A Voice and a Choice

Self Directed Support by people with mental health problems

A Discussion Paper

Rita K. Brewis

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Executive Summary

In Control are working towards self directed support being universally available to people, regardless of the diagnosis or 'label' that may have been given to them. This discussion document considers how Self Directed Support can help people with mental health problems achieve the same rights to full citizenship as others. 'A voice and a choice' has been informed by input from over 70 people across the UK.

The title and the report's content, can be seen to respond to the latest review of adult community mental health services in England: 'No voice no choice', which states that 'Our findings on how well people using services are involved in the care that they receive remains of particular concern. Independence is as important an issue for people who experience mental health problems as it is for cardiac or diabetes patients. Sadly however, many services still do not seem to realise this and the gaps in provision of services highlighted in the 2004 mental health and social exclusion report remain. (CSCI and Health Care Commission July 2007).

'A voice and a choice' presents and addresses the most commonly held fears and objections that could block equal access to Self Directed Support for people with mental health problems, starting with a lack of knowledge and the apparent loss of connection with the Local Authority in many mental health services. Twelve common 'myths' are answered with clear facts and suggestions. Similarly, concerns around money are noted and discussed. Broader systemic issues are then explored: the loss of the social perspective in mental health; the usefulness of the Recovery approach and the need to re-examine some of the unintended impact of the integration of health and social care services in mental health work. Finally successful strategies for making change happen are shared in an eight step check list drawn entirely from pragmatic approaches developed in the field by people making Self Directed Support happen.

Mental health services appear to be lagging behind other services, and there is a perception by some that it may prove to be the hardest place to win the respect for autonomy that other people with disabilities have fought for and begun to gain.

Surely the basis of equality of opportunity is that it is open to all on the basis of common humanity, and cannot be withheld on the basis of diagnosis. Mental health service users should have specific attention in our efforts to develop Self Directed Support not because they are a 'harder group' or 'more difficult' but because we must be alert to the subtle yet pervasive negative influence of prejudice and discrimination.

The paper argues that self directed support has been proved to be effective and is making a useful difference in people's lives. It aims to make explicit that there is a need to ensure active inclusion through the positive promotion of participation in self directed support across all mental health services and with individuals and their families or friends. This is seen to be essential to make sure that people with mental health problems have equal access to this radical change to social care support, and the increase in independence, confidence and opportunities it can bring.

Thanks

I would like to place on record my sincere thanks to all the participants in this project who freely gave their time and ideas to inform this discussion paper. Every contribution by over 70 of you has been noted and considered, and made the project possible. Particular thanks are due to Carey Bamber, Colin Williams, Peter Flanagan and Claire Hyde, of CSIP who drew people together for workshops in different parts of the country and whose support and advice has been brilliant; and to Jeanette Thompson, Robin Murray-Neill, Anna Coss, Wendy Lowder, Ruth Hicks, Barry Ruffel, Linda Thompson, Mette Jakobsen, Karen Ahmed and members of Sefton Recovery Network whose insightful comments based on their direct experience have been invaluable.

Final thanks are due to my family whose positive interest and understanding support all my work.

1. Introduction

This paper was commissioned by In Control, in order to explore how Self Directed Support can best be developed for people with mental health problems, alongside everyone else. It is important to emphasise from the outset that 'in Control's central interest is in ensuring that all disabled people, including older people and people with mental health problems, are able to achieve citizenship.' ('Evidence on self-directed support' Duffy Oct 2006.) It is a *universal* replacement for the current Social Care system, and as such must be made equally available for everyone with social care needs, of any age, who meets Fair Access to Care criteria.

The process of writing the paper has been deliberately collaborative and has aimed to reach out to hear the views of as many people as possible within a reasonable time. Several workshops and individual and small group meetings have given a wealth of information. (A full list of all contributors is at the end of the document. Un-referenced quotes are by participants.)

We have started a conversation with the purpose of effecting useful change and have not tried to make a complete representation of all the different perspectives surrounding the movement towards personalised support and individualised budgets. The essence of this piece of work is to briefly describe what is the current situation and what must be done to progress the radical evolution of social care support in mental health services, and to achieve the shift of power and control to individuals and their families and friends.

Perhaps one of the most essential first steps to progress, is to explode the range of myths currently surrounding Self Directed Support by people with mental health problems.

Through the course of this project it has become clear that the majority of these myths, whilst they may be presented in slightly different ways, are prevalent across many different services and are not exclusive to mental health.

Their power to influence may however be experienced differently because of the different context within which mental health services operate (i.e. a predominantly NHS system.) If we are to move to what one participant described as 'rights and entitlements not gifts and judgement' then this re-joining together of the divisions that service driven care has enforced may be one of the most useful tools. Nevertheless, several people have commented on the usefulness of people within the currently fragmented service system feeling heard, and that their experiences and perspective need to be understood. 'We all try to understand things from the place we're coming from and know.'

The willingness of many people to join in this discussion is worth noting. People are searching for useful information and solutions, as well as wanting their reservations and worries to be heard and considered. Therefore the information gathered has been collated and is presented as a series of perceived problems (or bundle of problems/issues) answered by clear information and suggested solutions. They are based on what people have found works.

2. Not knowing and not seeing as relevant

Mental Health Service staff appear to be largely unaware of Self Directed Support. For NHS Provider Trusts, where many social workers are now located, it may be seen as not their business, not one of their targets. Child and Adolescent Mental Health Services (CAMHS) are frequently left out of discussions completely, Self Directed Support is not identified in CAMHS policy guidance as a priority or target for service development, and CAMHS teams may be managed by organisations other than Mental Health Trusts. There can be similar issues for older people with mental health problems.

Local Authorities have had a target for the increased uptake of Direct Payments, but this is not made specific to different groups of needs. Therefore mental health service users having the lowest take up of Direct Payments has not impacted on Local Authorities' targets/star ratings, provided that other people are having direct payments in sufficient numbers. To quantify this: The Healthcare Commission's latest joint review, 'No voice, no choice' (published 30th July '07) states that: 'Within a generally poor picture of the provision of direct payments, people with mental health problems fare worse than other service groups. The latest figures show the figures of expenditure on direct payments as a percentage of the total expenditure per client group to be as follows: older people 0.5%, Under 65 with physical/sensory impairment 9.4%, under 65 with a learning disability 0.8% and under 65 with mental ill health 0.3%.'

People are also confused about how Self Directed Support differs from Direct Payments. (Appendix 1 has a brief description of differences). Many are still unclear about Direct Payments themselves. Even when information has been given, some services appear not to have heard what has been said or to see it as optional rather than some-one's right and the Local Authority's duty to offer. Despite a considerable amount of work, research and guidance, (e.g. 'Direct Payments for people with mental health problems: A guide to action' Department of Health Feb 06) there is a frustrating lack of progress, with a handful of notable exceptions. Direct payments are one means by which people can and do self-direct their support.

It is useful to acknowledge that some of the lack of clarity about Direct Payments, Individual Budgets and Self Directed Support is due in part, to the way in which the various terms have been used by different statutory and voluntary organisations. It is also vital to fully acknowledge the campaigning work done by disabled people who campaigned for 'personalisation' (under the description of 'choice and control') and developed the concept of Independent Living. There is now a joint statement between in Control and the National Centre for Independent Living defining a common understanding of key terms.

There is seen to have been far more resistance to making use of Direct Payments in mental health services as the following quotes illustrate: 'Huge persistence is needed. The person presenting the ideas is met with massive hostility.' 'We've found it the hardest group' 'The challenge to the mental health services is so much bigger because of the huge over-professionalization and the challenge of replacing a professional gift model with a citizenship model'. Certainly whilst we should pay attention to the low level of Direct Payments in mental health services this should not deter the movement towards Self Directed Support. It may also be useful to consider what may be some of the shared obstacles blocking uptake for older people, who appear to be similarly disadvantaged.

The level of flexibility and different ways to 'hold' the money available in Self Directed Support make it possible for the objections some people have made about the implementation of Direct Payments to be overcome. However, for the moment it is necessary to note, that the 'Individual Budgets Evaluation Early Findings' (Ibsen June 2007) include the following words of warning: 'Delivering Individual Budgets to mental health service users is taking longer than others. Self Directed Support is seen as more complicated to deliver, and some NHS workers in integrated teams are reported to be cautious about this new approach.' Feedback in this project has indicated that this cautiousness is shared between all staff, both Local Authority and Health. Information giving alone is therefore unlikely to shift the blocks preventing people with mental health problems being able to access Self Directed Support. Nevertheless, it is an important part of any change process.

2.1 Suggested Solutions

It is the view of in Control that only the effective implementation of a coherent, systemic change will bring about the full benefits of independent living to the maximum number of people. (The seven elements of independent living are clearly set out on the in Control web site: www.in-control.org.uk). However, it is equally important to recognise that the model developed by in Control as a new Operating System of Social Care, is evolving through experience as people use and adapt it. It is not possible within the confines of this paper to describe in Control's current model of Self Directed Support but both the model and tools to support its implementation are freely available on the web site.

Those Local Authorities who have been most successful have not waited for a 'perfect' model to be constructed but have put in place the essential building blocks and then got on with working with individuals and their families or friends and learning as they've handed over control.

A full summary of suggestions to support the implementation of Self Directed Support by people with mental health problems is given in section seven. For the purpose of making certain that mental health services are well informed about Self Directed Support the following steps have been suggested by participants in this project:

Backing from the 'top' and engagement though the whole system:

- Aim to have total understanding and widely expressed commitment from the senior management team.
- Challenge and encourage the Local Authority to fully engage or re-engage with the mental health social care agenda. Be prepared to go to DH for backing if necessary.
- Allow leaders in services and local politicians to hear clearly about the benefits to both individuals and communities.
- Pull together a steering group that includes the Chief Executive of the Local Authority, family members and service users and voluntary sector members.

Create an achievable plan:

- Put in place a clear project plan for self directed support, (if this is across all services then ensure it specifically includes mental health services) with steps that are achievable.

- Make sure someone has dedicated time to progress the plan.

- Set a target for numbers of people with mental health problems having Self Directed Support within a timescale. Monitor the target and feedback what is happening. Use the feedback to open up conversations about differences and address any persistent blocks.

Get the messages across:

- Explain and give information in person not by email or documents.

- A development worker within a team/service is very effective as it allows for a message to be re-iterated and openly discussed over weeks and months. It also enables teams to name their fears and begin to think more creatively.

- If it's impossible to have a development worker, find champions in each team/service but ensure they have good support and are linked together.

- Having a champion who is from the NHS (e.g. a modern matron) gives credibility in integrated teams.

- Champions should attend the Local Authority/Joint steering group and team targets should be fed back to this group.

- Support service staff should link in to team meetings and spend a couple of hours a week providing a place where staff can discuss any issues and questions about Self Directed Support.

- 'Huge persistence is needed as people can be met with massive hostility'.

- Don't rely on individuals going to training events and trying to take back the messages to whole teams. This won't work. (One reason that this is not effective is that Self Directed Support requires a change in attitude and approach. It is easier to relay procedural changes to others who were not present, but very difficult to recreate the change in attitude/approach which, if not previously familiar, soon becomes overwhelmed by the prevailing team culture)

- Use this document as a source to support addressing the myths and misunderstandings that may block progress.

- If there is a savings plan underway, clarify that this is a separate initiative and be sure how money for mental health services will be effected.

- Tell the stories of people who've successfully used Self Directed Support, or far better, ask people if they would tell their stories directly. This is the most powerful way to make a persuasive case for the need to change
- Examples of direct payments use also show the potential for Self Directed Support: if a few people can achieve such positive and individualised results within the current restrictive system, it suggests very strongly that far more will be able to do so in a system of Self Directed Support.

Even when people are provided with clear information, misunderstandings can flow from the myths and concerns that people hold, which can block change if left unaddressed. The following sections name and address the most commonly expressed worries and objections.

3. The Myths

Through this project, many questions have been raised concerning a fear that Self Directed Support is somehow OK for everyone else, but can't be made available for people with mental health problems. These questions can be answered as follows:

Q.1. Won't people be excluded by the mental health legislation?

A. The vast majority of people using mental health services have the same rights as everyone else. A small number of people, who are subject to legislation which limits their freedom to arrange their own care are excluded from receiving direct payments, by the requirements of direct payments not by the Mental Health Act itself. (These are, those subject to sections: 7, 17, 25A, 37, 42(2), 73(4) or 75(3) of the 1983 Mental Health Act.) This may sound like a long list but is in fact restricted to a few people. The clearest message is that in general the mental health legislation is not a bar to providing social care support in a more personalised and creative way. Clearly the usual 'rules' about anyone's 'capacity' would need to be applied and this may perhaps be more changeable for people with long term mental health problems, but good individual support plans can be made sufficiently flexible to manage this. The Local Authority must still demonstrate careful consideration of risk as well as striving to enable individual control, independence and citizenship.

Q.2. Are we allowed to offer Self Directed Support to people subject to section 117 aftercare requirements?

A. Yes. Section 117 is the duty (for section 3, 37 SCT in future) on the NHS and Local Authority to provide aftercare for mental health needs and subsequent case law has determined that this cannot be charged for. Again, the duty to provide aftercare does not preclude this being delivered via direct payments or Self Directed Support/individualized budgets.

Q.3. What about people who have substance misuse problems as well? Won't they drink the money away?

A. Similar concerns have been expressed in the past about the ability of people using other types of services to manage their own resources, and have proved to be unfounded. The evidence to date shows that people are prudent with the use of their money and use it wisely. However, there will always be people who manage their money better than others. Where concerns exist it is important to note that the Local Authority must agree and monitor anyone's proposed plan for how they will use their entitlement to social care funding to meet the outcomes they've agreed. This means that if the Local Authority believes that some-one is not able to control the money directly, then an alternative way of 'holding' the money would need to be put in place. (Please refer to the in Control website for an explanation of the six different options that are available.) If the person themselves is allowed to have access to the money then how it is used would be monitored, as with anyone else, and if mis-spent can be withdrawn. Monitoring needs to be proportionate to the perceived level of risk and arrangements to review and monitor can be as frequent as the situation warrants and can be changed as the situation progresses.

Q.4. Surely people with the kind of mental health problems which mean their decision making capacity fluctuates, (e.g. people who suffer with manic depression or acute psychoses) cannot possibly be allowed Self Directed Support?

A. All of us fluctuate in our ability to make decisions over time and depending on the stress or support around us- but of course the particular level of variability experienced by some people with severe mental illness needs to be acknowledged, and built into the support plan. Advance directives and forward planning agreements about another party taking back control of spending when necessary can be put into place. In at least one instance already however, someone with severe manic depression has managed to work out a Self Directed Support package over the last couple of years which has improved their life considerably, and also resulted in no hospital admissions (from a baseline of having about 3 sectioned admissions a year.)

'A particular barrier in mental health is the misconception that people with mental health problems lose all judgement as a result of their illness. At times of crisis people do struggle with decision making, but this is not a permanent state, and there are ways around it. Advance directives, in which individuals describe how they want to be treated when they are not in a position to decide for themselves, are becoming standard in the US. Participants can also nominate a representative, such as a family member or friend, to make decisions on their behalf when they are unable to do so. ''(Direct Dollars Vidhya Alakeson Mental Health Today March 2007.) These should perhaps more correctly be called 'advance statements' in the UK. In the Care Programme Approach they can also be a part of 'Crisis Plans', which are required to be in place for all people on 'enhanced CPA' and good practice for all those on 'standard CPA'. They are already in use in the management of Direct Payments, as seen in Pauline Heslop's 'Direct Payments for mental Health Service Users and Survivors' (NCIL, 2007).

Q.5. How does the Mental Capacity Act mesh with all of this?

A. The Mental Capacity Act enshrines the principle that people must be assumed to have capacity unless it is established that they do not. Capacity in this sense means that they are able to make decisions for themselves. The capacity is judged around a specific matter, not assumed to be total judgement for some-one's whole life. This is very important since 'even if they only have capacity to make some decisions but not others, or if their lack of capacity is temporary, they may still be able to make some clear choices and decisions. The Act explicitly acknowledges that people with capacity may make what some people would consider to be 'unwise' decisions', but that does not mean that they do not have the capacity to make those decisions, even if practitioner's and carers' views are at odds with them. Amongst other things the Act gives a new role to advocacy within the setting up of the Independent Mental Capacity Advocate service which, in specified circumstances, will support and represent people who have nobody else to speak for them when certain types of decisions are being made.' (Section 2.39. Independence, choice and risk guide 2007).

One participant in this project helpfully summarised the three distinct times in the process of Self Directed Support being put in place, when capacity must be considered:

- The first is at self assessment to consider 'Does this person have the capacity to do some or all of this? (with whatever support is necessary including

professional opinions if appropriate).' What is important is that the Act is clear 'do not treat a person as incapable of making a decision unless you have tried all you can to help them.' Section 2.40. Independence, choice and risk guide 2007).

● Once it has been established that the person has an entitlement to social care funding, the second point to consider capacity is when asking the question 'What might this person need to enable them to write their own support plan? ' If the individual themselves cannot write the plan, make sure that the planning is as 'close' to the person as possible, e.g. by partners/family members/close friends.

● The third point at which to consider capacity is when asking:'How much control is this person able to have directly over the money?' This is a critical question, since control over the money is what shifts the power in Self Directed support. But people can retain that power and still have another person or organisation deal with the practicalities of keeping and accounting for it. What will remain pivotal is that the individual decides how it is spent and that the spend is monitored relative to whether the agreed *outcomes* of the plan are achieved not how the money is spent. (Other than having to be legal, affordable within the entitlement and effective).

Q.6. In mental health work it has been said that the 'shadow of the coroner's court hangs over us all'. How can we square this idea of handing over control when we are so concerned to assess and monitor risk and prevent suicide, or the very occasional but headline-grabbing murder?

This is a critical issue for mental health services. As Lisa Rodrigues says in the latest NHS Confederation document 'Time and Trouble- towards proper and compassionate mental healthcare' (2007): 'At the heart of risk assessment and least restrictive practice is the need to balance choice with need.

It is clearly tragic when a mother, whose son has taken his own life, feels he would be alive today if he had been kept in hospital, when at the same time that young man was desperate to make his own decisions, and had the capacity to do so. And for every relative who feels this way there is another who would do anything to avoid their loved one ever going inside a mental hospital. Our greatest priority is to make inpatient care a therapeutic experience, and we still have along way to go to achieve this for the small proportion of people who need it.'

Louis Appleby recently wrote: 'Every year around 1,300 people who are in contact with mental health services commit suicide and another 50 commit a homicide. Many of these tragedies are preceded by a refusal to take treatment. We are therefore updating the Mental Health Act to allow clinicians the power to treat high risk patients after discharge from hospital. At the moment this can only happen in hospital. Twenty years ago these same patients might have been in long stay beds. Today we want to be able to provide them with the best that community care can offer. 'The changes proposed in the New Mental Health Bill indicated in this quote have been challenged by people who are concerned that freedoms are being eroded and choice removed. Whilst services begin to talk of adopting a 'recovery approach' within mental health care delivery, there is as yet little evidence of a sufficient focus on people's abilities, strengths and aspirations to counter- balance the arguments put forward for more state control which inevitably inform professional practice and influence the service culture.

Nevertheless, there have been massive developments in mental health services in recent years, perhaps most notably the introduction of successful early intervention, crisis intervention and home treatment teams to enable more people to stay in their own homes, avoid hospital admission and crucially, get back on with their lives as quickly as possible. Some of these teams employ people who have been through mental health crises themselves to help inform and challenge their approaches. Early Intervention teams are beginning to sort out the gaps between children's and adult services and provide effective treatment early enough to make a significant difference to people's lives. The suicide rate has been falling, though there remain some people who are more at risk than others.

The risks surrounding mental illness and the government's response to this in proposed new legislation are a cause of significant tension in a system which is only very recently moving away from individual blame and towards shared team working. People who use mental health services have also been striving to provide alternatives and different perspectives from the medical approach. Anne Beales MBE, Director of Service-user Involvement at Together says that ' Service user led crisis houses, self help and other groups distinguish developments in mental health above and beyond developments in the NHS in general' (Time and Trouble 2007).

For the purpose of this discussion paper, the brief answer to the questions around risk are to be clear that the Local Authority's duty of care remains, and all of the same legal and NHS duties remain in place. No-one is suggesting that a handover of power should be so absolute that it throws aside all responsibilities of the State in situations where there is genuine cause for concern. Giving people an entitlement to money with which to buy social care does not replace the rights they have to the best possible NHS treatment and CMHTs must not 'close cases because some-one has a direct payment or individual budget'.

Self Directed Support must surely allow the possibility that more people will find their own ways to stay well enough not to need a crisis response, and since they are choosing how and who provides support, they are more likely to be successful in their recovery journey. In addition, by people finding ways to grow the number of mainstream places and people with whom they're in regular contact, situations where the mental health service is the only contact some-one has will be reduced, and other people will naturally begin to be concerned with how a person is getting on. This must surely reduce risk. A participant in this project is clear that there are already good examples from the use of direct payments in lieu of mental health services to evidence this assertion.

There can be positive opportunities for growth that come from being enabled to take risk and for all of us, making decisions that could be deemed 'unwise' can help us to learn. For professionals, families and individuals who want to consider how best to work constructively with risk- it can be useful to have somewhere to talk. In Oldham, a Risk Enablement Panel has been set up to allow an opportunity to discuss and agree how complicated situations can best be worked through. Recording these discussions and reasons for decisions allows both shared risk taking and learning over time.

The recently published Independence, Choice and Risk framework may be most useful as a tool to enable practice development. 'Independence, choice and risk: a guide to best practice in supported decision making' DH May 2007, is 'for the use of everyone involved in supporting adults (18 and over) using health and social care within any setting, whether community or residential, in the public, independent or voluntary sectors. This includes all NHS staff working in multi-disciplinary or joint teams.'

'The governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same.

'Fear of supporting people to take reasonable risks in their daily lives can prevent them from doing things that most people take for granted. What needs to be considered is the consequences of an action and the likelihood of harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them……. We propose that arrangements be put in place to manage more complex situations where there are different views held between the individual, the family carers or the professionals to seek agreed solutions. Ultimately the Local Authority has a statutory duty of care and a responsibility not to agree a care plan if there are serious concerns that it will not meet an individual's needs or places an individual in a dangerous situation. ……Person centred planning approaches identify what is important to a person from their own perspective and find appropriate solutions. We recommend person-centred approached for everyone.'

Section 2.46 of the Guide focuses on mental health and states that '***Just as for everyone else***, it is important to take a pro-active approach to risk with people who have mental health problems. (author's italics)The same good principles apply, yet the impact of mental illness can add complexity to the risk management process. For example it is important to recognise that people's needs may fluctuate and therefore it is important to review and monitor risk agreements regularly. The engagement of the individual and their family carer in this is crucial.

The Department of Health has commissioned a programme of work to help improve the assessment and management of clinical risk in secondary mental health services. The National Risk Management Programme sets out to find a balance between positive risk taking among users of services, and safety to self and others. A review of the Care Programme Approach is also considering how positive risk assessment and management can be better integrated into care assessment, planning and review processes.

Our Choices in Mental Health (CSIP Nov 2006) provides a best practice framework for providers to extend choices and practical support for people who use mental health services. The values underpinning the framework are:

- Living a normal life as far as possible
- Being included in local communities and activities
- Not being stigmatised or discriminated against on any grounds
- Easy access to up to date and accurate information
- Genuine options and/or choices of care available locally

- Personalised care plans that are built around the wishes of each individual and their carer
- Services and staff that promote and enable recovery and well-being.

(Independence, choice and risk guide 2007).

Q.7. If there is self assessment, we're concerned people with mental health problems will 'underplay their needs', either because of an effort to seem more well than they are or because they 'lack insight' into their condition. How can this be managed?

A. The process of self assessment is one that is vital as a shift towards the person describing the impact of the illness/disability on their day to day life and to find and outline their hopes and dreams for the future. This is not something that anyone else, no matter how well trained can imagine with the same vividness and accuracy. However, for all of us, having friends and/or professional support to help us be thoughtful and challenge some of our ideas, can be a useful and sometimes necessary way to enable us to think through our hopes and ideas, alongside our needs or problems. The idea is for self assessment to be supported - but not taken over.

Throughout this discussion a reiterating theme is the danger of mental health services setting their expectations of the people with whom they work, too low. This may be for a whole range of reasons including the isolation of mental health services from other Local Authority or Health services, leading to institutional views even outside of the walls of a physical institution. Also, there may be an over–professionalisation that stems from an unspoken fear of becoming mentally ill and therefore wishing to continually distance the people who 'have it'. This can be pernicious if not actively challenged through good self- reflective practice and good supervision. People who use mental health services talk of the 'dehumanising' that seems to happen through professional training- leading to many, many comments over years, about people who use services preferring to be supported by those who have no professional qualifications because their attitudes and assumptions are perceived to be so much better.

Evidence is available to counter the negativity. 'It is assumed that the poor and the poorly educated in particular will make bad choices. Judi Chamberlain, a US consumer/researcher, argues: 'People have a good idea of what works for them. Their view is often a lot wider than people who work in the mental health professional system, who see it in terms of treatment A or B. Professionals see people rejecting treatment as a symptom rather than a choice. 'The evidence from the US self directed care programmes supports Judi's view. With adequate support, participants make good use of the independence self direction allows them. '(Direct Dollars Vidhya Alakeson Mental Health Today March 2007.) In the US Florida, Michigan, Iowa, Oregon and Texas are all currently operating or developing pilots in Self Directed Care for adults with serious mental illness 'Participants have so far proved to be good stewards of public money: individual budgets are regularly under spent.'

In the UK the stories of people with mental health problems who have been able to access Direct Payments demonstrate the creativity of the solutions which people find when allowed to find their own ways to have support- solutions that commissioners or care managers are highly unlikely to have ever thought of by themselves. For example; one person, in an effort to address their social isolation and depression decided that rather than have traditional support from a community mental health service, they would buy a dog. This individual is now less depressed, is active and meeting people in an ordinary and successful way. How many of us as mental health providers or commissioners can honestly say this would have sprung to mind as our approach?

Q.8. Won't the stress of having to create their own support package and handle the money prove too much for people who may already suffer from anxiety and depression or have low motivation because of long term schizophrenia?

A. On the contrary, people who use mental health service may appear more likely to thrive when allowed the chance to choose what will work for them and to begin to be allowed to dream again, and to believe their lives can improve. Again, there is the usual carefulness required not to suddenly dump responsibility on people unused to exercising choice (and then use any resultant failure as proof the person could never succeed, in a classic 'self fulfilling prophecy'.)

Competence in dealing with all the things life throws at us is something that evolves over time and with adequate appropriate encouragement and support, including professional advice. People may well need to have support from 'recovery coaches/resource brokers' to help them put together their own personal recovery plan. Similarly, they may need the money to be dealt with by another person or organisation, all of which can be made available (see in Control website for the 6 ways that money can be managed etc). In the US example 'Brokers are often other mental health service users who have been trained to support their peers.' Again, a participant in this project is clear that there is plenty of actual evidence from Direct Payments of both people benefiting from taking on greater responsibility/control, and of being supported in this process. It is here, particularly perhaps, that the existence and work of Direct Payment support services can be acknowledged and built upon.

In the recent 'Why Choice?' Conference (27th June 2007), Dr. Alan Cohen, a practising GP and primary care lead at the Sainsbury Centre for Mental Health, presented a cogently argued view that: 'making a choice about how some-one's mental health problem is managed is, in its own right therapeutic. This is not what was intended by the Choice Agenda (which was about driving up quality through competition), but is probably more important. Nearly 100 million working days are lost through mental health problems- 90% for anxiety and depression and only 10% of these people are in touch with secondary mental health services.

Choice is useful for GPs as well as for patients. It reduces consultation rates and helps the patient recover. The distress with mental illness is a lot to do with feeling out of control for weeks or months. Having choice is a first step to being back in control. Choice is therapeutic in its own right. (i.e. when three treatments for depression all with the same predicted outcome are offered and one is chosen by the patient, the success rate increases.) We all like choice and feeling in control, including GPs and mental health staff. For GPs and others a tension exists between having the confidence to 'let go' and the uncomfortable feeling of not being 'in control.' (Dr. Alan Cohen abbreviated notes from Conference presentation.)

Q.9. People with mental health problems suffer badly from social exclusion in many ways and may be profoundly isolated and lonely. How can self directed support help with that?

A. Yes it's certainly true that people with mental health problems are actively excluded by our society. The 'Mental Health and Social Exclusion Report' (ODPM 2004) stated that 'Adults with long-term mental health problems are one of the most excluded groups in society

Although many want to work, fewer than a quarter actually do - the lowest rate for any of the main groups of disabled people. Too often people do not have other activities to fill their days and spend their time alone. ….Social isolation is an important risk factor for deteriorating mental health and suicide… Individual Placement and Support programmes in the US have achieved employment rates of over 50% among people with severe mental health problems, but these have not been widely implemented in this country.'

The Social Exclusion Unit identified 5 main reasons why mental health problems too often lead to and reinforce social exclusion:

- 'Stigma and discrimination against people with mental health problems is pervasive throughout society……Many people fear disclosing their condition even to family and friends

- Professionals across sectors often have too low expectations of what people with mental health problems can achieve. There is limited recognition in the NHS that returning to work and overcoming social isolation is associated with better health outcomes.

- There is a lack of clear responsibility for promoting vocational and social outcomes for adults with mental health problems.

- People can lack ongoing support to enable them to work. £140 million a year is invested by health and social care in vocational and day services for people with mental health problems. But not all of these promote social inclusion as effectively as they could….

- People face barriers to engaging in the community. They can struggle to access the basic services they need, in particular decent housing and transport…..Many people do not want to participate in activities alone, but feel there is no-one they can ask to go with them…'

Given the above, imagine how different it might be if some of the '£140 million' currently spent on segregated services were given directly to individuals with which to buy their own personalised support: transport; some-one they knew to go with them to a new place, (that they could pay for their support); access to training in things that interested and excited them; being in mainstream places with other people; being able to find ways to contribute their skills and abilities that have been overlooked or ignored.

There is a recent example of some-one who used a little of their Self Directed Support money to be able to join a dating agency – and found a new way to building relationships. It is true that money may not be able to 'buy friends' but having hope in your own future, feeling worthwhile, being able to participate in sports or all kinds of local activities (arts, chess, choir, volunteering etc) can begin to allow far more opportunities to make positive contact with other people and reduce isolation. Self Directed Support offers a wealth of possibilities that are beyond the reach of statutorily provided services, and frequently beyond their imagination.

However, it is also important to remember the degree of hostility and abuse that people with mental health problems can face and to acknowledge the need to encourage and enable peer support networks and the option of people creating or maintaining 'safe places to be'. This does not have to mean traditional day care, but could mean a range of funded networks where people had opportunities to meet with others who have been through similar experiences. For any discriminated against group, this can be a chance to feel understood and have a place to recover from the pressures of dealing with that discrimination. User led services offer opportunities for people to also try new experiences and grow in confidence. Far too few of them have received regular and secure funding. Self Directed Support allows people to come together and pool their money around a common purpose if they choose to.

Q.10. How would any Self Directed Support plan fit with the Care Programme Approach?

A. Perhaps we need to begin to think rather how the CPA fits with some-one's own whole life plan? The Care Programme Approach (CPA) was introduced in 1990 to provide a framework for effective mental health care for people with severe mental health problems. Its four main elements were:

- Systematic arrangements for assessing the health and social needs of people accepted into specialist mental health services;

- The formation of a care plan which identifies the health and social care required from a variety of providers;

- The appointment of a key worker (care co-ordinator) to keep in close touch with the service user and to monitor and co-ordinate care; and

- Regular review and, where necessary, agreed changes to the care plan.

The importance of close working between health and social care services was stressed, as was the need to involve service users and their carers in the assessment and planning of service users' support and care. The CPA model was reviewed in 1999 with the publication of the Mental Health National Service Framework. It is currently being reviewed again, prompted by a number of key policy developments since 1999 and also the 'need to consider developments on: Connecting for Health (NPfIT); Payment by Results, Practice Based Commissioning; Individual Budgets and Direct Payments; MONITOR's service contract with Foundation Trusts and wider changes to assessment and care management processes in health and social care. ' (Reviewing the CPA 2006).

Participants in this project expressed a clear view that saw the CPA plan as being perceived to be an organisationally owned plan, not the person's own plan. There was a suggestion that, whilst the CPA, once revised may have to remain a responsibility of Health and Social Care secondary services, an individual's Self Directed Support plan could become the person's main support plan, covering all aspects of their life.

The current CPA review has gathered together evidence and is making clear proposals. There is said to have been a positive response to the initial work and consistency of support for the principles and process of CPA in parallel with concern for how it has become so bureaucratic. It is useful to consider the kinds of information about how CPA has been used to date: 'Concern about the loss of relationship with users of the service was evident throughout. There was disquiet that the CPA has become a managerial tool rather than a system of engaging with people. ………Service users expressed concern at the lack of attention to their wider social care needs within their care plan, particularly when the focus has been on problems, risk and subsequent treatment rather than building on their strengths towards recovery. There was equally concern by service users that not enough attention is paid to contingency planning or crisis planning. Carers also aired views about their lack of involvement as partners in the care assessment and planning process.'

Service user involvement has been continuously discussed in mental health services for at least the past twenty five years, yet there remains clear evidence that the person is still frequently left out of the most crucial part of their mental health service: The 2006 Mental Health National Patient Survey showed that only 58% of service users reported definitely understanding their care plans and of those surveyed, only 53% had been offered a copy of their care plan. Similarly, just 40% of service users reported being involved in deciding what was in their care plan.

Despite these results 77% of service users rated their overall care as excellent. One participant in this discussion document commented 'if this is excellent, what would a poor service look like?' There have undoubtedly been improvements in mental health services in recent years, and the increase in the number of people who said in the survey that they felt they had been treated with dignity and respect is to be hugely welcomed. Nevertheless, the overall model seems to be firmly rooted in a 'professional gift' approach rather than an 'active citizen' approach. In the first; people are assessed for whether they merit help and are then provided with professional care and treatment. In the second; people are seen as equal citizens with a right to access the support and treatment that allows them to live an ordinary life. Services are there to enable that access and the individual is recognised as having skills to offer as well as support needs to be met. Participants in this project spoke clearly of the value of being allowed to contribute as well as to receive, to be seen as active participants not passive recipients.

Several contributors have commented that 'a Self Directed Support Plan 'starts from a different place' from other plans. It starts with some-one's hopes and dreams rather than from their problems and illness. Several Local Authorities which are enabling people to have Self Directed Support are keen to ensure that the plans people write are not constricted into one format but are unique to each person, and proportional to the funding. Regulation of the plans would, they believe, lose the essential ownership of the plan, lead to unnecessary bureaucracy and diminish its effectiveness. Currently people have written all kinds of plans, using pictures as well as words, photographs catalogue information etc.

Q.11. With budgets overspending and no more new money coming in, how can you expect the public to stand for people using tax payers' money for gym membership, or to buy a dog, or buy a computer?

A. This is definitely a subject that needs careful consideration and a proactive response for all areas developing self directed support. There needs to be good examples of the problems and disabilities people were suffering that entitled them to the public funding, alongside evidence of how the money spent made a difference, in order to allow people to accept the shift away from traditional care to the creative use on money. The emphasis must surely be on effectiveness and therefore the wisdom of spend, rather than an endless debate over what public money should buy.

In Norfolk, the only one of the 13 Individual Budget pilot sites in England to focus solely on people with mental health problems, Gill Stewart, the lead for the area says that: 'It's almost as if the medicine has to taste bad in order for it to be doing you good. If people are not using or benefiting from services as much as they could then are we really saying that we want to spend money on those services?' Stewart recognises that there is a tension in society with many people on low incomes who would also like to be able to access the opportunities offered by individual budgets. But she stresses that people need to recognise that those with disabilities have extra needs on top of their social disadvantage.' ('Eastern pilots show promise' Gill Stewart tells Simeon Brody Community Care 21st June 2007)

Q.12. Surely not everyone will want this? Why should people be forced out of services they know and like?

A. It may well be that not everyone wants to rush to try new ways of doing things. In mental health services people have found things of value to them in the existing service arrangements and may be understandably scared that they may lose what little they have.

The move towards Self Directed Support can be taken at different rates. However, everyone can be told the amount of money that their current service is costing, and that this money could be made available to them, with support, to meet their support needs in ways that they may wish to choose. In this way, people are making a decision with full information. Similarly, letting everyone hear what some others are doing with their funding will enable people to see real life examples of alternatives. For people newly referred to services, there could be an expectation that self directed support will be the 'norm'. In some Local Authorities they have already started to offer self directed support to everyone newly referred.

One of the arguments that has arisen with Direct Payments is people asking 'why should some people taking their support in the form of a Direct Payment be allowed to destabilise the services that others are happy with and don't want to lose (by reducing the funding available)?' As Direct Payments are a right, the question can equally be put: 'why should some people, who want what is currently available, demand that others who wish for a different solution forgo that wish so that things can stay as they are?' The challenge is for providers to adjust to changing requirements and to work with those who continue to use their services to maintain the things that are of value within them. Work with providers and commissioners of services will be necessary to discuss transitions to new ways of working, notice periods etc.

Learning from Direct Payment schemes around the country also shows that it is crucial that we make sure that people who want to direct their own support, or who are considering it, have the support they need built in to our operating systems. i.e. it is not enough for a care co-ordinator to simply offer a sentence at review about Self Directed Support, there is evidence that this is not enough. It needs to be more pro-active than that and to offer support with any of the steps: self assessment, planning and managing the money; support that is sufficient for the person and their family, (alway remembering that too much support can be damaging too.)

4. Money Issues

This work discovered a whole range of related concerns about money to fund Self Directed Support in mental health services. These can be listed under a few headings:

4.1 Issue: not enough money

The principle worry is that there simply is not enough money provided by the Local Authority. Most of the money is given by Health. Certainly, in relation to money given to other groups of needs, mental health services frequently appear to be the lowest funded in social services and a bigger proportion of money is used within Health. Other services generally feel equally unfairly funded, and all feel under pressure and that they haven't enough to offer people what they want. Demand for many services appears to be rising, in line with changing demographics and spending continues to rise faster than increases in resources.

Suggestions

In a couple of Local Authorities at least, there has been a decision to put all of the social care money that is available into one 'pot' rather than cutting it up between different types of need. (People's eligibility to access this 'pot' is still decided by applying FACs criteria). Once a Resource Allocation System (see In Control website for information on this) is in place, then there is a clear set of criteria that links self assessment to a formula that can quickly establish some-one' indicative allocation. If all local people use the same system to access social care funding then there will be greater transparency, greater equity and people with mental health problems would be as able to access funding as any other person with a disability. There would be no more money available overall, and perhaps some groups who have been used to having more of the 'cake' may have less, but ultimately this approach ought to mean that the same levels of need are given the same amounts of resource, even though how those needs have arisen (learning disability, physical disability, frailty in older age, mental health problem) differ.

The issue of insufficient money to cope with demand has been an interminable source of worry and argument in all social care services for many years. A recent publication from CSIP, that explored how money for services for people with a learning disability could best be used and managed, could equally well be applied across all services: 'There is only limited scope for achieving better value for money within the current system of commissioning. Many councils have already tightened eligibility criteria, but spending continues to increase.' 'This report concludes that a shift towards Self Directed Support on a large scale offers the best chance for councils to meet increasing needs and get better value for money. '(Getting to grips with commissioning for people with learning disabilities 'CSIP April 2007.)

Self Directed Support can enable good evidence to be gathered of the effective use of public money in both cost terms and the quality of outcomes, (efficiency and effectiveness). For in Control, the key to personalisation is that people are re-instated as citizens, active economic and social participants in their communities.

The question of whether people are citizens or merely consumers has been examined by Jon Glasby, reader in health and social care at Birmingham University. In a recent Community Care article Glasby states that he thinks it matters hugely whether the goal of Self Directed Support, or 'personalisation' is consumerism or citizenship. Consumerism focuses on good service and a supple response to customer's needs. Citizenship by contrast, puts the onus on human and civil rights to a reasonable quality of life. 'If as a public body you take the consumer view, you're likely to focus on efficiency and keeping down costs, 'Glasby says. 'If your interest is in citizenship, you're likely to see direct payments and individual budgets as honouring a fundamental moral obligation to help citizens meet their needs.' Glasby says it's so far unclear which of the two principles the government has in mind. In the same article, Peter Beresford, professor of social policy at Brunel University and chair of Shaping Our Lives, the national service-user controlled organisation and network, says that 'I've always been worried about this quest to find savings from personalisation. If we do that, all the good things about it will be put at risk.' (Community care article 'Ground Control' 13th September '07)

4. 2 Issue: FACS

Fair Access to Care criteria and explicit assessments for entitlement appear to have become very little discussed or openly acknowledged in mental health services over recent years, where Community Mental Health Team staff conduct joint assessments of needs. People with mental health problems then frequently appear to suffer an entirely confusing and ill explained process to try to gain social care funding. A variety of different methods to decide funding are in place, sometimes with small amounts being distributed by local team managers. A funding panel may then hear requests from care managers for larger amounts of money. There appears to be no transparency, and outcomes can depend on how well something is argued for, who is on the panel, how much money is left etc.

In general people with mental health problems have not been charged for services (except perhaps for contributing towards residential care.) In some places, people currently receiving day services who have been assessed under FACS as part of a process of moving towards Self Directed Support, have been found not to meet the FACS criteria.

Suggestions

Fair Access to Care criteria would remain a central part of the Resource Allocation System. Entitlement would be established and charging policies would be applied. There is no justifiable reason why people with mental health problems would not be means tested for their ability to contribute, the same as everyone else, if Local Authorities choose to continue to levy charges. Training may be urgently needed if there are mental health services where staff are not identifying social care needs, and are not used to assessing using FACS criteria. For multidisciplinary teams, this may mean a change to the current assessment forms and processes that they are following. These changes will be essential if people who enter services through a 'health' door are not to be excluded from their rights.

The funding panels as they currently function would no longer be required but the support plan does have to be signed off by the Local Authority. The person will have to demonstrate that funding is used to meet the outcomes agreed in their plan, and the Local Authority will continue to have a key role to monitor that public money is being used appropriately, by monitoring outcomes, not by rigidly controlling how the money can be spent. If some-one currently using mental health services is assessed and found not to meet FACS criteria the Local Authority would surely have a responsibility to continue to support that person through a transitionary period, to enable them to find alternate sources of support. (The individual surely cannot be made to suffer for the Local Authority not having applied its own criteria for some time and allowing people to become used to having a service.)

At least one Local Authority has set aside some funding as a 'preventative grant' in order to be able to support some situations which fall outside of FACS criteria but can be seen to prevent deterioration into higher levels of need.

4. 3 Issue: Other services have had help to do this

Mental Health has not had access to a Development Grant such as that provided to Learning Disability Services and the Mental Illness Specific Grant is being reduced and has been used to pay for voluntary sector services.

Suggestions

It is true that mental health services have had different funding streams from some other services and have little if any money readily available for 'development.' This doesn't mean we can't do better with what there is. (Learning Disability services would argue that the Development Grant was existing money re-packaged.) Nationally there has also been input to mental health services' development through some NSF funding, and through NIMHE and then CSIP. Whilst each service area may in turn feel unfairly treated the reality is that all service areas are under pressure and none have sufficient to satisfy all need.

4. 4 Issue: No available money

All of the money that is in Local Authority budgets for mental health services is tied up in staff and buildings. There is none 'free' to give to people individually.

Suggestions

Most money being tied up in staff and buildings is true for other services too. As a start, people could have their identified money still paid to a provider but as an Individual Service Fund. 'This system of funding should be of immense interest to good service providers who want to offer truly individual services. The idea is that the provider receives the funding as 'restricted funding'. This means the provider cannot use the funding to provide services to other people and that any management or other charges must be set out and agreed at the beginning. The provider cannot 'help itself' to people's funding.

This approach has been pioneered by organisations like Inclusion Glasgow, Partners for Inclusion and C-Change for Inclusion. These service providers make a commitment to designing flexible individual support services and changing those services over time. In addition the individual funding is kept in an Individual Service Fund and the organisation is accountable to the individual and the local authority for how that funding is used.' (Duffy in Control website) In Control is working with others to consider further how commissioners and providers can increase access to money for individual support.

4.5 Issue: Range of funding streams

Self Directed Support allows for other funding streams to be brought together. For example, money from: the Disability Facilities Grant, Integrated Community Equipment Services, Independent Living Fund and Supporting People money. This range of funding streams, currently available to other groups (either through multiple routes or by being collated in some individual budget pilots), appears not to be so available or perhaps not be relevant to people with mental health problems.

Suggestions

It does seem to be true that the range of funding streams available to some other people is not accessible to people with mental health problems. For example, whilst the Independent Living Fund is available to people with mental health problems, the way mental health services are currently organised may mean many people can't access that funding.

For example, in order to be able to access the Independent Living Fund people have to be in receipt of £10,400 per year of social care funding, and workers' time doesn't count. Given that the main mental health service response is a worker, then many people using mental health services would probably not receive the minimum social care level of funding that would trigger ILF. It's worth remembering that ILF can start at 16 years old. Education services can also give money to Social Services who can then give it to a young person/family to use.

In a similar way many older people's care packages have traditionally been quite small, although Individual Budgets have shown that small changes can make a significant difference in some-one's life. 'A number of pilot sites mentioned how the Resource Allocation system has exposed the inequities between client groups in the current funding of care and support services' …'Some sites have had considerable success in bringing in additional resources to boost the individual budget available to the older person…An imaginative welfare rights assessment to maximise an individual's income is a clear pre-requisite.' (Older People's Services and Individual Budgets Good practice Examples and Ideas CSIP May 2007)

4. 6 Issue: Local Authorities will spend and PCTs will gain

Money that is used to successfully meet some-one's social care needs and therefore helps them remain well, avoid crises and stay out of hospital will cost Local Authorities but benefit Health services economically.

Response

It seems to be undeniably true that money that is used to successfully meet some-one's social care needs and therefore helps them remain well, avoid crises and stay out of hospital will cost Local Authorities but benefit Health services economically. This is an issue that cuts across all health and social care systems and is the subject of much current debate.

4.7 Issue: Health or Social Care - who should pay?

There is endless debate over who should pay for what- health or social care. This is time consuming, unhelpful and destructive.

Suggestions

The fact that there remains a long standing and unresolved debate over the relative importance and weight of social and genetic factors in *causation* of mental ill health does not stop Self Directed Support giving an individual the power to choose how to deal with the impact of an illness on their everyday life. There was much debate around this issue in the project. What is clear is that people can use their social care entitlement to buy whatever they want to meet their agreed outcomes, including services perceived to be Health services. In order to make such a decision with full information, people would need to know what services the NHS would provide to them for free, and within what time scale. They could then choose to buy some or all of those services privately if their budget were sufficient.

This issue raises the further question of when NHS money can be used for Self Directed Support. It is currently illegal for the NHS to pay money directly to individuals. There are however, joint commissioning arrangements with pooled budgets in some mental health services and these may perhaps offer some greater flexibility. In the United States, some states have broken down that barrier. 'This kind of flexibility recognises that mental health recovery involves all facets of a person's life, and that what is not traditionally considered to be healthcare may be exactly what an individual needs to stay healthy'……..'Participants in the Oregon programme are more likely than non participants to have moved into employment or education and training. Fewer crises and fewer days in hospital mean significant savings to the public mental health system'…….'It should be entirely justifiable to spend NHS resources on non health-related services where they can be shown to contribute to recovery.' Vidhya Alakeson Direct Dollars Mental Health Today March 2007).

5. The Social Perspective is lost

A re-iterated theme throughout the workshops and interviews for this project found that perhaps the clearest message was that 'the voice of social care is lost in mental health.' Several people had been strong supporters of the value of integration and had consistently strived to see services integrate. Now, with reflection on the consequences and the impact of that integration, people are beginning to revise their previous views. This is because, having hoped that social workers joining mental health teams would gradually lead to an evolution of the medical model into a social disability model, they see little if any evidence of this. On the contrary, social work in mental health seems to have become detached from Local Authorities, and perhaps also from its value base as a profession.

 'Although they may be part of a particular mental health team, they often feel that they are professionally isolated, that their contribution is not valued, that they are not receiving effective professional supervision, and that they are under enormous pressure. The lack of job satisfaction, a feeling of not being valued and 'burnout' was highlighted in research undertaken by Peter Huxley et al and reported in the Journal of Psychiatry 2006.' (Mental Health: New Ways of Working for Everyone (DH April 2007)

The emphasis in mental health services, as a predominantly Health context, has been on specialisation and therapy. The policy context which wraps around it and informs and drives service development and professional practice comes through the Health service, led by the Mental Health Tsar, Louis Appleby. In searching for an overlap between social care and health initiatives, it is hard to find any coherence. The latest documents are about specialist mental health services doing better, not about service users buying their own support packages.

One of the latest policy documents: Mental Health: New Ways of Working for Everyone (DH April 2007) is intended to further improve services through changes in workforce: 'In essence, it is about promoting a model where responsibility is distributed among team members rather than delegated by a single profession, such as the consultant. The aim is to achieve a cultural shift that enables those with the most experience and skills to work face to face with those with the most complex needs, and to support and supervise other staff to undertake less complex or more routine work.'

It is impossible to do justice to the New Ways of Working document (which is 164 pages long) in this discussion document. But it is necessary to comment that, whilst perhaps no-one could reasonably argue with the usefulness of making the best use of skilled workers to try to 'provide services that meet the needs of service users and their carers', where is the belief in Self Directed Support as a way that people can exert their own choice between these 'expert' secondary mental health services and alternatives?

Most people would probably prefer not to have to have services from specialist mental health services at all and would prefer to find support in mainstream services. Service users have consistently chosen to value very highly the support they're given by non qualified staff and fellow service users. Whilst there is plenty of reference to a recovery approach, the team response is expected to be based on 'your individual needs and strengths', rather than being clearly based on the person in their whole community and social context.

New Ways of Working claims to be about a big culture change 'Only when all service users and carers are genuinely involved in their care, when real choices based on knowledge can be made, and when service users and carers are truly enabled by services led by their needs to move forward on the long journey towards their recovery, will some of the past, entrenched methods and practices become the exception and enlightened inclusive care become the rule.' IS this a big cultural change? Being involved in care is not the same as deciding how you would prefer to meet your own identified support needs. Services that are based on needs seem unlikely to find the strengths and skills that people have to offer. Recognising and 'including service users and carers as valued and respected members of the healthcare team' seems to pull service users ever more into a system that is all about specialism and separateness, even whilst it talks of promoting social inclusion. The shift of power that can happen when people are given the money with which to choose is not mentioned in the document.

The newly formed NHS Confederation Mental Health Network has as its first publication 'Time and Trouble- towards proper and compassionate mental healthcare' (2007). The report seeks to tell the story of change, highlighting success where possible and setting out key challenges. The sole mention of self directed support is on the back page, where Steve Shrubb, the (newly appointed) Director of the Mental Health Network, outlines his vision for the future and includes 'services that are committed to and able to support a model of self directed care- with service users and their families having greater influence over the design, delivery and resources of their care…'

The latest DH document 'Breaking down barriers Clinical Case for Change: Report by Louis Appleby May 2007, eloquently describes some of the barriers that exclude people from living ordinary lives, but does not mention self directed support. It repeats that at the heart of changes will be workforce reform. The split between the Choice agenda, as understood in social care, and the Choice agenda as understood in the Health context was clearly evident at the recent 'Why Choice?' conference (27th June 07). The Health service is aiming to enable there to be excellent services provided by a skilled workforce, that service users may choose between. The social care world is seeking to promote a total transformation of service delivery, through personalisation led by devolving money and therefore power, to those who require support.

Suggestions/comments

5.1 Articulating the social model of disability in mental health

At its most simple, a social care approach reflects the social model of disability, focusing on removing the barriers to people's social and economic participation. The social model of disability is about working out ways to overcome the impact of a disability or illness on some-one's whole life, rather than focussing on diagnosis and treatment of the illness. This approach does not always translate well under a healthcare model, which is generally about making the individual better or rehabilitated. It is important to consider how, for a variety of reasons, mental health has remained 'outside' of the broader disability rights movement and has consequently been largely left behind in the progress made by others to explain and promote this perspective.

The social care model needs to be far better articulated in mental health services to begin to influence the predominant culture. 'Medicalised individual models of mental illness continue to predominate in the policy practice and analysis of madness and mental distress, even though they have been subjected to challenges from both professionals and service users over the last thirty years…. ' (Peter Beresford 'Psychiatric system survivors, the social model of disability and a social model of madness and distress' Brunel University project- completion due August 2008)

5.2 Re-energise the social work role

There may be many ways to do this: re-emphasising the relevance of social work core principles and best practice, reinforcing the validity of those principles, finding ways to talk about the social model of disability in mental heath services, re-connecting Local Authorities with social work in mental health and calling for clearer, stronger leadership of the social perspective in mental health.

Social work values, skills and knowledge already encompass the approach set out in current government policy documents. The recent consultation paper 'Roles and tasks of social work in England' March 2007, jointly produced by the General Social Care Council (GSCC), Social Care Institute for Excellence (SCIE), Children's Workforce Development Council (CWDC) Commission for Social Care Inspection(CSCI) and Skills for Care (SfC) gives a succinct and clear description of the principles and roles of social work. At its best it states that 'Good social work places the service user at the centre of everything it does, concentrates on abilities rather than impairments, balances rights and risks appropriately for children and adults, families and communities, strives for social justice and challenges discrimination and exclusion.'

Similarly, an article in Community Care in July 2006 commented that:'Social workers practised social inclusion before the term had been invented. Above all in mental health, it challenges the traditional medical model which does not fully acknowledge the patient or client as best informed about their needs.'

One participant described their view of how the social work role for the future can be seen to include four main aspects:

- less assessment, as people increasingly self assess but more time spent on review i.e. monitoring the outcomes of peoples' support plans;
- More time to focus on Adult protection issues
- The re-emergence of Community Development work or 'place shaping' to ensure that there are sufficient community resources accessible to people with a range of different needs
- Time to focus on well-being initiatives in local communities- preventative work and promoting mental health.

The recent article in Community Care ('Ground Control' Sept 13th '07) examining self directed support, includes the following: 'Personalisation has an affinity with another concept beloved of the think tanks: social capital, the networks and resources that sustain people in their communities. Service users should be able to spend individual budgets in a way that stimulates existing social capital-relatives, friends, neighbours, lunch clubs and so on, -rather than exploit it as traditional services have done. Despite the new vocabulary, older social workers, may sense faint stirrings of the community social work that once attracted them and was believed to have been killed off by the Thatcher government. In the 'partnership of equals', their role will be to act as advocates and advisors, informing self assessments rather than doing the job themselves.'

5.3 Clarify and promote mental health social work leadership

Most people in this project were uncertain who was the principle leader in the country of social workers in mental health. Several people suggested asking that such a role be defined and promoted. This echoes the recommendations made in New Ways of Working which include that there should be:

- 'explicit representation of social care interests in decision making processes throughout the organisation, up to Board level,
- strong ongoing local authority engagement in mental health issues where the Trust is leading on delivery of social care
- proper resourcing of the social care management and leadership tasks'

The document goes on to state that: 'Social work values, skills and knowledge already encompass the approach set out in current government policy documents. These all emphasise the need for service users to participate actively in their care. Social workers have historically sought to work together with service users and their carers in partnership. More than any other profession, their value base is most closely aligned to his approach.' Mental Health: New Ways of Working for Everyone (DH April 2007)

5.4 Training for Person centred planning

Person centred planning is not widely used in many services, although there is much talk of it. This is a problem that could readily be addressed through training. To be most effective, participants have found that such training needs to also include training in outcome planning, self directed support and to be mandatory and across services, not exclusive.

6. The Recovery Approach

There is still a degree of confusion around this term, and there were views expressed that all organisations are claiming to take such an approach. 'People who use services are often concerned that if the recovery approach is adopted by mental health services, the person-centred and empowering aspects could be lost, and existing services merely re-labelled as recovery services (BME focus group 2006 in 'A Common Purpose: Recovery in Future Mental Health Services (RCPsych, CSIP,SCIE May 2007)….'recovery has been defined as a deeply personal, unique process of changing one's attitudes, values, feelings, goals skills and roles. 'It is a way of living a satisfying, hopeful and contributing life, even within the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness'' (Antony 1993 in 'A Common Purpose'2007).   The challenge, as one group commented in this project, is to ask Mental Health Trusts 'What are you doing to instil hope and optimism? How are you enabling independence?' 'Show this tangibly don't just say it'.

There is so much that is useful in the paper and relevant to this discussion paper that it is impossible to capture all the essential points made. However, a few key quotes may be illustrative: 'Recovery is the process of regaining active control over one's life.' 'This includes accessing useful information, developing confidence in negotiating choices and taking increasing personal responsibility through effective self care, self management and self directed care.' 'Recovery is significantly about recovering an emphasis on the relationship people have with their problems as a counterweight to the endemic tendency to see people defined as and by their problems.' 'Recovery creates a community that all can take part in as it erases the distinctions of position, age, skin colour, religion, language and education and joins us in our common humanity.'

'Finally, it is a widely accepted recovery competence that in order to provide effective recovery services staff and service organisations need to attend to their own hope and morale. Both hope and despair are contagious and for the first time we are considering the guiding principles and values for our work that emphasise that the health and well being of the practitioner, and their organisation are a pre-requisite for effective practice.'

Piers Allott (National Fellow for Recovery) writes that 'Publication of the joint position paper, is a milestone on the journey of setting hope of recovery at the heart of mental health service development…..As an approach it may well be useful in a range of other ways and with other groups of disabled people since at its core is self management and self directed care.'

7. Integration and 'Involvement'

The integration of health and social care may have improved co-ordination and communication between staff but it has not yet delivered the holistic, community rooted, user led approach that some had hoped for, neither has it succeeded in significantly pushing forward the social inclusion agenda. At the same time people's other health needs: their physical health needs, have continued to be neglected. The blurring of roles seems rather to have narrowed both health and social care responses. Perhaps it is an appropriate time to re-consider the partnerships and organisational structures adopted to date? At the least, it seems to be time to critically re-appraise how integrated services are working. If any structural change were to be proposed however, we would need to ensure that some of the benefits that have been won by integration are not thrown away. Crucially, any thought or debate about structures and partnerships must not delay the more important shift of power, away from mental health services and to individuals and their families.

What evidence is there that people with mental health problems are not having the best treatment for their physical health in integrated services? And what evidence is there that the social inclusion agenda is not being significantly advanced in integrated services?

 'International evidence shows that people with long term mental health problems on average die 10 to 15 years younger than other citizens, often from preventable illnesses. They also live with poorer physical health which means people who are already exceptionally socially excluded- on every measure from education and employment to housing and social networks-often face the additional challenge of diabetes, heart disease or other long term physical illness. This makes it harder to participate socially and economically as well as harder to play an active, valued role within the family and community' (Disability Rights Commission. Equal treatment: Closing the Gap Interim Report into a Formal Investigation into Health Inequalities. 2005)

The very latest joint review of adult community mental health services in England:' No voice, no choice' (CSCI and Healthcare Commission 30th July 2007) vividly highlights both of these issues: that more focus is needed on physical health and that services are not yet sufficiently helping people to recover and become part of their communities again. The review reiterates some of the findings from the CPA review mentioned earlier in this document, and then goes further. So, for example, key findings include that:

- 'Many people who use services were not fully involved in decisions about their own care.

- Too few people are being offered or are receiving a written copy of their care plan.

- People are not always aware of who their care co-ordinator is.

- Not enough care reviews are being carried out.

- Too few people are involved in decisions about their medication.

- More focus is needed on physical health….It is crucial that this aspect of people's care is directly addressed as part of the overall planning of care, and not the subject of further neglect.

- People need help with employment. Far too often professionals across health and social services have low expectations of what people who experience mental health problems can achieve. Employment opportunities can have a direct correlation with improved mental health, and employment assessments are required by the Care Programme Approach. Yet our review found that only half the people who said they wanted help in finding employment received it. ….

- Problems with dual diagnosis. There is continuing concern that the Care Programme Approach is not adequately supporting people with a dual diagnosis (those who misuse drugs and alcohol for example). It is part of a general concern that the Care Programme Approach does not fully take account of broader issues such as dual diagnosis, homelessness, parenting responsibilities and personality disorders for example, when planning and assessing care.

These failures in the provision of services directly relate to the poor and inconsistent implementation of the Care Programme Approach.'

The most pressing areas identified for further development in 'No voice, no choice' include the following: 'the Care Programme Approach is not working well in many areas and people who use services are still not receiving a copy of their care plans. These people said that their needs were not reviewed on a regular basis or when significant changes occurred. Consequently they did not feel engaged in either the Care Programme Approach process or in their own care. People who use services also reported that they did not feel that there was a seamless approach to their care, and that the Care Programme Approach was not a method that put their needs first. '

Is any more evidence necessary to demonstrate the need to re-think how integrated services can be improved?- and to demonstrate the need to move towards a person centred planning process, with the power to decide how support needs are met given directly to individuals and their families?

'No voice, no choice' stresses that robust primary/secondary care arrangements should be in place to address and record the physical health needs of people using mental health services. Importantly, it also reports that 'specialist services for those from black and ethnic minority background were not widespread and the needs of these populations were not fully considered. Recording of ethnicity was often lax, and therefore services were not planned accordingly. 'In this project, examples were shared of how the use of Self Directed Support had enabled some people from minority ethnic groups to employ support workers who matched their ethnic and cultural background and that this was successful and popular.

Within the mental health system it has been shown that people from Black and minority ethnic groups have been subject to both over-representation and neglect on account of stereotypes, cultural ignorance and ingrained racism. (Ndegwa and Olajide 2003; Fernando 2002). Therefore it is important to acknowledge the 'multiple oppressions' impacting upon all those who have mental health issues and who also belong to a Black and Minority Ethnic group. (Thompson 2001).

Cash payments would appear to offer an excellent opportunity to provide more culturally specific support to Black and Minority Ethnic groups, and to enable people to have more choice and control in their lives. Yet it has been shown that 'in fact, black and minority ethnic communities are the least likely to be offered the direct payments option by Local Authorities, despite their mandatory duty to do so' (Stuart 2006)

This discussion paper is calling attention to the evidence that, without focussed attention, clear goals, monitoring and action, discrimination and exclusion is highly likely to persist. The introduction of Self Directed Support as a universal system provides an opportunity to begin to redress current inequities.

Finally, for the purpose of this report, it is useful to reflect on the findings in 'No voice no choice' about Direct Payments and involvement in care: 'The take up of direct payments remains low, and within this, the take up by people who use mental health services lags behind other groups. Direct Payments are an important way for people to take control of their own care by directly purchasing the services they require. We found that the councils that demonstrated good progress were those with well-informed staff who were able to provide information about direct payments, had good support systems, and provided advice and assistance to people who use them.' Alongside the lack of support for employment, the fact that people using mental health services were also being given little opportunity to control the way that their care needs were met by being offered access to direct payments leads the review to state: 'These are both crucial components of the social inclusion agenda that are being ignored.'

'Our findings on how well people using services are involved in the care that they receive remains of particular concern. Independence is as important an issue for people who experience mental health problems as it is for cardiac or diabetes patients. Sadly however, many services still do not seem to realise this and the gaps in provision of services highlighted in the 2004 Mental Health and Social Exclusion report remain.' (No voice no choice July '07 summary and main report. CSCI and Healthcare Commission.)

Participants in this project were keen to ensure that, having recognised that current integrated systems have not enabled the anticipated progress on these key issues, we find alternate ways to enable both health and social care services to be the best they can be. Suggestions were made that Health services be supported to re-integrate all aspects of health (mind and body) and social care services be supported in championing a renewed social disability approach to inform all mental health work, not just social work.

Both services, (as one integrated mental health service), then put services users in the centre, not on the basis of whether the mental health service system chooses to allow that and benevolently grants 'involvement', but through a rights based approach that gives entitlement to money and adequate support to enable maximum independence and the possibility of a far better life. 'Respect for the autonomy of people who use services must be considered obligatory for all professionals working within community mental health services.' (No voice, no choice July '07)

This demand for multi-disciplinary team members to respect people's autonomy reminds us that 'social work', (and by definition social workers) cannot be the only route by which the principles which underpin a change in culture must come. It should be recognised that many 'health staff' have made Direct Payments and appreciated the change of culture needed, and that many social workers simply have not. This is not a 'social work' issue alone; it is a whole system issue. Holistic mental health services are supposed to be provided by all mental health staff. The task remains to set mental health services in their entirety within a social context and to make certain that people with mental health problems are not excluded from the move towards Self Directed Support.

Academics Melanie Henwood and Bob Hudson, whose report on personalisation is expected to be published by the Department of Health in the autumn, say that 'with the right strategic support from the centre', the transition should take between five and seven years. They are optimistic, seeing it as the 'first genuine attempt to empower service users.' 'Personalisation is about a major paradigm shift. It is probably the most radical shift in social care for 60 years. 'Similarly, Jon Glasby, reader in health and social care at Birmingham University speaks of a 'partnership of equals' between users and practitioners that should have resulted from the 1990 Act but was thwarted because employers guarded their power jealously. Personalisation is a second chance to get it right. 'This is not old-style user involvement dressed up; this is new' he says. ('Ground Control' Community Care 13th Sept '07)

Peter Beresford, Professor of Social Policy at Brunel University and chair of Shaping Our Lives, the national service-user controlled organisation and network, whilst acknowledging some progress, also calls for an acknowledgment that 'we are unlikely to make much progress on user involvement and advancing service-user agendas without yet more blood sweat and tears. Much more campaigning is going to be needed if we are to match our achievements in putting service users at the centre with out aspirations. We will need new alliances, for example between social care workers and service users and between different groups of service users so that we can't be divided and set against each other. '('Nothing about us without us' Community Care 13th Sept '07).

8. Steps to Successful Implementation of Self-Directed Support

This final section pulls together a check list of ideas that has been generated by participants in this project. The first three steps were mentioned earlier, when considering how to address the lack of knowledge about Self Directed Support in mental health services. All eight steps are summarised here for ease of reference:

8.1 Backing from the 'top' and engagement though the whole system:

- Aim to have total understanding and widely expressed commitment from the senior management team.

- Challenge and encourage the Local Authority to fully engage or re-engage with the mental health social care agenda. Be prepared to go to DH for backing if necessary.

- Allow leaders in services and local politicians to hear clearly about the benefits to both individuals and communities.

- Pull together a steering group that includes the Chief Executive of the Local Authority, family members and service users and voluntary sector members.

8.2 Create an achievable plan:

- Put in place a clear project plan for self directed support, (if this is across all services then ensure it specifically includes mental health services) with steps that are achievable.

- Make sure some-one has dedicated time to progress the plan.

- Set a target for numbers of people with mental health problems having Self Directed Support within a timescale. Monitor the target and feedback what is

happening. Use the feedback to open up conversations about differences and address any persistent blocks.

8.3 Get the messages across:

- Explain and give information in person not by email or documents.

- A development worker within a team/service is very effective as it allows for a message to be re-iterated and openly discussed over weeks and months. It also enables teams to name their fears and begin to think more creatively.

- If it's impossible to have a development worker, find champions in each team/service but ensure they have good support and are linked together.

- Having a champion who is from the NHS (e.g. a modern matron) gives credibility in integrated teams.

- Champions should attend the Local Authority/Joint steering group and team targets should be fed back to this group.

- Support service staff should link in to team meetings and spend a couple of hours a week providing a place where staff can discuss any issues and questions about Self Directed Support.

- 'Huge persistence is needed as people can be met with massive hostility'.

- Don't rely on individuals going to training events and trying to take back the messages to whole teams. This won't work. (One reason that this is not effective is that Self Directed Support requires a change in attitude and approach. It is easier to relay procedural changes to others who were not present, but very difficult to recreate the change in attitude/approach which, if not previously familiar, soon becomes overwhelmed by the prevailing team culture)

- Use this document as a source to support addressing the myths and misunderstandings that may block progress.

- If there is a savings plan underway, clarify that this is a separate initiative and be sure how money for mental health services will be effected.

- Tell the stories of people who've successfully used Self Directed Support, or far better, ask people if they would tell their stories directly. This is the most powerful way to make a persuasive case for the need to change

8.4 Sorting out and using FACS:

- Explore how joint eligibility criteria to mental health services mesh with Fair Access to Care criteria.

- Train all members of multi disciplinary teams in how to decide whether some-one is eligible for social care funding.

- Be prepared to adapt existing assessment forms and processes to ensure that the duties of the Local Authority can be met, and that people who approach services through a 'Health' door are not disadvantaged or excluded from social care support when they are provided with services by a Mental Health and Social Care Trust.

- Discuss with commissioners and providers how this aspect of an integrated Mental Health Trust's work will be assessed.

- Ensure that Local Authority IT systems are accessible to mental health staff if this is a vital part of organising Self Directed Support.

8.5 Make sure training happens:

- Make training in Self Directed Support mandatory and run the training in mixed services not exclusively for mental health. This will start to break down the unhelpful idea that people with mental health problems are different or problematic.

- If necessary allow mental health workers some specific training where their particular concerns can be fully explored and responded to.

- Where Local Authority and NHS staff are integrated, integrated training is mandatory, will need to be done more than once and attendance tracked.

8.6 Keep it simple, make it easy:

- Make sure all the necessary processes are clearly explained and that the system and forms are as simple as possible.

- Make all the forms readily available and downloadable on computer, as part of a flow-chart.

- There are self assessment forms that several authorities have created and adapted with use. It may be worth sharing these.

- Make monitoring proportionate to the 'size' of the support spend, and keep focussed on outcomes, not minute detail of receipts etc.

8.7 Make it achievable:

- Make certain that people who use services and carers have lots of opportunities to hear about Self Directed Support and give information in a variety of ways: through meetings, telephone calls, videos, proactively going to where people meet etc.

- Re-energise the social perspective and talk about the social model of disability, using the ideas discussed in this paper.

- Ensure there is support for people to have a finance/benefits check.

- Be aware that a change in power can have an impact on relationships and family systems that have been used to an individual being perceived to be ill.

- Be respectful of the concerns of family members who have had many years of services telling them that the current system is what is best for their child/partner/sibling etc.

- Connecting up the self assessment form with support planning has been helpful.

- Care co-ordinators working with independent workers and the individual to create the support plan has worked well.

- Put in place a variety of support options at the key points where decisions about capacity in decision making will be made: self assessment, support planning and holding the money.

- Put in place a risk enablement panel to support these new ways of working and to enable learning.

8.8 Don't delay – be optimistic:

- Don't wait-people have lives they can't put on hold-just do it and learn as you go.

- Begin to offer Self Directed Support to everyone newly referred, at transitions between age-defined services, and at all reviews so that it is seen as the 'norm'.

- Have plenty of patience and it will happen!

Many of these suggestions are applicable across all services, not just mental health services.

9. Conclusion

This discussion paper has explored how Self Directed Support can best be developed for people with mental health problems, alongside everyone else. It has drawn on the wealth of experience and ideas of people working in and using services currently, and on recent policy and research.

The key findings echo those from a recent book review by Frances Hasler, Head of User and Public Involvement Commission for Social Care Inspection, (of the book' Direct Payments and Personalisation of Care' edited by Charlotte Pearson) 'the overwhelming sense from the book is the enduring power of the status quo. The efforts of disabled people and their supporters to bring about transformative change have been met by a deep conservatism in local services. The lessons I hope people will draw from it are that the excuses for not implementing direct payments are flimsy and that the knowledge of how to implement them properly is readily available. What is required is the recognition that disabled people deserve and should get equal opportunities to participate in everyday life; direct payments are a tool to help that to happen.' (Hasler in Book Reviews edited by John Glasby Health Services Management Centre University of Birmingham 2007)

How can this discussion paper be useful in developing Self Directed Support by people with mental health problems? Many of the fears and objections to Self Directed Support, thought in mental health services to be special and significantly different, are common to other services, and have been named and seen to be based in myth or misunderstanding. Successful strategies have been shared. Ultimately, this is an issue of equal opportunities to rights of citizenship.

Mental health services appear to be lagging behind other services, and there is a perception by some that it will be the hardest place to win the respect for autonomy that other people with disabilities have fought for and begun to gain. Surely the basis of equality of opportunity is that it is open to all on the basis of common humanity, and cannot be withheld on the basis of diagnosis.

Mental health service users deserve the attention of our efforts to develop Self Directed Support not because they are a 'harder group' or 'more difficult' but because we must be alert to the subtle yet pervasive negative influence of prejudice and discrimination.

There is already ample evidence that, given the chance, people with mental health problems make creative and effective use of Self Directed Support. Importantly, people report that sometimes relatively small amounts of money can make a significant difference to some-one's well-being.

And beyond that, 'It's not just about getting hold of the money. It's permission to have a life again. Permission to dream'

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11. Contributors

1. Colin Williams   CSIP North East
2. Maxine Naismith   Darlington
3. Lisa Holdsworth   Darlington
4. Lynne Heslop   Darlington
5. Anthony Craven   Gateshead
6. Diane Whitehead   Hartlepool
7. Geraldine Martin   Hartlepool
8. Louise Carder   Middlesbrough
9. Catherine Stokeld   Middlesbrough
10. Penny Hardman   Newcastle
11. Ian Holliday   Redcar & Cleveland
12. Mary Mohan   Redcar & Cleveland
13. Pat Haslam   Stockton
14. Liz Parkes   Surrey
15. Connie O'Brien   USA
16. Henry Woodhall   Surrey
17. Mike Ward   Surrey
18. Dr. Alan Cohen   SCMH
19. Robin Murray-Neill   CSIP
20. Bernadette Simpson   CSIP
21. Anna Coss   West Sussex
22. John Dixon   West Sussex
23. Carey Bamber   CSIP
24. Barry Ruffel   West Sussex
25. Kevin Mordue   West Sussex
26. Chris Moon-Willems   West Sussex
27. Martin Routledge   CSIP
28. Peter Flanagan   CSIP Yorkshire and Humber
29. Claire Hyde   CSIP Yorkshire and Humber
30. Sefton Recovery Network   Sefton

31.	Jeanette Thompson	Sheffield
32.	Wendy Lowder	Barnsley
33.	Ruth Hicks	Middlesborough
34.	Linda Thompson	Newham
35.	Mette Jakobsen	CSIP South East
36.	Karen Ahmed	Brent
37.	David Morris	CSIP
38.	Piers Allott	CSIP
39.	Sheila Hall	N. Yorkshire
40.	Ralph Edwards	York
41.	Cath Gormally	Bradford
42.	Mark Humble	N. Yorkshire
43.	Ann Walker	NE Lincolnshire
44.	Sheila Dent	NE Lincolnshire
45.	Sue Sumpner	Rotherham
46.	Gill Wheeler	Rotherham
47.	Jim Leyland	Wakefield
48.	Samantha Clark	Inclusion North
49.	Jane Johnstone	Manchester
50.	Andrea Koudellas	Manchester
51.	Jill Buchanan-Huck	Lincolnshire
52.	John Singh	Leicester
53.	Loretta Rogers	West Sussex
54.	Paul Novack	Lincolnshire
55.	Bob Marshall	Lincolnshire
56.	Bruce Bradshaw	CSIP
57.	Stella Charman	CAMHS Consultants
58.	Sarah Nyandoro	Brent
59.	Jane Hannon	Brent
59.	Wayne Eckersley	CSIP
60.	James Seward	CSIP
61.	David Sallah	CSIP
62.	Nadine Schofield	CSIP
63.	Jane Gilliard	CSIP
64.	Sandra Hudson	CSIP
65	Bernadette Hollingsworth	Wigan

66. Sally Prescott   CSIP

67. Laurie Bryant   CSIP

68. Lu Duhig   CSIP

69. Margaret Errington   Bradford

70. Mariann Spencer   Kingston upon Hull

71. Ursula Klingez   Leeds

72 Diana Wontner-Smith   North Yorkshire

73. Janine Parkin   Rotherham

74. Vanessa East   N.E. Lincs

75. Jenny Briggs   N.E. Lincs

76. Mary Hardiman   Sheffield

77. Tony Mays   Sheffield

78. Approx. forty members of Choice Conference workshops.

79. Members of in Control Core Group

Appendix 1

Background Information clarifying the relationship between Direct Payments and Self Directed Support.

Disabled people led the campaign for direct payments as a means of achieving the choice and control necessary to achieve independent living. The principles of independent living are consistent with the concepts of recovery and social inclusion, and the operation of the Care Programme Approach. Local Authorities have had a duty to make direct payments available to those people who are able to choose to have them and who wish to have them, since 2003.

However, few people with mental health problems (and relatively small numbers of other people) have so far had access to direct payments, despite a great deal of work to promote their use, and clear and helpful guidance being readily available. This reinforces the fact that, across the board, the current community care system needs remodelling to make the aspirations that lay behind direct payments a reality for all.

Self Directed Support is a system for delivering social care which builds on all of the work and progress made by those who have argued for and won the right to direct payments. It will increase and extend what has been possible so far, by making direct payments one option in an entire system based on the principles of independent living and recovery. This will allow people to choose other ways of managing their resources to achieve the choice and control currently only available through direct payments. It will differ from the current operation of direct payments in the following ways:

- Following an assessment of eligibility to receive support, it starts with a self assessment, which then gives an indicative amount of money decided through a new resource allocation system (RAS).
- The process is transparent and does not require a funding panel since it is linked directly to an indicative amount of money.
- Self Directed Support can enable other funding streams to be put together into one sum of money.
- The money can be used to buy both in house and other services.

- Self Directed Support can be used to pay family members or friends for support including people living in the same household.

- The individual themselves does not have to manage the money, (as is currently possible in direct payments- but the range of options is bigger in Self Directed Support) -a family member could hold it on their behalf or an Agent or the care manager, or they could have a Trust set up, or the provider could hold it as an Individual Service Fund. 'The idea is that the provider receives the funding as 'restricted funding'. This means the provider cannot use the funding to provide services to other people and that any management or other charges must be set out and agreed at the beginning. The provider cannot 'help itself' to people's funding. These service providers make a commitment to designing flexible individual support services and changing those services over time. In addition the individual funding is kept in an Individual Service Fund and the organisation is accountable to the individual and the local authority for how that funding is used.' (Duffy in Control website)

- Whilst there has to be a broad accountability to demonstrate that the money has been used as agreed, there is maximum flexibility given over what is purchased. Provided that the service is legal, affordable and effective in achieving the agreed outcomes, then it's accepted. It is the outcomes that are monitored.