

Don't be fooled by the Law

A report from In Control, following a conference held on 1 April, 2009

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Foreword

In Control is a social enterprise with the mission of assisting in the creation of communities of empowered and valued citizens, where people control their own support, their money and their lives. Much of In Control's activity since its establishment in 2003 has been focused on the task of building *Self-Directed Support*, a new operating system for Local Authority social care. As the Law Commission recently observed "social Care law remains a confusing patchwork of conflicting statutes enacted over a period of 60 years." This, together with the fact that there has been no new legislation to underwrite the Government's stated policy of implementing Self-Directed Support has meant that many citizens, families and Local Authority officers have been left in a state of confusion about the legalities of aspects of the new approach.

In Control's response to this difficulty has been a pragmatic one. Our perspective has been and remains that the present legal framework does in fact contain sufficient flexibility to *permit* Self-Directed Support – but we are equally clear that the framework is far from *helpful* in that task. We entirely support the Law Commission's desire for consolidation and reform of social care law, and have been asked to support them in achieving this. In the meantime we see it as a part of our role to provide encouragement, support and advice for citizens, families and Local Authority officers who are seeking to make full and effective use of the existing legislation.

In Control has sometimes been criticised for not giving the legal aspects of Self-Directed Support the level of attention they warrant. We believe this to be more an issue of perception than of substance. With this perspective in mind however, and in response to what felt like significant demand particularly from Local Authorities, we undertook to bring together some of the country's leading thinkers and practitioners on these issues at a conference at Old Trafford, Manchester on 1 April, 2009. We also undertook to use the conference to review, refresh and re-launch our approach to legal issues, and particularly to improve the way in which we use our web-site and other communications media to further debates and to provide helpful legal advice. In that spirit, this document aims to be something other than a conventional conference report, and indeed to provide a useful resource for those doing battle with these issues on the ground. Given the state of the legislation alluded to above, we are not seeking to provide legal advice or opinion – we are not lawyers at In Control – but what we do wish to do is to share best practice, and amplify the ways Local Authorities are working with the existing legal framework to promote choice and control.

We are very much aware that these matters are far from "cut and dried." As we found at the conference itself there are many views and perspectives. In Control's approach is what is sometimes called *heuristic* – that is to say we discover things by testing them, and it is in this spirit that we ask you to consider the contents of this report. We intend to run a second conference on legal issues later in 2009. As optimists, we hope to be looking back on significant progress and growth in understanding of these matters by that date.

The report begins with an introduction by Simon Duffy, the former Chief Executive of In Control. This is followed by a series of questions and issues, with proposed answers and examples of best practice; this section concludes with information about the In Control website and background about the conference. You are also referred to the document *Reforming Social Care Law* by Simon Duffy. This sets out how In Control's important Statement of Ethical Values might influence reforms to social care law. The questions and issues section is based upon the keynotes, workshops and Q&As from the conference in Manchester, and on the experience of In Control members.

Introduction by Simon Duffy, Chief Executive* of In Control Partnerships

When In Control began life in 2003 we were asked by our Local Authority members to design a new operating system for Social Care which (a) didn't cost any more money and (b) which was legal. Now of course if you believe that the current system always spends money in the best possible way and you believe that the current law only allows Social Care to be organised in one fixed way then this is an impossible challenge. However what we have found is that there are better ways of spending money and that the key to doing this is to give people more control, and that it is legal to give people more control.

To meet the first challenge In Control found ways of changing the way decisions are made. By making information about resources more transparent and by giving people the means to make more decisions for themselves or with their family and friends then the quality of decisions has improved and so has the efficiency of the system.

To meet the second challenge In Control found new ways of organising things which fitted within the overarching structure of the law. In particular In Control encouraged Local Authorities to see that old forms of practice cannot be the only way, and are often a very poor way, of meeting their moral and legal obligations. Here are just a few examples:

Assessment - The old form of assessment was been that a care manager would gather large amounts of information about someone and then write a care plan detailing how the person will be supported. But this is not always the most effective assessment process. In Control has demonstrated that the quality of the assessment increases if (a) people can be given a reasonable indication of what funding they are likely to receive and (b) people are able, with support where necessary, to develop and design the support solutions to fit their own lives. This re-thinking of assessment is not a denial or abrogation of the right to an assessment - it is an attempt to meet the duty to assess properly.

Equity - Local authorities also have duties to ration their resources fairly and reasonably. Yet the old form of rationing has led to highly inequitable distributions of resources where there are no transparent principles for allocating resources, high thresholds to support and enormous inequalities in what people

actually receive. Instead In Control has worked with Local Authorities to develop systems that make transparent how decisions are made while allowing for appropriate flexibility.

Control - In the old system there were typically only two control options: (a) services are purchased or organised for you or (b) you are given an amount of money (probably less than you would have had if the service was pre-purchased) and a little bit of support to employ your own staff. In Control's view was that this was an entirely unsatisfactory and unnecessarily extreme choice. Many people want friends or relatives to manage their funding, many others are happy for professionals to manage the funding but want more flexibility in how the funding is used. By opening up other control options we have found that each individual can find the right form of control for them.

Interestingly the law is sometimes perceived as an obstacle to some of these improvements, and sometimes it is seen as spur to make these improvements. In fact sometimes Local Authorities who are nervous about making these changes have found that the threat by citizens that they will take the authority to court for failing to give them choice, control, flexibility or appropriate resources has helped the Local Authority introduce the new improved system.

For in fact Self-Directed Support, at bottom, has always been a system with one fundamental design principle - to ensure that the Local Authority is equipped to do the very best possible for those people who need extra help in our communities. It is because Self-Directed Support enables Local Authorities to fulfil their fundamental duty of care that we have seen so much progress over the last few years. As one Director of Social Services put it to me recently, "You don't often get sued for doing the right thing." And it is for this reason that it is highly likely that any case law that emerges in the years ahead will underline the imperative to shift away from the old system that demonstrably fails to do the best by people.

But having said all of this the problem of the law and the relationship between the law and Self-Directed Support is likely to be an on-going problem for some time. There are at least four reasons for this:

Laws don't tell you what to do - Law are sets of rules or principles which people are meant to follow. This does not mean that laws can tell you what to do. At their best they may tell you what not to do or tell you what 'kind of thing' you should do. But laws are always too general to be the only guide to action. Laws provide a framework within which we make specific judgements and they always require some 'interpretation' in order to make sense.

Laws often conflicts with each other. The Community Care Law and the Disability Law often conflict with each other and therefore do not always offer protection to disabled people. The present legislation around Social Care and Disability discrimination is piecemeal often leading to confusion and complexity. It is so complex that Local Authorities are faced with challenges that conflict with Social Care Law. In an ideal world the Law would benefit the disabled community to have one universal piece of legislation to cover all aspects of Social, Health Care and Disability Rights to gain the best protection and equality for disabled people to give an independent life.

The Law is sometimes wrong - It is an obvious but important point that laws are not always good or right. This is the reason why have a parliamentary system which enables us from time to time to reflect on our own systems and make sure they improve. For instance many of us feel that the Law, as it stands, does not make it clear enough that people who are frail or who have a disability are thereby entitled to support. If the Law is not right then it will not be surprising that good people will seek ways of interpreting the Law so that it can be as good as possible within what is legal.

The Law is almost always out of date - A less obvious problem, which applies much more to the Law around welfare services than it does to Criminal Law, is that positive laws, laws which try to dictate what things are to be done and how they are to be done tend to go out of date because society and our understanding of best practice tends to change much more quickly than the Law. We see this everywhere in Social Care Law from old references to "workshops... and hostels" up to current assumptions about the meaning of a "Community Care Assessment". The Law is usually written by people who are not disabled and who look on, from some distance at systems that are constantly changing, and people rely on models of best practice which are quickly out of date.

Social Care Law is deeply incoherent - In addition Social Care Law has some extra problems which have arisen by the fact that the older attempts to reform it have been partial and multi-layered. It is not at all clear what the fundamental principles of Social Care Law are, nor which piece of legislation applies when, as the Law Commission states: "There are numerous examples of the tortuous complexity of adult social care law." (p. 21)

It is for this reason that In Control is keen to work with all its members to support the Law Commission in its work to reform Social Care Law. And it is important, in the meantime, that when our members make decisions about what they think they can and cannot do that they return to the fundamental question - if you introduce these reforms are they more or less likely to help you do the best possible job.

I would like to encourage all our members to read this useful report and to have the courage to make the necessary changes. Our experience to date is that, even in this confused legal framework in which we operate reform is not only possible, it is necessary.

^{*} Simon resigned as Chief Executive in June, 2009.

Some Key Questions and Issues

The following questions were all raised in one form or another at the conference. They are also the questions that recur in our discussions with Local Authorities and others. Sometimes we have combined similar or overlapping questions that cropped up more than once, and occasionally we have re-worded the question to try and get at the real sense of what is intended. For these reasons we have not tried to attribute specific questions to individuals. Usually one of the expert speakers sought to provide an answer, which we have tried to capture, but again we have sometimes attempted to combine what was said, and therefore once again have not attributed comments to named speakers. We have usually next given In Control's view of best practice in Local Authorities (which may sometimes differ from the advice of the speaker). Sometimes we have also felt the need to set out how we might see the Law operating ideally – perhaps after the Law Commission has proposed its changes and Parliament has enacted a new law.

Q1. Does the Resource Allocation System dispense with the need to apply Fair Access to Care Services (FACS) criteria?

No, as things stand all Local Authorities have to make use of FACS. Resources for individual social care applicants —whether allocated through the Resource Allocation System (RAS) or through any other method — can only be provided for "FACS-eligible" persons. This means that Local Authorities currently need to have some means of screening people to ensure that those being assessed under a system of Self-Directed Support are "FACS-eligible."

There does, of course exist a separate system of small grants for Third Sector groups. There also exists the Well Being Powers of the Local Authority, which empowers Local Authorities to do anything which they consider is likely to achieve the promotion of economic or social well-being or of the environment of their area. (see more below on the Well Being Powers, and see the paper by Essex CC on the In Control website).

In Control's view is that FACS is not in fact "fair" and should be abolished, and that a RAS should become the single, clear and transparent way of determining the indicative resource allocation for individuals. Local Authorities set criteria in which a disabled person has to meet those criteria to qualify for care services.

Often the criteria are set at Substantial or Critical and often disabled people will not qualify for services even though they are deemed disabled under the Disability Legislation. This approach clearly conflicts with the Disability Discrimination Act 2005 (Section 49A) in which Local Authorities must have "due regard" to disabled people when considering their policies and procedures, so in fact can be challenged. See below for more on this.

Q2. Is Self-Assessment illegal?

Several speakers reminded the conference that Local Authorities have a duty under s 47 of the 1990 NHS and Community Care Act to assess, and that duty cannot be delegated. If pure Self-Assessment is seen as the sole means by which they discharge that duty then it is illegal. It was suggested at the conference that Local Authorities could be deemed "potentially negligent" if they do in fact "delegate" in this way.

In Control proposed several years ago now that we re-think this whole issue, and see the statutory duty to assess in a different light. Perhaps the simplest way of describing the revised approach and one which meets the criticisms noted is as a full **Self-Directed assessment** - a process that incorporates both the **Resource Allocation** and the **Support Planning** elements of the seven step model. It is thus fuller and more person-centred than the traditional approach. The assessment duty is most certainly not "delegated" in any crude way. This approach is one whereby citizens are empowered to articulate both their **needs**, and the **ways in which those needs might best be met**. Local Authorities retain and strengthen their capacity to allocate resources in a manner which is fair and equitable. Many of our Local Authority members have adopted an approach of this nature, and with their help we continue to test it and to modify the detail.

For these reasons, In Control now suggests that in those places where they have been used, we drop the terms "Self-Assessment" and "Self Assessment Questionnaire" as inaccurate, unhelpful and confusing.

We now suggest that we move towards an alternative term, perhaps "Needs Questionnaire", to describe what the questionnaire is for.

In reality, very few Local Authorities have elected to describe what they do as "pure" Self Assessment, most taking the very sensible view that citizens need significant *support and guidance* to make sense of their own needs even before they reach the stage of Support Planning, and that this support should be tailored to individual circumstances. Like much else with the model, it should be *proportionate* - Cambridgeshire, for example use the term *Support Questionnaire*. To quote another example, Hampshire County Council recently spent some time reviewing processes and paperwork following a pilot in Basingstoke, and as a result agreed a Supported Self-Assessment process which retains a very clear role for the care manager: this is not so much "delegation" as a sharing of the task in a way which involves people more completely.

Sometimes Local Authorities worry that if they allow too much leeway through the assessment process some people will "over-state" need in order to get

a higher allocation. There is also an equal and opposite concern that many others (perhaps older people especially) tend to under-state their need and thereby lose out. In Control's view is that this is one of the areas which does need legal clarification. In Control has certainly never intended Self-Directed Support to operate perversely for older people, or anyone else. Ultimately, Self-Directed Support is built upon the bedrock of a simple and transparent system of assessment and resource allocation, and to work effectively such a system does reauire an element of "delegation" to citizens and families – together with the provision of whatever support and advocacy they may need to make this effective.

There is a specific issue about people who are deemed to lack capacity and their ability to make their wishes known through the assessment and support planning process. In Control has always been clear in our Guides and supporting documentation that each individual should have the appropriate level and style of support that suits him or herself at each and every point in the process. Many people need someone to help them with the first stage of the assessment process, and some are reliant on someone else to actually speak for them: it is then important that this fact is recorded by the Local Authority. Everyone – not just those who "lack capacity" - needs guidance and outside assistance in writing a support plan. In Control has been particularly insistent that such support must be available for those people who find it most difficult to make and articulate decisions and choices. Much of the early work of In Control focused on how best to work with these groups in ways that are truly flexible and person-centred, and the relevant documents and many personal accounts remain available through our website.

Q3. The law says that Local Authorities need to "meet assessed need." There can be no financial ceiling, such as that proposed in In Control's Resource Allocation System. Does this not make the RAS illegal?

No, this is based on a misunderstanding of how RAS is intended to work, and how Local Authorities are using it in practice. In Control has been clear from its inception that the RAS allocation is *indicative* – that is to say it provides a helpful indication of what resources might be necessary and appropriate, and in giving this indication it enables people to start making realistic plans, based on a realistic budget. The RAS does not provide a "ceiling," and there are many instances of circumstances where people have ended up with more than their indicative allocation - or indeed less, where they genuinely don't need it. This is entirely appropriate. One conference speaker made the entirely proper point that if the RAS is used in this way, then Local Authorities must put in place a "transparent process that is procedurally fair" to scrutinise RAS outcomes and agree final allocations. Just such processes are now in place in Local Authorities – and whilst they do of necessity share some features of the old Panels (ie they make final decisions about funding levels), the basis on which they make these decisions and the criteria they apply are very different.

The above is well illustrated through data from Hartlepool, which we will publish later in 2009. This data shows very marked variances between (1) initial desktop estimates of costs (2) indicative allocation using RAS (3) actual allocation,

following the Support Planning phase. Most interesting of all perhaps, these differentials themselves differ across groups of people, with older people and people with physical impairments finding that the RAS allocation was often much more generous than they required, and people with learning difficulties finding that it was not generous enough. There are clearly implications for both RAS levels and for the market, but the key point for us to note here is that the RAS is not operating here as a ceiling in the way that critics suggest it does — rather, it is an indicator of funding levels and a means to ensure that citizens needs are met fairly and proportionally.

We can also pick up here another objection made at the event – that "self-assessment" (see above) means that those who are articulate and powerful get more. Such unfairness has in fact been a very evident feature of the old system, as demonstrated by the baseline data and personal stories collected by In Control from many member Local Authorities and highlighted in the Phase Two report. A strong RAS on the other hand smoothes out the peaks and troughs in the allocation of resources, and an effective and open system to scrutinise and signoff indicative allocations provides flexibility and realism. If the outcome remains that powerful, articulate or influential individuals are indeed allocated more resource, then this is contrary to In Control's Statement of Ethical Values, and our advice to Local Authorities is that they then need to look to revise local decision-making processes.

There will always be situations and circumstances that are not captured by the RAS: it is at least as much art as science, and we continue to accumulate learning as more people are guided through the process in more places. For these reasons, In Control has recently begun to suggest that Local Authorities consider putting in place a standing RAS Overview Group as a means to keep oversight of process and budget, and to ensure that decision-making is sound and consistent in ways which will conform to Disability legislation.

Q4. In Control talks a lot about choice as well as control, but what choice is there when there are only limited services to buy?

This is not really a legal issue, but it is one which was brought up in one of the presentations, and one which is often raised as an objection. It is of course self-evidently true that choice depends upon being able to access options, and this is an issue in some places where the pre-existing system (ie prior to Self-Directed Support) has meant that there are sometimes limited options available to care managers or Local Authority commissioners to place in front of people.

But the evidence from those areas that have introduced Self-Directed Support is now clear: limitations in markets have most emphatically not prevented people achieving the outcomes set out in their Support Plans. Hugely encouraging self-reported improvements in quality of life were described in In Control's Second Phase Report, and we are now beginning to capture very detailed local experiences, such as that in the counties of Cambridgeshire and Worcestershire in the reports recently published on our website, which illustrate the breadth and variety of solutions that ordinary citizens are able to devise.

There is little doubt of course that the focus and style of much social care provision does need to shift, and what is required is a greater range of smaller, more local, better connected services that people really want to buy. In Control's Provider Network and the recent NAAPS micro-provider project in Oldham and Kent are both attempts to nurture such developments. Whatever the proposed solutions, lack of choice is clearly not a consequence of Self-Directed Support as a model operating system: in fact Self-Directed Support of itself seems to be an effective lever in beginning to influence and open markets in very positive ways.

Q5. In reality the RAS is rarely transparent. Sometimes there are multiple versions of the Self-Assessment completed ("user," "carer," "care manager"), and then all the power is in the hands of the Local Authority to interpret this data and allocate resources as it wishes.

Of course, any system is open to abuse and in a situation of budgetary pressure it would be remarkable if there were not examples of Local Authorities which found ways to make use of the reformed system to achieve short-term savings in ways which conflict with the Disability Legislation. Sometimes, individual managers who are under pressure to deliver savings targets do this, on other occasions there is little doubt that SDS is seen from on-high as a way to contain costs, and little more than this. This is extremely sad. In Control is absolutely adamant that it is unacceptable, and we are equally clear that it is not the Government's intention in its Putting People First policy. Where we encounter such bad practice our approach is firstly to remind the Authority concerned of the Statement of Ethical Values which they agree to on joining In Control –this is the bedrock of all our work – and secondly to offer advice and guidance as part of our leadership development programme, and thirdly to thirdly to advise them that they are liable to challenge under the Disability Discrimination Act 2005. If a Local Authority is challenged under this legislation, it may well be faced with Judicial Review Proceedings which will cost large sums of public money.

Q6. In Control's system relies on families and (especially) on women staying at home to provide unpaid care and support. It is basically conservative and sexist.

In response to this: firstly it remains clear that Local Authorities must satisfy themselves that "carers" are willing and able to care – or "to provide support" as we prefer to see it. Authorities need systems and processes to do this under the old system, and Self-Directed Support does not change this. Secondly, we might observe that in reality SDS, with its championing of open discussion and real citizenship for all (including women and other family members) prevents the sort of "guilt tripping" and "moral blackmail" that women sometimes find implicit in the Carers' Assessment process. Once again we refer to the In Control Statement of Ethical Values.

One conference speaker reminded us of evidence that disabled people are much more reliant on family and much more cut off from community than are most other people; families have often been "there for people" when statutory services have let them down. There is no question at all that many individuals feel let down by statutory services, and that families frequently have had to go the extra mile for the person they care so much about. But this is surely no argument for

setting up systems which marginalise and exclude families – and which in doing so do, do more emotional harm than good? Our argument is that this has been precisely what the old social care system has done, featuring as it does high levels of conflict, and an over-reliance on geographically distant quasi-institutional solutions.

The comment at the head of this section about more women staying at home is very far from the self-reported reality of Self-Directed Support for women and families. They talk about the new system as liberating and empowering, and many of them are now part of a widening movement, which includes family-led organisations as diverse as Mencap, Partners in Policymaking and Our Future. See the stories section of the In Control website for some inspiring accounts of this. Finally - the grain of truth - yes In Control does advocate the use of social capital, what we call "family wealth," and the resources of community. Our perspective is that to do this, to make the most of the freely-given contribution of those who know and care about a particular older or disabled person is positive and healthy – and to work in this way clearly represents a challenge to aspects of the old bureaucratised and institutionalised care system.

Q7. The old system is not broke. In fact, rights and duties have been established in statute law and by judges over the past decades, and there is no need for reform, just to make good use of what is there.

There is no doubt that there is a lot of truth in this, and In Control is extremely appreciative of the work of legal experts, including several of the conference speakers who have brought many of the relevant judgements to the attention of Local Authorities.

The difficulty that In Control perceives is two-fold:

- (1) that whatever the flexibilities and permissions extant in the pre-existing system, Local Authorities have not been using them systematically to facilitate choice and control. The system whether "broke" or not has most certainly not been working well in practice for the benefit of citizens for many years now, as evidenced by many accounts by individuals, families, service providers and commissioners.
- (2) Whether the Law is as it should be or not is clearly a moot point. For the most part In Control believes that there are at the very least some significant adjustments needed. The present Law on Social care is effective insofar as it creates a framework of guidance for Social and Health care. The problem lies with Local Authority policies and procedures which are so inflexible and rigid that they do not promote independent and equality for disabled people as the Disability Discrimination Act now requires. Each Local Authority when considering its policies and procedures for social care services needs to take into consideration its "duty" under the disability legislation to have "due regard" to disabled people (DDA 2005 Section 49A) in order to promote equality and eradicate discrimination. This leads to the requirement for far-reaching changes in policy and practice. Only thus will we prevent unnecessary challenge and litigation. The Local Authority needs to consider carefully the scope and implications of the

Disability Legislation, to ensure that their practice promotes equality and fairness for disabled people.

We note the strongly worded observation of the Law Commission that "the legislative framework for adult residential care, domiciliary and community care, support for carers and adult protection is inadequate, often incomprehensible and outdated" (op cit., p. 128). The Commission's preferred option for moving forward (pp. 130-131) is the establishment of a coherent legal framework across ten key areas, areas which in effect cover the territory currently described as Adult Social Care.

Q8. It is very difficult for good political reasons to reduce the RAS levels for new people to the system, whilst keeping it higher for existing people, and the 1997 Gloucestershire judgement makes it clear that it is impossible to cap someone's allocated care package. Hence, Self-Directed Support is no better than the old system in managing down spend.

This observation is based on the assumption that the object of the exercise is to "manage down spend" – something which we do not accept. The starting promise of In Control is in fact the need to develop a system to help people get control of their lives, and to assist Local Authorities to devise ways to do that efficiently as well as effectively. The celebrated Gloucestershire case only came to court in 1997 because of a funding dispute, of the kind which has bedevilled the old system. Self-Directed Support will not dispense with all disputes, but the evidence to date is that it is far more likely to lead to a consensus between all concerned – so in fact we are less likely to feel the need to "cap a care package", because that package will be genuinely jointly owned, and in many (but not all!) cases will be based on RAS levels.

Q9. A Direct Payment can already do what In Control claims for a Personal Budget or Individual Budget. There is no different legislation underpinning Self-Directed Support, and the only way IBs or PBs can legally be delivered is as a Direct Payment.

It is incontrovertibly true that there is no new legislation to underpin Self-Directed Support, though of course as several speakers at the conference reminded us the law in relation to Direct Payments was recently amended through section 146 of the Health and Social Care Act, 2008.

In the glossary on the In Control website, we define Individual Budgets and Personal Budgets as:

The money you get to pay for your support and other things in your support plan. The difference between the two is:

- > A Personal Budget is money from Social Services.
- An Individual Budget is money that could come from several places including Social Services, the Independent Living Fund and Supporting People.

The real question is perhaps whether or not there **needs** to be new and extensive primary legislation to make Self-Directed Support work as it should. It was pointed out at the conference that many - but perhaps not all? - the goods and services which people buy with their Direct Payments are in fact allowable under pre-existing legislation (a speaker at the conference mentioned life coaching, personal training, college courses, support at university, support to shop, purchase of a holiday caravan and more as allowable) - so long as these goods and services are specified in someone's "care plan." In Control argues that we should in fact move away from a model of traditional *care plans* with lists of services to be purchased, and instead develop *support plans*, where outcomes to be achieved are the focus. We argue that irrespective of what the Law might currently *allow*, in practice the system as it operates, and particularly the way many Direct Payments schemes work, does not give people the flexibility they need to make good use of their money.

Essentially those Local Authorities which are wishing to make a success of Self-Directed Support have adopted one of two approaches to this issue. Some, including the London Borough of Newham and Hartlepool Borough Council have retained a Direct Payment scheme – as regulated by the existing Direct Payment law and regulation – at the heart of their approach to Self-Directed Support. In doing this, they have also taken measures to develop other means by which citizens can gain control, without managing their budgets themselves. In Control suggests that there are five such means (that is in addition to that of making the payment direct to the citizen him or herself). The money can be routed to the person's representative; to family and friends; to an independent organisation: to a service provider; to a professional. (These arrangements are all described in much more detail in In Control's Guide 4 on Individual Contracting.) All of the arrangements, except perhaps the last need to be regulated by clear contractual arrangement managed by the Local Authority. Where a Local Authority professional manages the money, there needs to be clear guidelines and procedures in place. In those instances where a person does in fact ask to receive and manage the money themselves, they then receive a Direct Payment.

Some other Local Authorities, including the counties of Essex and West Sussex have taken legal advice which has persuaded them that they can legitimately make use of Part 1, Section 2 of the Local Government Act 2000 (the so-called "Well-Being powers" of the Local Authority) to allocate Personal Budgets to individuals. Essex County Council in particular have provided background to this approach in a paper which is available on the In Control website. The helpful point was made at the conference that if a Local Authority is to follow this route it is a clear requirement of the legislation that the rationale for the allocation of monies to individuals is clearly specified in a local Well Being Strategy – that is to say that the Local Authority needs to set out how acting in this way is "good for the overall area."

Use of the Well Being Powers does not substitute for the necessity to grow and nurture the other five routes to managing the money, something West Sussex CC for example recognised from early in the process, and there is no doubt that

for many Local Authorities this whole area is one requiring careful thought and planning.

Q10. If someone is allowed to "save" money by finding and purchasing a cheaper good or service than that specified in a "care plan," and spend that saving on something they "wish for" rather than "need" then this is a questionable use of public money, and may also be unlawful.

We question whether this is in fact a helpful way of framing this concern – albeit, it is one that we hear frequently. The difficulty with this approach to the question is that it leads us straight to solutions described as functions and services, rather to the individual and their unique circumstances – and solutions. The desired end-point is we argue to reach a situation where the person's needs are met in a way that they wish for.

There is a growing body of evidence of instances which show individuals, families and those supporting them - sometimes including Local Authority care managers finding better, and less costly solutions than those bought by professionals using the old system. These new solutions sometimes include "goods and services" but usually there are other things - "free goods" - included too. If things have gone well, these solutions will be the result of more imaginative and more "person-centred" thinking than those bought off the peg in the past. Moreover, the distinction between "wishes" and "needs" is fuzzy at the margins for most people. It may be the most important thing in the world for someone at a given time to have the opportunity to visit an elderly parent overseas before that parent dies – but the Local Authority would in the past have always defined this as a "wish" and not a need, and therefore not fundable. What Self-Directed Support does is to encourage Local Authorities to treat their citizens as true adults, capable of making the best choices for themselves at any given time, and with a fair allocation of money on which to base those choices. There is a growing body of evidence now from In Control's member Local Authorities that individuals and families are not only best placed to plan their own support, in many instances they are the best and most prudent custodians of the money that funds that support.

Q11. There is no need for monitoring, review or safeguarding, Personal Budgets can be part of the Benefits System and people can be left to look after their own money.

In Control has published extensively about monitoring, review, the Local Authority's duty of care, risk management, and safeguarding issues. It is absolutely not our view that Personal Budget holders can or should be left unsupported at any point of the process. What we do say, on the basis of what disabled people have told us, is that these things need to be done differently, and in particular that financial monitoring systems need to be proportionate and sensible. Auditors need to have confidence in these systems, and it therefore remains our advice to Local Authorities to involve auditors from the inception in designing and signing off new processes. We are largely supportive of the CIPFA guidance, cited at the conference in this regard.

Q12. The Law talks about the Local Authority's duty to provide services, not about outcomes. Isn't this problematic for the Self-Directed Support model?

Yes, it is somewhat. It might well be better if the language of the Law was coherent with that of recent public policy documents such as Putting People First and the two Local Authority Circulars which have followed, where an outcomes framework is indicated. However, the Department of Health has encouraged Local Authorities to be pragmatic and to encourage citizens to think in terms of outcomes, despite the extant legal terminology. Ideally that language should be changed. Additionally, it would be wise for Local Authority policies and procedures to encourage citizens to think in terms of outcomes in order to meet its duty to have due regard to disabled peoples entitlement to a fulfilled life style.

Q13. If someone makes manifestly bad decisions on spending their Personal Budget, and is left with unmet-needs, does this reflect on their mental capacity, as defined in law? And in these circumstances does it fall to the local tax payer to double-fund?

No. Mental Capacity as defined in the Act is not compromised by unwise decisions of this sort, the legal test is that of whether a person lacks capacity to do a *given thing at a given time*. We need to start with the presumption that someone does have capacity unless it can be proved otherwise. It would be entirely wrong to take action under the Act on the basis, simply because someone has "blown" the money. It is also important in law to give the person all the help they need to make decisions, before inferring a lack of capacity. This fits very well with In Control's approach to supported decisions (see In Control, Policy on Supported Decisions, available on the In Control website), an approach which effectively situates decision-making precisely where there is the greatest incentive to make the best decisions, that is with the individual and those closest to them.

What does make sense in circumstances where someone is found to have spent their money inappropriately and where needs remain un-met, is for the Local Authority to take action to manage the person's Personal Budget through a social worker or care manager, at the earliest sensible opportunity. Local Authorities will only be able to do this if they have strong approaches to review, whereby they are alerted when and if outcomes are not being achieved.

In reality, the number of instances of this sort to date amongst the ten thousand plus people with a Personal Budget is tiny. Where someone is legitimately deemed to lack mental capacity then the new Court of Protection can appoint deputies to work with the person to determine and represent their best interests. There are clearly implications here in terms of someone's consent to accept payment, as well as decisions about management of the budget.

Q14. Local Authorities often worry about the consequences of Judicial Review. How can they avoid this, and are there any particular early warnings?

One of the conference workshops was helpful in setting out the key questions and the grounds for taking an Authority to Judicial Review. Citizens are much less

likely to take an Authority to Judicial Review when they are satisfied, and they are much more likely to be satisfied under a system of Self-Directed Support.

We need to understand is that Judicial Review is *redress of the last resort*. Before arriving at this point, individuals must have been through and exhausted the statutory complaints process. The issue which is then subject to challenge is straightforwardly the way in which the public body makes its decisions – not the wisdom of the decisions themselves. The grounds for such challenge are illegality, procedural impropriety or irrationality. The one exception to the necessity of pursuing the statutory complaints procedure route arises if it is considered that a citizen is at risk of significant harm due to inappropriate care or lack of services, in which case "a detailed letter before claim" will be sent to the Local Authority and its legal department giving them a reasonable time limit to provide the citizen with support. If the Local Authority does not carry out their statutory duty then urgent Judicial Proceedings may be issued by the High Court to seek a Mandatory Order to compel the Local Authority to provide that citizen with support. At all stages a Local Authority legal department will be kept informed of any potential Judicial Proceedings.

One important early warning for Local Authorities in terms of the threat of Judicial Review is a request for disclosure of a written contract. Such contracts are often legally very weak, and they can lead to searching questions about decision-making.

Q15. What are implications of the Disability Discrimination Act (DDA) for Self-Directed Support?

One of the workshop presenters made the point that the original Act was weak and was rooted in a medical model of disability. The 2005 amendment to the Act improved matters. One of the improvements was a requirement to review the policies and procedures of public bodies such as local Authorities to ensure that they took due regard of the needs of all people with disabilities – and indeed allowed for "more favourable treatment" where that would help to promote equality of opportunity. Policies in relation to Self Directed Support and Personal Budgets are subject to such review and clearly sit within the scope of the Disability Discrimination Act 2005 (section 49A). If such discrimination were to arise, the likely basis of the challenge would that services did not have due regard to disabled peoples needs.

There was a question at the conference with specific reference to a "points based RAS". In Control is not aware of any examples where a policy or a tool such as the RAS has been disallowed by a Disability Impact Assessment. The intent of the Act is to ensure that public bodies ensure that policies and procedures conform to the law to promote equality and diversity for disabled people as a whole. As we note above, much of In Control's early work focused on making the system work better for people with particularly high levels of need, finding ways in which they could have a real voice in planning, and enabling them to get a fair allocation of public resources. It would be surprising and disappointing if Self-Directed Support was judged to have failed this group.

Possible examples of legal challenge to the Local Authority under the DDA include:

- > Where the Authority decides to implement a policy which means that a citizen is only able to buy services from two or three care agencies, thus not giving choice or control of their support.
- Where an Authority states that they are changing their policy to stop funding transport for a group of young disabled students to college, suggesting that the students should use their Disability Living Allowance for this purpose.

These examples might both be held to contravene the fundamental basis of the current disability legislation, and leave Local Authorities open to prosecution.

Q16. Do citizens have a right to a Personal Budget?

No, not at present under statute law. In Control believes that there should be, so perhaps the law needs to change. Local Authority members of In Control have signed up to the Statement of Ethical Values, which makes the assertion that people have such a right. It is therefore arguable that the right now exists in these Local Authority areas. See the paper, *Reforming Social Care Law*, where we make the point that the *ethical case for entitlement* to a Personal Budget is the proposition that people *should know* what they are entitled to.

Q17. What is the correct procedure to be followed when a Personal Budget user seeks to terminate the contract of Personal Assistant?

The process to be followed in this situation is a standard sequence: letter; meeting; resolution or termination. If the contract is terminated as the outcome, then one of six "fair reasons" for this needs to be stated under the following headings, which are: redundancy; a substantial reason; misconduct; contravention of enactment; retirement; disciplinary. ACAS provides further helpful detail.

Q18. Can the NHS make a Direct Payment?

The Department of Health says no. However, one of our speakers said that there is a strong human rights argument that suggests yes, and that he intends to take a case to court to test this. The Gunter case makes it clear that NHS money can be paid direct to an Independent Living Trust – but this is not sufficient.

The Department of Health is currently initiating a series of Personal Health Budget pilots, and has signalled a clear intention to change the law in this regard.

Q19. Is it now legal for a Local Authority to dispense with the old system of organising social care?

Yes, it is, so long as they ensure that there is a full range of options to allow people to manage the money in different ways – including through the Local Authority.

Q20. Many of the critiques of Self-Directed Support say that older and disabled people would be more poorly served by gaining a right to a personal budget, if they also lost the right to have their needs met. The fact that the old system has not worked well is a consequence of a lack of funding and of lack of legal representation. There is no inherent problem with the old "operating system" itself.

This was a view strongly articulated by several of the speakers at the conference. In Control respects that view. We differ however: our view is that there is no prospect of significantly greater sums of public money being made available for social care, no prospect of vastly increased legal representation – and more fundamentally we see a system that by its very nature separates and distances people from their families and communities, and that rarely bestows good lives. The "right" to have needs met as currently defined is a fiction, and without an unlikely degree of radical social and legal change sadly it will remain so.

Q21. Is it true that funding panels contravene the law?

This was certainly the consensus amongst the lawyers present at the conference in Manchester. They are, however almost universal. This is one of the aspects of the old system that is perhaps unlawful.

Q22. Is it legal for a Personal Budget user to be asked to use some of that budget to pay for brokerage services?

One of the conference speakers said that probably it is not, because these services (probably) fall under the heading of the *management of community care services*. Local Authorities are specifically prohibited from charging for these services, so the practice is illegal.

In Control's view is that the jury is still out on "brokerage," and we have a research group looking to define best practice, based on the evidence concerning what people are actually finding most helpful at the point at which they are engaged in planning and in organising their support. An important part of this work here is to define who is best placed to deliver these services, as well as how they are funded. In broad terms, we can define brokerage as assisting someone to plan, and to get what is in their plan. It is heartening to report that the leading Local Authority members of In Control remain just as committed to the principles of maximum choice, control and person-centredness in developing these aspects of the new operating system, as in other aspects. If it is indeed the case that it is unlawful to include charges for brokerage in this way, then either the model will need to flex to accommodate what is lawful, or the law will need to change.

Conference Information

The speakers at the Manchester conference were:

Simon Duffy (video presentation)

Until June 2009 Simon was CEO of In Control guiding in Control's strategy, philosophy and practice. Simon started work as an NHS General Management Trainee but left the NHS to work in the voluntary sector in 1990 and has been working ever since to shift power and control away from professionals into the hands of those who need support. In 1996 Simon founded the charity Inclusion Glasgow, an organisation dedicated to offering personalised support and maximum control to people with severe disabilities. Simon went on to help set up a range of further organisations and the Scottish federation of person-centred organisations, Altrum. Simon is also the author of Keys to Citizenship, a practical handbook on how to be in control of your own life. In 2007 Simon was award the RSA's Prince Albert Medal for social innovation.

Julie Stansfield (conference chair)

Julie is the Managing Director of In Control. She is also Lead for the north east region and site support manager for Hartlepool. Julie is the main link between in Control and the Department of Health and other central government departments. Julie was one of the founders of in Control and works within in Control partnerships as the Managing Director. Julie says: 'ALL people should have the chance to have choice and control in their lives, but the truth is that the majority of people needing support have little or no choice and control. Being very aware of this keeps me driven to change the way things are!'

Luke Clements

Luke Clements is a Professor at Cardiff Law School, and is solicitor with Scott-Moncrieff Harbour and Sinclair (London). As a lawyer, Luke represents disabled and older people and their families. He also acts as a specialist adviser for many of the UKís leading charities in this sector. Luke has also specialised in the rights of other marginalised persons, including Roma on whose behalf he been involved in a number of European Court and Commission of Human Rights cases. Luke helped draft and guide through Parliament the Carers (Recognition and Services) Act 1995 and the Carers (Equal Opportunities) Act 2004 and has been an expert adviser on the Independent Living Bill. Luke Clements has written widely; his recent books include: Community Care and the Law (Legal Action Group 4th ed 2007 - jointly written with Pauline Thompson) and Carers and their Rights (Carers UK 2nd ed 2007). A brief biographical note is at:

www.law.cf.ac.uk/staff/ClementsLJ

Belinda Schwehr

Belinda offers training and consultancy on health and social care law, having taught and practised as a lawyer in the public law field. She qualified as a barrister, then lectured and published in the university sector, before returning to legal practice as a specialist solicitor-advocate. She now runs the website www.careandhealthlaw.com. Her main interests are the legal framework for services for adults and mental capacity law. She trains staff in more than 50 councils and advises widely in the field. She gives pro bono advice

to individuals when she can, and is helping the Law Commission with its review of Adult Social Care Law. Her most recent project is a CD on Deprivation of Liberty for care homes and hospitals.

Rita Hardaker

Rita is Senior Solicitor and Head of the Community Care Department at Pannone LLP, Manchester and is soon to start as a Community Solicitor at Fazackerley Advice [FAIR] in Liverpool. Previous to this she was a community solicitor in Not for Profit organisations in Liverpool and Manchester. Rita is involved in all aspects of Community Care, Disability Rights, Human Rights and Public Law. She has won ground-breaking cases with regard to NHS Continuing Care, Housing and Mental Health issues and disability rights. Rita is herself registered Blind and Deaf and has faced institutional and social exclusion throughout her life. She is active campaigner for disability rights and promotes the social model of disability. She has recently completed research into the "meaning of disability" in equality legislation.

Stephen Lodge

Stephen specialises in Public Law, Community Care Law and Human Rights work. Stephen qualified as a solicitor in 1994 and worked at Tyndallwoods Solicitors for a number of years specialising initially in employment and discrimination work and later in public law, before helping to found Public Law Solicitors in 2003. Stephen has particular interests and experience in community care, access to Health Services and Public Law issues relating to transgendered people, including obtaining gender re-assignment treatment. He also specialises in Public Law issues relating to services for disabled children and care leavers. Stephen provides specialist advice in community care law through the Legal Service Commission Specialist Support Service. He also provides training in a number of areas of Public Law including community care law.

Mathieu Culverhouse

Mathieu trained with Linder Myers and qualified in 2005 before joining Irwin and Mitchell in October 2008. He is based in Irwin and Mitchellis Manchester office. Mathieu specialises in patient rights, community care and mental capacity law. Mathieu acts for clients who have ongoing difficulties with Social Services, the NHS and other public bodies. He has brought judicial review cases on behalf of army veterans in order to secure their War Pension rights. Mathieu also acts for the Official Solicitor on behalf of vulnerable adults who lack capacity to make decisions regarding their health and welfare.

Yogi Amin

Yogi was admitted as a solicitor in 1998 and joined Irwin and Mitchell in 2001 after dealing with a broad range of judicial review work in London. He became a partner there in 2007. He has extensive experience in conducting successful judicial review cases in relation to a wide range of public functions: Social Services, Healthcare, Housing, Education, Immigration, Criminal Justice and Prison Law. He specialises in the healthcare and community care fields. He has advised on Fair Access to Care Services, eligibility criteria and charging policies, and other issues in relation to disabled and older people. Yogi has acted in a number of challenges brought against a NHS PCTís decision of refusal to fund life saving treatment. He has also become involved in adult welfare proceedings brought by local authorities, mainly acting for the Official Solicitor in declaratory High Court or Court of Protection proceedings, or guardianship proceedings, in the county court, involving individuals who may lack capacity to manage their affairs and decide on welfare, residence, contact and healthcare matters themselves. He has advised and represented individual clients, care homes, charities and other institutions on matters involving the Disability Discrimination Act 1995, Mental Capacity Act 2005 and Mental Health Act 2007. Yogi has also provided business immigration advice to individuals and institutions.

Glenn Hayes

Glenn trained at Irwin Mitchell and qualified as an employment law specialist in August 2002. Glenn has day-to-day responsibility for the Manchester Employment Law team. Glenn advises businesses of all sizes in both the public and private sectors on all aspects of employment law. He acts for a number of household name blue chip PLCs, Small and Medium Enterprises and owner-managed businesses as well as advising individuals in all aspects of employment law. Glenn has considerable advocacy experience, particularly in the field of discrimination law. Glenn regularly presents in-house seminars and workshops for clients, and has primary responsibility for preparing the Employment Law department's client update bulletin. Glenn also undertakes advice in relation to

complex restructuring exercises in both the private and public sectors.

Sam Karim

Sam Karim is a barrister and Associate Fellow of the Institute of Advanced Legal Studies.

Caroline Tomlinson

The conference was organised by Caroline Tomlinson. Caroline is events and membership lead for In Control Partnerships.

Andrew Tyson

This report's primary author is Andrew Tyson. Andrew is a social worker and leads on policy for In Control, having previously co-ordinated the Total Transformation programme. Andrew is currently working on In Control's Phase Three report, to be published in 2010.

Find out more at www.in-control.org.uk

The In Control website at www.in-control.org.uk contains much of the information below in more depth, dispersed across a number of pages and downloads. We continually review the website with the aim of making the information easier to find. All of the key documents can be found under the Search and Library button. There will also be a new section on the Law, which will include this report and other legal documents.

The key documents are:

- Guides to Self-Directed Support. Guide Preface and seven Guides on each of the seven steps to Self-Directed Support.
- In Control's two reports on our evaluation and learning, phase

- one published in 2006 and phase two in 2008. Much of the underlying evidence concerning the success of Self-Directed Support is to be found in these reports. Our third phase report will be published in late 2009³.
- Presentation materials from this conference (on the website under Members and Events).
- Policy Bugs and Fixes (on the website under the Technical Information button)
- A series of new evaluation reports, produced jointly with Local Authorities implementing Self-Directed Support and giving data for outcomes and for improved efficiencies. For example reports for Worcestershire and Cambridgeshire are referenced below².

Notes

^{1.} Law Commission (2008), Adult Social Care, A Scoping Report

^{2.} In Control (2009), *Doing It Your Way* and *Rowing My Own Course*, two reports in a series published by In Control and available at www.in-control.org.uk

^{3.} Poll, C et al (2006), A Report on In Control's First Phase, 2003-5; and Hatton, C. et al (2008), A Report on In Control's Second Phase, Evaluation and Learning, 2005-7. Both reports published by In Control



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