we're not there to work with people on an ongoing basis until there is something they need us to be involved in supporting them to speak up about.”

- 4.132 There are important differences between models of citizen advocacy and formal 'best interest' advocacy processes, which can present advocates with some challenging situations, as this person described:

“It's not our business to look at best interest; it's the professionals, the decision-makers that are supposed to work from a best interest point of view;

ours is to look from the perspective of the client. Now that isn't always the same thing, but one hopes that mainly it is."

And

"The difficulty we face obviously as advocates, we are not best interest advocates; we are not IMCA. We are there whether we think it's a wise decision or not (...) if I was taking the best interest position, I might be advising or talking through with this person that there might be other solutions to the problem."

- 4.133 As this interviewee described, it is entirely possible to support people with complex needs and to ensure that their preferences are being addressed, but such work takes time and has to be skilled:

"We have learnt a lot from looking across the country at (...) how to support people through those risk kind of areas. Making sure it's supported; making sure they are safe. And even for people with the most complex needs (...) once you have worked with people and got to know them really, really well, you (...) do know what's making the person happy and what's making them unhappy."

(Learning disability services manager)

- 4.134 Some advocates expressed their concerns and uncertainty about the implications of personalisation developments. Some of these concerns relate to wider questions of risk and whether people using personalised budgets are at greater risk of being dominated by close relatives, for example:

"From that point of view yes, we feel it could lead to more dependency on the family and more families pursuing their own agenda."

- 4.135 Other uncertainties concerned the place of advocacy in the future and how it might fit with the development of brokerage services, particularly where one of the core principles of advocacy is seen as *"it's free and freely accessible"*. If paid brokerage develops it may be that advocacy is recognised less and less as a need, but arguably the two roles are different, albeit with some overlap. In one of the councils which had piloted *In Control* models problems had arisen because a service that had been identified to provide support and brokerage was also a service provider who recommended that people buy their services. Not only were there some conflicts of interest, but people using the brokerage resented the amount of their money that was being deducted, as this comment illustrates:

"We have done a lot of work with carers and individuals are brokering their own packages. The people in the pilot have realised they got very little for their money because they paid for their brokerage as well in the pilot. They have looked at it and thought, well I could do that; I paid you £2,500 and actually you did nothing that I couldn't already do!"

(Learning disability team manager)

4.136 One of the five councils had established an arrangement with a Centre for Independent Living to manage all Direct Payments on its behalf. However, this support service is different again from either advocacy or brokerage but is concerned with providing people with the advice they need to operate a Direct Payment, and if necessary to provide a payroll service for people who choose not to act as direct employers of staff. In future this service might develop into brokerage, or might want to be involved in accrediting brokers to help people in choosing how they go about finding a broker that is best suited to their needs. This raises wider issues about the role of regulation in the new personalisation agenda and whether and how new roles, including brokerage and advocacy, should be regulated.

4.137 In two of the councils in-house brokerage was operating for people using personal budgets. As a director of adult services explained, this was a pragmatic response that enabled best use to be made of staff skills:

"We've got a whole workforce of people who are trained in social care, who like doing it, who understand it and who'd quite like to work in this new way, please, if given half a chance (...) we can't have both – we can't have independent brokerage and a whole workforce."

4.138 With some notable exceptions advocacy services typically were acknowledged only in passing as important to the personalisation agenda. However, it is apparent that this is a complex territory and involves some highly skilled work. There is a popular assumption that advocacy is just about giving people support and advice, but this is in many ways the precise opposite of what it actually entails, as this advocate explained:

"If people can instruct (...) perhaps it's very unwise choices they're making, but what we would be doing is taking people through understanding their issues, getting the communication right with that person, getting them to think through all the different options, and trying to help them independently just make a decision that they are really comfortable with, with access to independent information, and that's different from having advice (...) what one hopes with advocacy is that you get clients in a much better position to be making the choices they want, and that's different from actually giving them advice (...) for us, we're very clear that we don't say what is the best option."

4.139 In all the councils involved in the fieldwork it was reported that advocacy services were under considerable pressure, and demands were managed via waiting lists. For people who needed immediate support in planning their lives this was far from satisfactory. People with complex needs, particularly where these included communication difficulties and cognitive problems, require highly skilled and specialised advocacy. Many parents and relatives interviewed in the study commented to us that while their child might have limited or no verbal communication skills, they understood a lot of what was

said, and people who knew them well could interpret their behaviour and non-verbal communication and know what their preferences were. When people act in what they believe to be the best interests of a person, they do so from a position of trust. However, as we have described previously, not everyone is as well motivated, and in situations where relatives are less engaged with a person, or have different objectives, or are simply absent, the best interests of the person needing support can be jeopardised.

4.140 Most people we spoke to who were using Direct Payments or personal budgets had assembled support for themselves, or with the help of strong families, with minimal support from any other parties. Advocacy or brokerage were rarely identified as central to people's plans. This does not mean that they are unimportant, rather it suggests that they are relatively unknown. The contribution that could be made by advocacy and brokerage support remains an unknown quantity at this stage. What *is* evident is that there is a clear role for highly skilled interventions in helping people with complex needs to navigate the support they need; there is also considerable scope for people to have greater knowledge of what might be possible and what exists, or how to judge the quality of their experience if they do access support. Certainly some people's experience of brokerage suggested that they would have been just as able to manage things on their own behalf, and would have been in a better financial position if they had done so.

Flexibility and accountability

4.141 Finally, we turn to consider the balance between flexibility and accountability. This was a recurrent theme in all the fieldwork sites and was recognised as an area of tension in all discussion of personalisation. In all the councils it was acknowledged that public money needs to be used responsibly, but most people also favoured a light touch audit process to ensure people could maximise flexible use of Direct Payments. These positions were not always easily compatible. The following comments epitomise the difficulties:

"There is always going to be one or two that are just going to take off with a Direct Payment and you don't see them again and you never get your money back. And there is always going to be families that maybe because the person could be vulnerable, who take the money. But it is going to have to be audited really isn't it?"

(Learning disability, team leader)

"I think the dilemma for services is (...) being able to move back and say right, let that person be in control you know. I still think there is an issue around well what's the money being spent on? What's the service definition?"

(Support worker, Transitions)

4.142 Guidance issued to auditors by the Audit Commission in October 2008 recognised the need for proper arrangements to ensure accountability for public money, but stated that the responsibility is on councils to have such arrangements, and therefore:

"If payments are made under lawful powers and in accordance with relevant statutory and professional guidance and there are proper arrangements in place then how the payments are spent is not a focus for audit work."⁶⁸

Auditors are urged to focus on the effectiveness of the authority's arrangements to review, approve, allocate and assess such monies.

4.143 It was recognised in our councils that spending Direct Payments on activities or support that bears little resemblance to what people would recognise as 'services' or even as 'social care' is at the heart of these dilemmas around accountability, but whether that spending achieves the desired outcomes for people is the most important question, for example:

"I think provided that we are as clear as we can be that we are meeting an assessed need, I would argue it doesn't matter so much how that assessed need is being met. And I would like to see a whole lot more flexibility and a lot more autonomy."

(Team manager, physical disabilities)

"There are some rules and regulations about what we want and what has to be achieved by using this resource. And I think for us, we have looked at sort of global statements – as long as it's not illegal what you are doing; as long as you are looking to improve the person's social inclusion; improve the person's opportunity for employment; improve the person's social relationships and maintain and develop those relationships; improve their housing opportunity. As long as we can see the package and the support fitting under those headings – then I think we should be able to hopefully, have the discussion with the wider community about why maybe it is right to do that."

(Team manager, learning disability)

4.144 The two comments above represent one end of a continuum of views; other people struggled with this liberal interpretation and tended to see the budget for Direct Payments in traditional terms where different elements needed to be identified to pay for particular aspects of support, as this person remarked when commenting on the possibility that a person might go on holiday to Tenerife rather than going into respite care:

"Well I don't know which bit you would pay for with a Direct Payment. For the support you mean? To take a support worker with you. Because you couldn't

68 Audit Commission (2008), *Individual Budgets and Direct Payments*. Audit Commission guidance to appointed auditors.

pay for someone's board and lodging in Tenerife for a week from public money could you? (...) I think people should pay for the holiday bit of it."

4.145 Others believed that it made no sense to have to account for Direct Payment money separately, and that there was a case for simply giving people the cash as if it were a benefit and leaving them to sort out what they used it for:

"It is not beyond me to say that 20 years down the line people will be getting it as a Giro and we [social services] won't exist (...) it is a perverse thing to say that you can use your benefits to buy that but you cannot use this pot of money, because for you or I it would just be the same pot."

(Head of learning disability)

4.146 The balance between flexibility and accountability was work in progress across all the councils in relation to all people using more personalised support, including people with complex needs. In the absence of any clear guidance beyond some general principles about how money could or could not be spent, most councils were taking a pragmatic approach. However, it was also evident that flexibility typically reflected the particular understanding and ideological approach of individual staff. The style and culture of each council that was set by the executive team either created the pre-conditions for personalisation to flourish, or ensured that it would develop incrementally and cautiously.

Conclusions

4.147 In this section of the report we have explored the operational issues that were being addressed in developing support for people with complex needs and how this was being approached in the context of personalisation, and in addressing issues of independence, wellbeing and choice. Below we review the key findings that have emerged.

Assessment and care management

- Much assessment and care planning remains deficit-based and concentrates on what people are unable to do rather than understanding them as individuals with a range of strengths and qualities.
- Examples of good practice in person-centred planning were identified (particularly in developing individual communication passports) but it was recognised that in practice the quality is variable.
- The transition between children's and adult's services raises particular issues about the importance of good assessment and care planning.
- Self-assessment was bringing a new dimension to assessment and care planning and was at different stages of development.

- In many ways self-assessment was viewed as a misleading term since this implies that a person undertakes their assessment with no support. In practice, and particularly for people with complex needs, self-assessment entailed intensive support from care managers. The result was seen as a better outcome, but it was more demanding of staff time and skills than traditional professional assessment.
- The five sites were at different stages of development in addressing self-assessment in the context of personalisation and RAS development. In all sites there was an evolution of approach and of models.

Direct Payments and Individual Budgets

- The approach to Direct Payments is one indicator of how councils are promoting choice and independence, although this does not capture the breadth and depth of engagement with personalisation.
- While there was broad support for the principles of independence and choice, this was qualified by certain reservations, including doubts about the applicability of the model across all client groups, particularly in relation to people judged to have 'chaotic lifestyles' and people with severe learning disabilities.
- The rate of development of Direct Payments historically often reflects the approach and attitudes of specific members of staff and how actively they have encouraged take-up. Historically in at least one of the sites, Direct Payments had typically been offered only to people who were dissatisfied with mainstream services.
- There is a significant minority of people using services, and of carers, who are hostile to the idea of Direct Payments or personal budgets. These objections were often based on a fear of being left to cope with inadequate support, a misunderstanding of the implications of personalisation, and a reluctance to take on what were seen as onerous demands.
- People with complex needs are using Direct Payments in a variety of ways – from simply fine-tuning conventional support packages to developing highly creative and individual support.
- Moving from Direct Payments to new models of personal or Individual Budgets was generally approached on a pilot basis as a foundation for wider roll-out. Most pilot activity had focused on developing alternatives for people with learning disabilities, or for young people in transition.
- Scaling up from pilot development to wider transformation creates many difficulties about the pace of change.
- In all the councils there was frustration that – at the time of the fieldwork – the national evaluation of the IBSEN project had still to be published. People were anxious to learn from experience and were concerned that useful messages were not being shared.

- A significant minority of council staff expressed scepticism about the Individual Budget model and the *In Control* approach which they did not believe had been adequately tested in supporting people with complex needs. Many of the best-known success stories emerging from the Individual Budget projects were believed to feature articulate people with relatively simple needs.
- Restrictions on the use of Direct Payments were often seen as inappropriate and unfair, particularly by people using services and by their families who favoured greater flexibility.
- The rules restricting Direct Payments to people who have capacity to consent have limited developments for some people with complex needs. In some sites councils had found creative ways around these legal impediments (such as through user-controlled trusts) and are well placed for moving ahead in the wake of the relaxation of rules following the Health and Social Care Act 2008.
- There is considerable uncertainty in the development of personalisation and for some providers this environment was a worrying one, while for others it was a time for identifying new opportunities as well as risks.
- Personalisation is not just about Direct Payments or personal budgets and some councils were also addressing how choice and control could be enhanced for people who were not using Direct Payments, including people living in residential settings.
- In all the councils in the study, and also in the Individual Budget pilot sites, concerns were expressed about equity between different groups of people who use services. Most concern was expressed about the more limited opportunities (and financial support) available to older people.
- Inequities have not been caused by personalisation developments, but they *are* rendered more transparent by the RAS process.

Range of services

- Whether there is a sufficient range of services available to support choice and control was a major theme and concerns were identified over limited, traditional and insufficiently flexible services.
- A significant proportion of people with complex needs using services, and of their carers, were highly conservative in their service preferences and resisted attempts to reconfigure support – particularly day opportunities.
- For carers in particular the reliability of a building-based day service is central to them being able to cope and to know that the person they care for is safe and ‘looked after’ for a large part of the day.
- Some of the attempts to modernise services have been unpopular and are not believed to offer good quality support, particularly for people with the most complex care needs. However, new approaches have also

enabled people to get into the community and participate much more in ordinary activities. Readiness to use more innovative services is likely to develop over time as experience and confidence develop.

- Typically councils were having to double-run traditional and new models of support and to approach the transition between the two with caution.
- Recruiting people to work as PAs raises many challenges particularly when the social care workforce is under considerable pressure. However, many people using Direct Payments had adopted innovative approaches to recruiting PAs and were engaging people who did not come from social care backgrounds, but were drawn from the wider 'social capital' of their local community.
- Pressures on day services also reflected reduced service availability in other areas, particularly in the more limited availability of education opportunities because of reduced LSC support and the requirement for courses to demonstrate progression, which for many people with complex needs would not be possible.
- Many of the success stories in using Direct Payments and personal budgets for people with complex needs featured new patterns of ambitious support often developed with the help of exceptional caring families and of visionary and committed care staff.

Support and advocacy

- The balance between choice and control on the one hand and increased risk on the other was identified as a concern in all the councils. Many staff identified worries that personalisation will increase the vulnerability of some people by exposing them to greater risk of exploitation and abuse, both by family members and by the wider public.
- Some staff pointed out that because Direct Payments enable people to buy support in an unregulated market, unscrupulous people will deliberately seek out these more vulnerable people and work in a market where they will be less easy to detect.
- The personalisation market also has the potential to exacerbate the workforce challenges confronting social care providers because some staff will migrate to a sector where there is more flexibility and potentially better remuneration (because of lower overheads).
- Advocacy services were generally under-developed in all the councils (with some notable exceptions), and demands were managed by crude waiting lists.
- Advocacy is more likely to develop where there is a strong local tradition of user-led organisations.
- There is considerable confusion about different types of advocacy and how it differs from brokerage.

- Some people using personal budgets have been obliged to buy brokerage services which they have experienced as costly and irrelevant. Who should pay for this service is an unresolved issue.
- Advocacy generally exists to address specific issues and *not* to provide ongoing support. Who should provide this support is also a matter that is the subject of debate, and in some councils in-house brokerage was attempting to use the skills of care managers to provide ongoing support and service navigation.

Flexibility and accountability

- In all the councils in the study it was recognised that there are tensions between maximising flexibility for people using services while also ensuring accountability and appropriate use of public money.
- Across the councils people expressed all shades of opinion on such matters, from the most liberal interpretations of allowing any use that was not illegal or immoral, to others who struggled to see beyond any use of money outside of traditional service categories.
- The balance between flexibility and accountability was continuing to evolve but there was growing recognition that the most important criterion for judging appropriate use of resources should be whether or not it addressed the assessed needs of any person and delivered the agreed outcomes.

5: Conclusions

- 5.1 Throughout this report we have highlighted our key findings, and there is no virtue in repeating that exercise. Rather, our conclusions return to reflect on the central question of our investigation: how are councils and other agencies responding to people deemed to have complex needs, are those needs properly addressed, and how are they being approached within the new personalisation agenda for adult social care?
- 5.2 There is one overriding, if axiomatic, message that dominates this special study: that people whose needs are multiple and complex require correspondingly multiple responses from a wide range of professions and agencies if their needs are to be properly met. Often this requires complex interaction, but the experience of the person receiving support must be one of coherence and integration. Effective partnership working can be difficult to achieve at the best of times, and these difficulties will increase in line with the number of interstices to be managed. They will also increase in line with the growing recognition of the multi-faceted nature of individual needs and aspirations, and of the moral obligation to acknowledge human individuality, all of which are inherent in any attempt to deliver genuine personalisation.
- 5.3 The traditional response to these challenges has often been to ignore or deny complexity, or to address it through specialist, often remote and poor quality services. Typically, services have tended to define people by reference to dominant mono-professional norms, classify them by diagnostic label or general client group and require them to fit into existing organisational arrangements. Indeed, this narrow and unilateral approach is still very much in evidence in too many councils. Our study has given many examples of people with multiple and complex needs being categorised inappropriately by one criterion or another – their learning disability, their mental health, their physical or sensory disabilities – and accordingly allocated to one section of a council's activity rather than another, or being labelled as a 'health' or a 'social' responsibility. In some cases agencies seek to pass the costs of support (which can be considerable) on to other agencies; in all cases it is vulnerable individuals who are at risk of losing out.
- 5.4 None of this is to suggest that those who directly support people with complex needs (including frontline staff, middle and senior management) are not generally acting with proper professional concern and motivation. Indeed, in some cases, they are doing so with amazing and inspirational results. Rather the issue is that where such outcomes are achieved this is *despite* rather than *because* of the systems that are generally in place. People with multiple and complex needs stretch inter-agency partnering skill and commitment to the limit, and the evidence of this special study is that robust partnering is not routinely available. It is against this background that we have recorded some

accounts of immense human fortitude and courage, as people seek to live their lives and fulfil their aspirations, and often by circumnavigating the organisational impediments strewn in their way.

- 5.5 The service delivery fault lines identified in this study are already well known, and the contribution of the report is to have confirmed the existence of these fissures and their cumulative impact over a wide range of user and carer experiences. We have identified different views on how the issue of 'multiple and complex needs' is conceptualised, on how this is constructed as a problem, and on how it is thought it should be addressed. Running beneath these differences is a Byzantine maze of administrative, financial, organisational and professional boundaries, sometimes pulling in different directions.
- 5.6 The response of the Government to this situation has been twofold – to exhort or impose a more joined-up approach, and to promote the idea of 'personalisation'. Attempts to improve inter-organisational responses through good practice guidance, national frameworks and even legislation have characterised policy on the key fault lines around transition to young adulthood, and the link between children's and adult social care, the use of out-of-area provision and the relationship between social care and the NHS. None of these strategies could be described as entirely successful, not least because they seem to regard policy problems as technical questions, resolvable by the systematic application of technical expertise that is imposed by an executive body. The reality is altogether more complex and is mediated by numerous variables. It can never be taken for granted that policies will be implemented on the ground as intended because those responsible for doing so inevitably apply official policies in ways and places at some distance from close scrutiny by superiors, and having regard to many other influences and demands.
- 5.7 The emergence of a new policy paradigm in the form of personalisation can in part be understood as a response to the deficiencies of partnership working – in effect the Individual Budget-holder (with appropriate support where needed) takes on a personal coordinating role and is thereby enabled to focus more sharply on the outcomes most likely to improve individual health and wellbeing. Here the emphasis is not so much upon means (joint arrangements) as upon ends (or outcomes) underpinned by values (personalisation).
- 5.8 This study has explored the ways in which the emerging paradigm of personalisation is developing locally and, in particular, on its application to the circumstances of people with multiple and complex needs. While some councils are engaging with the agenda for people with complex needs, believing that if they can make it succeed in such situations it can work for everyone using social care, others are altogether more conservative and limited in their ambitions. Indeed, we found a general suspicion that the

personalisation model has, as yet, been insufficiently developed for people with complex needs and that the most widely showcased examples of success highlighted in the Individual Budget pilots and other schemes have addressed some rather 'easier wins'. While all of the councils in the study were engaging with the challenges of personalisation to some degree, all were struggling with the requirements of moving from pilot developments to mainstream operating systems. The enormity of the challenge to skill up and scale up are apparent, and even the most enthusiastic and committed councils will take many years to realise their ambitions unless significant acceleration is achieved.

- 5.9 An effective authority structure presupposes that the people operating within it are themselves internalising the rules it lays down and critically evaluating their own conduct according to its precepts, but we have found that this is far from being the case with personalisation. Whilst hostility to the principle of personalisation is relatively limited (or rarely articulated), the study shows how – in myriad ways – local stakeholders who are so inclined can dilute, defer, deflect or even simply oppose implementation, with potentially devastating consequences for people denied opportunities to maximise their independence in both small and large decisions.
- 5.10 Many commentators have used the concept of 'paradigm' and the notion of 'paradigmatic change' to describe the emergence of the personalisation model in social care. In this study all of the key stakeholders were only too well aware of the potential significance of the new approach, and it may well be this awareness that itself generated anxiety – the agenda is *so* enormous that some are simply dazzled by the glare of the lights and unable to move ahead decisively. In the scientific literature the choice between competing paradigms is portrayed as that between fundamentally incompatible modes of understanding that are not amenable to reconciliation. In this study, however, councils seem to be seeking ways of combining the established paradigm (of professional determination of events) with the emerging paradigm (of user determination of events). This is an uncomfortable and, at times, impossible compromise.
- 5.11 This 'pick-and-mix' approach might well be appropriate in this early phase where the emerging model still contains many uncertainties that will only be answered as progress is achieved. Time after time in this study local stakeholders (including people who use services and their carers) have expressed uncertainty as to how the notion of personalisation can work effectively in practice, with repeated calls for lessons to be learned and widely shared. This has especially been true in the case of supporting people with multiple and complex needs. The danger of not openly addressing the 'technicalities' of implementing the personalisation paradigm is that the legitimacy of the paradigm itself can be called into question.
- 5.12 This special study is a snapshot of an unfolding 'paradigm war', and the picture it reveals may well look very different in another year or two.

Currently the situation is mixed and messy. In some councils there are some (albeit at this stage relatively few) people with complex and multiple needs who have been supported to achieve inspirational and life enhancing outcomes through creative application of the personalisation paradigm. In others there are individuals (often carers but sometimes also people using services in their own right) who have settled comfortably for the dominant paradigm – traditional separatist provision which takes little or no account of individual needs and circumstances. And in others again there are cases of people trapped in inappropriate services who are desperately seeking greater degrees of flexibility and control.

- 5.13 Achieving change and ensuring that everyone using social care services is able to benefit from personalisation is a human rights issue, and human rights principles and approaches should underpin every aspect of the steps to personalise support to people with multiple and complex needs. This includes commissioning, service delivery and ensuring person-centred practice. A human rights approach challenges a number of attitudes revealed in this study, and offers the way forward in ensuring that all of those people who want choice, flexibility and control are supported in their endeavours, even – or perhaps especially – when their needs are so complex and their capacity to communicate their preferences is extremely limited. Anything less would constitute a betrayal of people with the greatest needs, and a failure to realise the true transformational potential of personalisation in their lives.

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CSCI-ARP-161-100-TRI-012009