

Adobe Acrobat Version (full paper)

For download visit <http://www.emprise-international.com/njam.htm>

NOT JUST ABOUT THE MONEY

*Reshaping
social care for
self-determination*



A joint publication
by -

*Community
Living* - and -

Emprise
International Training and Consultancy

Sponsored by -



NOT JUST ABOUT THE MONEY

***Reshaping social care for
self-determination***

Published jointly by -

Community Living

*Walclare
The Street
Herringswell
Bury St. Edmunds Suffolk
IP28 6ST*

<http://www.communityliving.org.uk>

Emprise International Training and Consultancy

*UK Contact address:
12 Lynton Road
Stockport
SK4 4RQ*

<http://www.emprise-international.com>

Copyright © 2002 the author, Steve Dowson. All rights reserved.

Information about how to obtain copies of this paper, and also details of any associated events or other developments can be found at -

<http://www.emprise-international.com/njam.htm>

Design and layout by Steve Dowson

Not just about the money:

Reshaping social care for self-determination

A paper written by **Steve Dowson**, drawing on the discussions of a group that comprised:

- Rohhss Chapman** *Supporter to Carlisle People First Research Group; PhD student Open University; Trustee, Values Into Action.*
- Andy Docherty** *Project Director, Carlisle People First; member, National Forum*
- Steve Dowson** *Partner, Emprise International Training and Consultancy (<http://www.emprise-international.com>); formerly director, Values Into Action.*
- Malcolm Eardley** *Campaigns Officer, Carlisle People First.*
- Stacey Gramlich** *Swindon People 1st Research Team*
- Andrew Holman** *Independent Advocate and Service Adviser; Editor Community Living journal*
- Helen Langley** *Head of Social Work and BSc in Learning Difficulties Studies at Havering College of Further and Higher Education*
- Gordon McBride** *Swindon People First Research Team; Trustee of Values Into Action*
- Tony Phillips** *Director, Realife Trust; lead consultant for the National Development Team; Chair of the Association of Supported Employment Agencies*
- Alison Short** *Service Manager for a large provider organisation for people who have learning difficulties*
- Val Williams** *Researcher, Norah Fry Research Centre; supporter to Swindon People First Research Team*

NOTE: The affiliations of the group members are shown above to indicate the range of knowledge and experience within the group. However, the members of the group are involved as individuals, and the organisations with which they are associated do not necessarily support the views expressed in this paper.

The origins and status of this paper

This paper came about because a group of people began to share their disquiet about the limitations of Direct Payments. They also felt an increasing concern that although the goals of the White Paper, *Valuing People*, were excellent, its proposals were not sufficient to deliver those objectives. Some proposals appeared to be in conflict with the stated objectives.

The members of this group are listed at the front of this paper. The group met only once, for a weekend in November 2001, and continued its discussions by email. Publication was made possible by the generous assistance of Havering College with the cost of printing.

With implementation of *Valuing People* already in progress, the group was anxious to publish its conclusions as quickly as possible. For these and other reasons, this paper does not examine every issue in detail. But it was never intended to offer a blueprint for an alternative social care system. Its aim is to argue the case that the structure of the service funding and service delivery system needs to be re-examined from first principles, and preferably before implementation of *Valuing People* proceeds much further.

It needs to be said that this paper focuses mainly on the concerns of people with learning difficulties, reflecting the experience and expertise of the group members. It does not necessarily reflect the views of people with learning difficulties, except those who were members of the group. There is no obvious reason why the analysis of the current system, or the recommended changes, should not apply just as much in the context of other user groups, though some of the suggested remedies may seem to some to be less relevant. Nevertheless, it is of course for people in those groups to decide whether they support the proposals.

A note about terminology:

The term 'people with learning difficulties' has been used in this paper in preference to 'people with learning disabilities' because it is the term which the people who have to live with the label say they prefer.

Contents

EXECUTIVE SUMMARY	vii
PLAIN LANGUAGE SUMMARY	viii
1 INTRODUCTION	1
2 THE LOGIC OF THE SOCIAL CARE SYSTEM	3
2.1 Structures and outcomes	3
2.2 Change and its obstacles	3
2.3 The importance of role separation	7
3 ROLE CONFLICT IN THE EXISTING SYSTEM	10
3.1 Care management	11
3.2 Service provider agencies and their staff	15
3.3 Standards and quality assurance	16
4 A RATIONAL MODEL FOR FUNDING AND SUPPORT DELIVERY	18
4.1 The principles of a rational system	18
4.2 An alternative structure: Individualised Funding	21
FREQUENTLY ASKED QUESTIONS ABOUT SERVICE BROKERAGE	26
4.3 Organising and funding service brokerage	27
4.4 Parents and self-determination	28
4.5 The effectiveness of IF	30
4.6 IF and larger goals	33
5 SETTING THE IF MODEL INTO THE UK CONTEXT	36
5.1 Individualised funding and welfare benefits	36
5.2 Independent Living and Direct Payment Support Schemes	36
5.3 Implementation issues	39
5.4 Associated policy issues	39
6 RECOMMENDATIONS	45
BIBLIOGRAPHY	47

Executive Summary

In common with many recent public policy developments, Valuing People emphasises the need for closer collaboration and partnership between stakeholders, with a blurring of their roles. However, the White Paper also acknowledges the importance of Direct Payments as a means to improve the lives and self-determination of people with learning difficulties. This paper argues that the real significance and strength of Direct Payments provision is that it creates *greater* role separation, and re-allocates one part of the funding and support delivery system – the purchase of supports - where it rightly belongs: with the disabled person. While it would be wrong merely to transplant consumerist ideology into social care, a comparison with mainstream commercial and civil systems reveals that the existing social care system is riddled with conflicts of interest that would not be tolerated by most citizens.

For these reasons Direct Payments should be regarded as the first step towards a system in which all the functions are allocated logically and clearly, avoiding conflicts of interest. Systems which follow this model, generically termed Individualised Funding (IF), already exist. Some fifty programmes are under way in several countries. Evaluations of these programmes are only now emerging, but reveal outcomes that are strikingly positive. Although the evidence is not, as yet, conclusive, there are also strong indications that a comprehensive IF system would be more effective in supporting self-determination, especially for people with learning difficulties, than the current Direct Payments provision.

The development of Direct Payments into a comprehensive system of Individualised Funding would involve -

- Permitting people who require support services, and wish to use IF, to develop and cost their own support plans, reflecting their own life aspirations. This would replace community care assessment.
- Creating a system in which the limitations of public funding are balanced against the requirements of the individual through a process of open negotiation between the person and the council, based on the plan prepared by the individual.
- Providing funding to individuals who require assistance in developing their plan, so that they are able to purchase this help from a source that is independent of Social Services and service providers, and who is accountable solely to the disabled person. In the terminology of IF, people who provide this help are commonly called service brokers.
- Ensuring that help is available to people who receive IF in the administration of their funding, and, if required, in meeting the legal responsibilities as employer of personal assistants. In some circumstances the required help may be available from mainstream sources, such as banks, but there is also a role for specialist agencies. Existing DP support agencies and similar schemes that offer this service need to be strengthened and extended to provide this role, but their role and accountability may need to be reviewed against the principles of role clarity and separation.
- Encouraging the development of a market of support provider agencies who are willing and able to provide services tailored to the requirements of individual IF recipients.
- Authorising and funding an agency in each locality to regulate the supply of independent service brokers, and to provide an access point for people requiring brokerage services. These regulatory agencies should be controlled by disabled people.

The logic on which IF is based also has important implications for –

- Partnership working
- Person-centred planning
- Inspection and quality assurance.

NOT JUST ABOUT THE MONEY

Making sure people have choice and control over their services and support.



Valuing People says that many people with learning difficulties still do not have good lives.

Most people still don't have their own homes, or real jobs. And they don't have much freedom or choice.



So far, all the conferences, training courses, and new ideas in services, haven't made much difference to the lives of people with learning difficulties.

The way things are now, people who work in the system often have conflicts of interest - they have more than one job, and are being pulled in two directions at once.



For example -

Care managers who do assessments are supposed to be helping people get the services and support they need. But they also have to try to keep down the amount of money or services that people get.



Care managers who organise services for someone - who they probably don't know very well - are likely to prefer a set of services that is easy to organise, and not risky.



When people who provide services are involved in individual planning, they will find it difficult to admit that the person would be better somewhere else - because they probably want to believe that they provide a good service, and because the agency will lose money if they go somewhere else.



We think there has to be a better way of organising things so that people with learning difficulties get the support they want and need.



Direct Payments have shown that things can be done differently, when people take over the job of organising and paying for their supports, but very few people with learning difficulties are using Direct Payments.

The whole system needs to be changed, to make things better for most people with learning difficulties.

There is a way of organising the system differently. It's called **individualised funding**, or **IF**.



The people in an IF system who give help with making plans and organising supports are called service brokers.



Brokers are not care managers. They are not employed by Social Services, and they are only there to offer help to the person. They only give their help in the way the disabled person wants. It is the broker's job to support you to make decisions and take control.

To make this happen we think that:

- ◆ You should decide for yourself what your 'needs' are.



- ◆ If you need help in making your plans, or to find support, you should be able to get the help from a service broker who doesn't have any links with government or with service providers.



- ◆ You should have control over the way the money is used to buy support from an agency or to employ support workers or personal assistants.



- ◆ If you need help with dealing with the money to pay for your support, you should be able to get this from people who are independent, if that is what you want.



- ◆ People who are providing support services should not have a big say in individual planning meetings.



- ◆ As far as possible, you should be left to decide for yourself whether the support you get is good enough. This is far better than rules set by government.



An IF system needs to include some way to check that the service brokers are doing their jobs properly. People who want the help of a broker also need to be able to get information about the brokers who are available.



A good way to make sure this happens is to have a new kind of organisation, sometimes called a community service brokerage agency. This agency should be under the control of disabled people.

The government should tell social services departments to start changing Direct Payments into real individualised funding systems.



It's good that the Government sets some rules about standard of services that people get, so that people don't get hurt by services. But the rules should not stop people choosing how they want to live.

The person whose life is being discussed should be in charge of making plans about what kind of life they want, and decide who is going to be at planning meetings.



The laws on consent should be sorted out to give people the right to make decisions about their lives. A supported decision-making process should be used when people need any extra help.

The aim of this report is to start a discussion about how Government policy and services need to change so that disabled people - especially people with learning difficulties - have control over their lives.

1

Some time around 1996 . . .

We're going to arrange a nice package of care services for you.

No thanks! Just give me the money and I'll sort out my own.

2

Some time around 2002

We'll going to organise your person-centred planning meeting for you. Don't worry - you can be sure it's person-centred, because we'll be following agreed PCP guidelines.

We're the very nice people who manage your excellent services, and we're going to decide whether your services are what you need.

I'm going to assess you and decide what your needs are.

We're going to decide how to measure whether your services are good enough for you.

No thanks! I don't need you to do that – and if I do need help, I'll get someone who's there just for me.

1 *Introduction*

The tide of policy in adult social care is strongly in one direction. In *Valuing People* (Dept. of Health, 2001a), and in many other recent government directives, there is an expectation of greater coordination, collaboration, and joint working, summed up in the central notion of partnership. The case for partnership seems, at first sight, persuasive; indeed, self-evidently the right way to go. If successful, the effect will be to blur the boundaries between agencies, and to draw the actors in the system of funding and support delivery into shared policy-making and operational responsibilities. Collective managerialism, driven by the goal of excellent and efficient service delivery, is replacing the old corporate paternalism. The new philosophy, nevertheless, continues to endorse the assumption, dominant since the creation of the welfare state, that the state needs to have a controlling role in all the main processes of allocating funds and delivering services. Unlike the previous paternalistic system, the new partnerships will include the recipients of services: their representatives will be given 'seats at the table'. However, the table will be owned by the statutory agencies and services providers.

But this tide has an undercurrent. It is reflected in the separation of commissioning and service provision – the product of another era and a different political philosophy, yet still a major feature of social care. It is also evident in the creation of the National Care Standards Commission, removing the responsibility for inspection from local authority control. Both cases represent an acknowledgement of the need to create some 'open space' in the system, to *increase* separation and role clarity. The most significant example, however, is the advent of Direct Payments, by which one component of the system – control of spending on supports – is not merely passed from one section of the professional system to another, but handed over to the disabled individual.

In this paper, we argue that the transfer of spending control should be regarded as the first stage in the evolution of a funding and support delivery system that makes a virtue of separate, distinct roles. It is a system that, rather than attempting to reduce or hide conflict through collaborative working, brings the inevitable conflicts of interest out into the open, where they can be properly addressed. It also removes additional functions from state control. Plainly, this paper is going against the tide.

Since it is so contrary to the current wisdom, the logic and the evidence in support of such a system are explained in detail. Much of the logic is based on comparisons with systems beyond social care. Direct Payments provision (DPs) at last begins to make consumers into customers, and takes a step closer to the structure of commercial systems by which ordinary citizens obtain products and services. It isn't necessary to be an extreme advocate of consumerist ideology to see that this makes sense. Commercial systems – and indeed mainstream civil systems also – have evolved over centuries so that the major roles are separated, and appropriately regulated, in the way that is most likely to deliver the required outcomes efficiently. They embody rules that match a common, taken-for-granted understanding of what is right and fair. These systems are not perfect, of course, but the public reaction when the rules are broken reveals how strongly

people believe in them. It isn't necessary to explain why people might want a public enquiry after a train crash, or a clampdown on price-fixing cartels, or be concerned about the police 'handing out rough justice'. It's self-evident that, in situations such as these, some fundamental principle has been disregarded.

Yet those rules have never been applied to the world of adult social care. The principles that operate in social care are completely different, and would be unthinkable elsewhere. For example, if cars were made available like social care services, they would be designed by committees – committees, moreover, that consisted of people who never travelled by car, though they would be keen to show that they sometimes consulted car users. Anyone who wanted a car would have to undergo an official assessment (focused on their walking ability, without reference to where they wanted to travel), to determine whether they really needed a car or could make do with a bicycle. If agreed, the car would be provided from a shortlist of approved manufacturers. And then, once a year, the manufacturer would hold a meeting to decide whether the car was providing what the customer needed.

It should also be noted, at the outset, that a sudden, wholesale transformation of the social care system for disabled people is not a concluding recommendation of this paper. Although there is evidence from programmes in several countries that the system does work, the evidence that it will result in better outcomes, compared to those from Direct Payments, is not conclusive; and, in any case, the general model would need to be adapted to the UK situation. Full implementation would require a significant shift in policy, and probably statute; but the first stage could take the form of local pilot projects.

Whether or not the alternative system is developed, the logic of role separation also has implications for aspects of current policy, especially *Valuing People*. Moreover, the ultimate aim is to enable disabled people to be able to take control of their own lives. It can be envisaged that, eventually, the proposed alternative system could become the default option, so that people would opt out rather than opt in. Nevertheless, expansion of the alternative system should be the consequence of the free choices made by individuals who require support.

It is both right and predictable that an apparently radical proposal, so out of step with predominant thinking, will be received with scepticism. However, it needs to be stressed that the paper draws its logic from highly evolved mainstream systems, and makes use of the learning from innovative programmes, based on similar principles, in many countries, as well as Direct Payments in the UK. Its aim is entirely consistent with government intentions. *Valuing People* states that

the Government's objective is to enable people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive.

This paper offers a way to achieve that objective.

2 *The logic of the social care system*

2.1 *Structures and outcomes*

People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change . . .

- White Paper, 'Valuing People' (2001)

In the last thirty years, vast amounts of time and money have been used in an effort to improve services for people with learning difficulties, and the quality of life that those services enable people to experience. Without doubt, improvements have been achieved, especially in the broad pattern of service provision: the closure of most of the large-scale residential institutions is one important example. The new White Paper sets some welcome targets for the future, but it also acknowledges the lack of progress that has been made so far. In spite of the changes in statute and regulations, the evolution of professional training, the innumerable research projects, conferences, and innovations in theory and practice, it remains generally true that people with learning difficulties remain socially excluded, are denied the rights of ordinary citizens, receive services that do not meet their needs and preferences, and have little control over their own lives.

It seems not only reasonable, but vitally important, to ask why the efforts of three decades have done so little to improve the position of people with learning difficulties in these fundamental respects. If the question is not answered, the many initiatives set out in the White Paper may likewise fail to deliver.

2.2 *Change and its obstacles*

Most of the efforts to improve services, and their outcomes for users, have focused on the way in which individual sections of the service system – day service providers, for example, or statutory workers assessing individual need – should carry out their work. These various sectors may have been required by statute to work in different ways, but more often have been presented with new information and ideas – 'supported employment', 'self-advocacy', 'community participation', and so on. Less attention has been given to the relationships between sections of the system, and where new recommendations or requirements have emerged, they have almost always advocated closer relationships. The call has been for inter-disciplinary teamwork, joint working and partnership, or more opportunities for 'user participation' in the policy decisions of social services agencies. Good practice, it would seem, almost always involves a blurring of the boundaries and roles between the various actors in the process of delivering the assistance that people with disabilities require.

There have been very few occasions when the basic structure of the system has been subject to re-examination. Although there have been shifts in the division of responsibilities between professional groups (for example between learning

disability nurses and social workers), these have concerned subdivisions of roles, rather than changes in the allocation of the major functions that must operate in order to provide individual with the assistance they require.

With the development of the welfare state came the assumption that all these major functions had to rest with organisations directly accountable to the state. If an individual required personal welfare services, it was the state that would identify what assistance was required and (perhaps implicitly) decide whether it was affordable. The state would organise the delivery of assistance and have

Figure 1: Allocation of duties, pre-1990

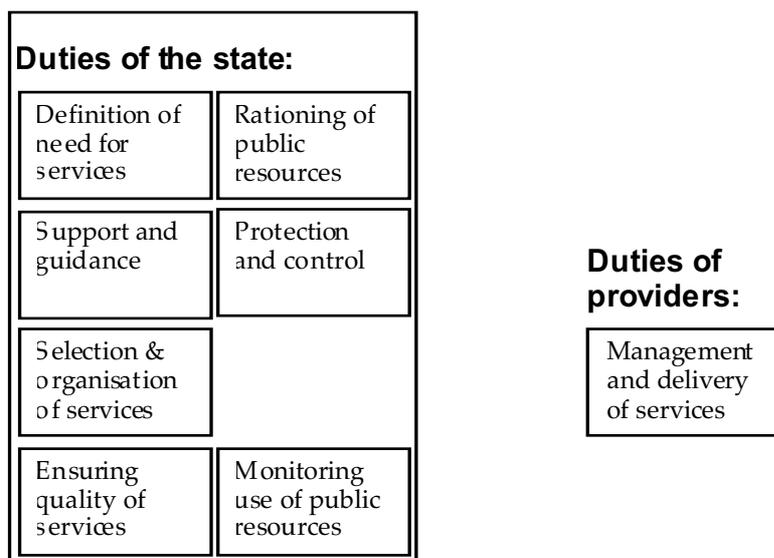
Duties of the state:	
Definition of need for services	Rationing of public resources
Support and guidance	Protection and control
Selection & organisation of services	Management and delivery of services
Ensuring quality of services	Monitoring use of public resources

management control of the services provided. And the state would continue to review the services provided, to decide whether the assistance was appropriate and justified. (See figure 1.)

The only significant open challenge to this assumption was made in the Griffiths Report in 1988. This report argued the case for a separation of the function of service purchasing from that of service provision. The change recommended by Griffiths would place the delivery of services more appropriately outside local authorities, in a competitive market place of provider agencies. Social Services Departments would retain responsibility to assess individual needs; convert the needs into service requirements; and then purchase the services from independent agencies. This system was brought into being by the National Health Service and Community Care Act (1990). Some directly managed services still remain, and the exact role of care managers varies between local authorities, but the Griffiths vision has now become the familiar reality of social services. These days it is entirely accepted that the state does not need to have direct control over service delivery. (See Figure 2.)

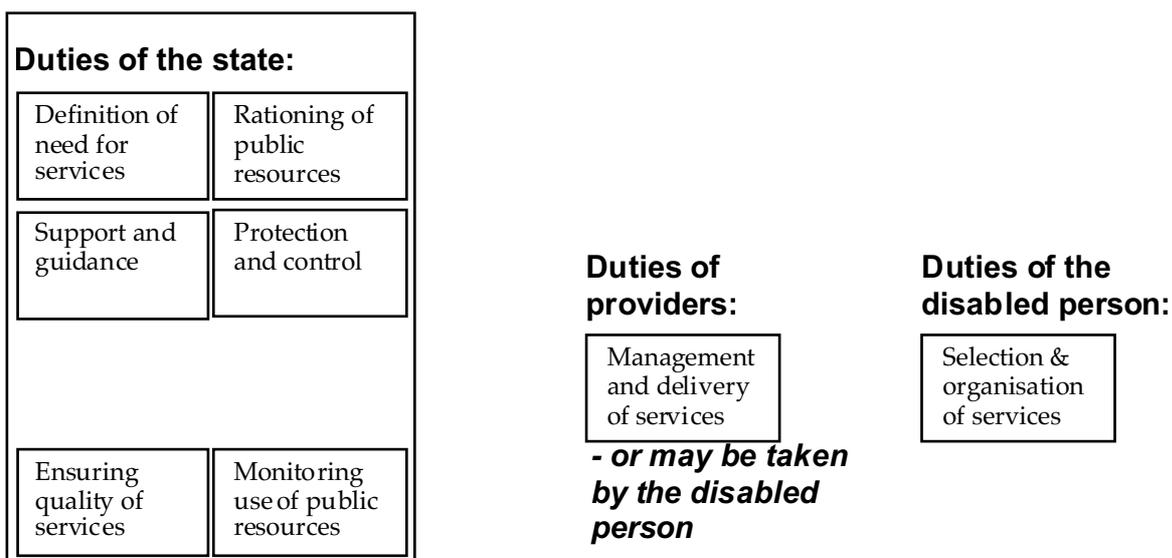
There has since been another development that challenges assumptions about the necessary role of the state in the personal social services system. However, it has so far only affected a few thousand people. It was driven not by central government ideology but the demands of disabled people, and the legislation itself did little more than clear away a small legal obstruction. For these reasons,

Figure 2: Allocation of duties following NHS and Community Care Act (1990)



its full significance has been little discussed. Nevertheless, the introduction of Direct Payments in 1996 removed more functions from the control of the state. Technically, Direct Payments provide a way for disabled people to receive money to acquire their own services, instead of having a package of services arranged for them. Its real importance to the recipients, however, is that it gives them the power to select the agencies and/or individuals who will provide their support. It also, especially if the support is given by people who are directly employed by the disabled person, gives them the power to direct how their support will be provided. (See Figure 3.) The NHS and Community Care Act had made care

Figure 3: Allocation of duties under Direct Payments



managers the customers of the provider market, while the users of support continued to be powerless consumers. With Direct Payments, the consumer is also the customer.

These two policy developments demonstrate how effectively a re-allocation of functions between the main 'players' in the funding and service system can achieve a shift in the balance of power. Service agencies need to learn to be more responsive to the needs and wishes of their users – not only because it is simply right that they should, but because it will speed progress towards the other goals, such as real jobs and independent living arrangements, that disabled people are demanding.

So what strategy should be used to help services become more responsive? On the one hand, they can be bombarded with good practice guidelines, shown examples of innovative schemes gathered laboriously through research programmes, and be allowed to discuss the merits of 'user empowerment' at interminable conferences and training courses, in the hope that some good ideas will permeate through to practice. Alternatively, they can be put in a position where the growth or failure of their agencies will be a consequence of their success in delivering the support that people actually want. There can be little doubt which strategy has greater potential to produce change.

There are, however, a number of weaknesses in Direct Payments provision, rooted in its origins. The legislation simply took one aspect of the whole system (individual spending decisions), and parcelled it out to disabled people, wrapped up in some brief regulations. It was plainly not the outcome of a comprehensive analysis of the allocation of roles and functions, and how these might be rationalised in favour of user self-determination. As a consequence –

- Care managers, in the 'social work' aspects of their role, are still the only source of help that is reliably available to assist people in choosing and finding services. This function has remained within social services, with the result that people who choose to escape the system may find themselves marooned without assistance. In an increasing number of areas there are schemes to provide this kind of help, but they are not yet available everywhere. Moreover, the schemes themselves vary in the services they offer, their expertise, and their accountability arrangements. For assertive and intellectually able people (those who were originally envisaged as the primary users of Direct Payments), and people with strong advocates, this lack of assistance may not be a problem, but it is an obstacle to others. The patchy availability and variable services of DP support schemes is undoubtedly one factor that has led to the low take-up of Direct Payments by people with learning difficulties¹ (Dept. of Health, 2001a; Holman and Bewley, 2000; Swindon People 1st, forthcoming).
- There is an awkward relationship between the process of community care assessment and the user's control of their Direct Payment. The guidance (Dept. of Health, 2000) requires assessment to be completed before a Direct Payment is offered as an alternative to a care package. So, while the DP recipient will have some latitude in how they use the money (for example in where they obtain their support), they may have to keep to categories of need that have been defined by the care manager. Even if

¹ *Valuing People (Dept. of Health, 2001a) states that in autumn 2000, of the 3700 recipients of Direct Payments, only 216 were people with learning difficulties.*

there is no formal requirement to use the money within each category in a certain way, the process of assessment is likely to have set the options within a framework that reflects professional perspectives, knowledge and convenience, rather than the true hopes and wishes of the individual. For example, the assessment will be focused on 'need'; eligibility will have been judged by a yardstick derived from an arbitrary conception of 'independence'; and the amount of funding may have been calculated on the assumption that personal assistance will be required, ignoring other possibilities.

- It may be that there are other functions remaining within the control of the state that should be moved elsewhere. This possibility has not been examined. In particular, there is currently much concern in national policy development with the question of quality, in terms of care standards, safeguards, and monitoring. Why should the state assume it is in a better position to judge whether services are up to standard than the people who receive the services?
- Having control of the money for services is very important to the people who receive Direct Payments. But it isn't, ultimately, possession of the money that is important. On the contrary, it brings a range of responsibilities and chores which few people welcome. The hassles may be worth it, however, because it means having greater control over the support services (or personal assistants). In that case, could there be a 'shortcut' – a way for people to take control without having to take the money?

One of the consequences of these shortcomings has been to impede the take-up of Direct Payments, especially by people with learning difficulties. While DPs theoretically offer a way to have more control, the policies of councils, and the practices of their staff, place numerous barriers between people with learning difficulties and the possibility of truly having control of spending on supports.

2.3 The importance of role separation

In the ordinary world, beyond the realms of social care, the importance of role clarity and role separation is taken for granted. It is embedded in the UK's constitutional principles; in company law; in rules covering the practices of professional groups such as doctors; and in many aspects of consumer law. In any situation where fairness and justice may be at risk, it is critical that people should have roles which –

- are clearly identifiable, with well defined limits;
- do not represent an excessive concentration of power;
- do not contain accountability or loyalty to more than one set of interests, if it is possible that those interests may be in conflict – especially if the existence of a loyalty or accountability may be concealed.

In practice, there are many different benefits in organisational systems that define roles clearly, and avoid role conflict -

- **When the conflicting interests of different individuals or organisations are separately represented, it is less likely that one set of interests will be ignored or suppressed.** For example: the independent representation of the defendant in courts of law, separate from the prosecuting lawyers. Also note, for example, the widespread public suspicion towards the single government ministry that was supposed to be concerned both with the interests of farmers and of food consumers.
- **Separate representation can be built into formal procedures in which conflicting arguments or interests are set out 'side by side', so that their relative merits can be (and be seen to be) evaluated in an even-handed way.** For example: procedures in law courts and tribunals, legislative procedures in parliament; formal business meeting protocol.
- **Where there may be some conflict of interest within a role, good systems require that the possibility of conflict is made known, so that other people can judge the value of the opinion, advice, or assistance being offered.** For example: Regulations that require financial advisers to inform customers about their association with financial service providers, commission rates, etc; regulations requiring company directors to declare any interest if it affects the decision being made.
- **Where there is a suspicion that an organisation has been, or might be, too much swayed by one set of interests, checks and balances can be provided by the addition of an agent representing the interests at risk.** For example: Auditors – who are required to be independent – investigate and report on a company's activities to protect the interests of shareholders; parent members of school governing boards; public 'watchdogs' such as Ofcom (the regulator for the UK telecommunications industry), that represent consumer interests.
- **When responsibilities bring power, the risk that the power will be abused is reduced if the responsibilities are divided into separate roles.** For example, law-making (by parliament) is kept separate from law enforcement (e.g. the police), and both of these are separate from the judicial system (the courts).
- **Even when people share the same ultimate aims, and no significant conflict of interest exists, it may be helpful to separate roles when different styles or perspectives are required.** For example, non-executive members of a company board, or charity trustees, may be better able to maintain the required focus on overall aims than the executives who have to be concerned with day to day operation.

Examples of regulations and practices designed to promote role clarity and separation are to be found almost everywhere, and are closely associated with our sense of what is fair and right. This does not mean, of course, that they are always effective, but there is nevertheless a common recognition that people's interests – whether as citizens, employees, shareholders, or consumers – are at risk without them.

Equally, the importance that is attached to role clarity and separation does not imply an assumption that the people who operate within these systems would otherwise be corrupt. Even without controls, businesses would not habitually cheat their customers or their shareholders (not least because, ultimately, it would be bad for business). Schools without inspectors or external governors would not inevitably neglect their students. However, it *does* imply a general acceptance that it isn't good enough simply to assume that people will *always* act according to high principles and with scrupulous honesty. In any case, the need for safeguards is not limited to situations where people or organisations may deliberately choose the path of corruption. It is also a recognition that people with the best intentions may nevertheless drift into a bias towards one side in a conflict of interests. The auditor who spends too much time playing golf with the company board members; the keen financial adviser who wants his branch to win the annual sales awards; the doctor so convinced of the benefits of a new drug that she doesn't think that patients need to know about the risks. Ultimately it is simply a recognition that people can't be expected to have the wisdom of Solomon.

3 *Role conflict in the existing system*

The procedures, regulations and ethical controls that exist in ordinary life represent an acknowledgement that people are not always working in unity towards a single goal, but are responding to different and sometimes conflicting duties, pressures, and interests. This is not so clearly reflected of the traditions or culture of social care. As previously mentioned, the need for role separation was brought to the surface by Griffiths in the late '80s, and has now been acknowledged by the creation of the National Care Standards Commission, as an inspectorate that is independent of local authorities.

But these are rare examples. Moreover, the conflicts that do get addressed are those which occur within the care industry, not those between the industry and the people who require assistance. Complaints procedures only acknowledge that the system, presumed to be generally benevolent, may occasionally fail. This is not the same as structuring the system on the basis that there is bound to be a tension between the interests of the state and the users, and between the providers and users. Initiatives in participation and consultation that put users alongside professionals on committees and agency boards implicitly aim to blur the differences, not to formalise and face up to them. The new Guidance on Partnership Working (Dept. of Health, 2002) envisages partnerships 'based more on collaboration than on competition' and asserts that –

It is impossible to achieve the vision of the lives of people with learning disabilities set down in Valuing People unless all the relevant people and organisations work in partnership with one another.

There may be a kind of partnership in which the partners view each other respectfully from a distance, and regard conflicts as the sign of a healthy relationship. This is not the kind of partnership that the government evidently wants to see. The guidance advocates partnerships based on shared values and aspirations, and which have 'common interpretation of where and how services are currently succeeding and failing in meeting people's needs and wishes'. Such close partnerships no doubt have an importance place. They make sense, for example, between statutory agencies providing different kinds of service, such as housing and social care. (Even here, partnership working which extended into operational issues could in effect merge the roles of landlord and support provider, against the interests of consumers.) But the unqualified endorsement of partnership between all stakeholders – even including advocacy organisations – suggests an undue intolerance of conflict. The dream at the end of the partnership rainbow is a hegemony of stakeholder organisations, united in their common concern to deliver whatever they have jointly decided that people need.

Unfortunately, this is a denial of the reality that the stakeholders have conflicting interests, some of them inherent in their role. The social services department, quite rightly, has an interest in limiting public expenditure on social care. The disabled person, with equal justification, will seek to obtain the services or funds they require for their support, whatever the cost. The service provider wants to

retain business, whereas the disabled person should be free to obtain support services from whatever source they choose. Conflicts such as these may be concealed, but they cannot be removed.

When they are picked up by complaints procedures, conflicts will be recognised as disputes between two sides, each with their own case to be heard and assessed. But, left to lurk beneath the surface of professional activities, conflicts will be perceived in different terms. Like professionals in other fields, social care workers may not even see the conflict, and instead slide unconsciously towards one side or the other. Progressive policies, or strong professional values, may move the worker towards the side of the disabled person. Other influences will tug the other way. On one side the department or agency that pays the salary; on the other the person who requires supports, often dependent and disempowered. There will be loyalty to professional identity, and to professional peers and friends. The certainties of regulations, and the comfortable reliability of bureaucratic systems, will be weighed against the risks of messy, unpredictable 'real life'.

Although these factors suggest that the overall bias will, more often than not, work in favour of the agencies and their workers, this is not the primary cause for concern. The main problem is that while these conflicts remain implicit in the decisions of professionals and in the structure of the system, there is no way to monitor the interplay of these factors in decision-making, or to ensure that the outcome reflects a fair assessment of the legitimate interests of each side.

The following subsections examine three areas of the existing system where conflicts of interest undermine the interests of people who require support services¹:

3.1 *Care management*

Care managers, and equivalent social services staff who carry out community care assessments, operate in part in the traditional helping role of social work. This role is — or in principle should be— focused on the individual. In essence it involves helping the person to identify their preferences for the future, and the services and other resources that this future will require, and then making all reasonable efforts to organise those resources. If required, this should involve acting as advocate with the person, or on their behalf. But the care manager has a second role, as representative of the agency that rations public funds. The process of assessment, notwithstanding references in the guidelines to consultation and self-assessment, will be completed using a procedure determined by the local authority. It will be a process in which the professional expertise of the care manager over-rides the knowledge of the individual about themselves and their own lives. Often, assessment involves a great deal of form-filling – a pseudo-scientific procedure that suggests personal needs can be probed in the same way that a doctor can diagnose an illness by physically examining a passive patient. The care manager has a duty to make a decision, based on the local authority's policies, about which of the identified needs are eligible for services. Within this role (though retrograde social work impulses may say otherwise), the care manager has no duty to advocate for more resources.

¹ These conflicts are analysed further in Dowson, 1991

There is plainly a conflict of interest between the two roles. Something of the same kind existed in the role of social worker in the days before the community care reforms, but care management, by translating resources into budgets and needs into costs, has racked up the tension. Care management inherited two other problems from the previous system. There are duties of care and protection which conflict with the more liberal aim to support people in making autonomous decisions. And, typically, there is a lack of time available to establish a relationship with the person that has any depth or continuity.

These role conflicts will, to varying degrees, affect the care manager's effectiveness in assisting the person to acquire the assistance and the lifestyle that they would like to have. Problems will occur in the following ways:

3.1.1 An inability or unwillingness to start from the person's true aspirations.

The standardised forms that usually dominate the community care assessment process may include a question about the person's general aims and preferences for the future. This has little benefit if the rest of the assessment, keeping to its fixed format, does not take the person's answer as the foundation from which to build a practical plan. Moreover, many people, confronted by a stranger who represents social services, and who sits with pen poised over form, will not give an answer that provides a good starting point. Some people may not know, for example, that employment could be an alternative to the day centre; or, after years of devaluation, may have decided that they are not capable of employment. Other people will know very well what future they would like, but not mention it because they assume that it will be considered out of the question, or don't wish to seem ungrateful or excessively demanding.

One of the constant principles in person-centred planning, in all its different versions, is that planning has to start from the person's true aspirations, without regard to what is 'reasonable' or achievable – and hence often termed as 'dreams'. Often people need help, information, and time to identify their dreams. (This is especially true for people who do not communicate by conventional means.) An over-worked care manager who does not have a strong relationship with the person, and is required to follow a set assessment procedure, cannot offer any of these. A procedure that focuses on gathering factual information about the person's present circumstances and abilities does not have the capacity to define life goals.

It should be noted that, in addition to its effect on the outcomes for each person who uses supports, an assessment process that does not discover people's true support needs, as derived from their life aspirations, will lead to statistics that under-state the gap between need for services and services provided.

3.1.2 Reluctance to support high cost solutions

As representative of the local authority, the care manager cannot set aside concern with costs. Even if they do not have direct responsibility to allocate funds, they will be mindful that they will have to submit the costed package (or Direct Payment proposal) for approval. The cost

issue will be present throughout the process, not just when a list of service requirements has been identified, and so there will be an incentive to steer discussions towards solutions that will not have problematic cost implications. Many disabled people will not have anyone 'on their side' to counter this tendency. Some may have advocates, but while good practice acknowledges the value of advocacy, the structure of the funding and service delivery system does not incorporate and empower the role of independent advocate.

3.1.3 Disincentive to identify inconvenient or risky solutions

Some plans are easy to implement. They involve familiar types of service, known to be available from social care agencies, or from the provider side of the social services department. At the other extreme a plan might involve setting up a series of different supports, each involving access to mainstream resources and/or the voluntary commitment of community members. When such a plan is made, there is no certainty that it can be achieved, and no guarantee that it can be sustained. It is possible that a service agency will be available locally with the flexibility and creativity to take on the job of implementing the plan, and the agency might also undertake to 'pick up the pieces' if something goes wrong. But if not, the plan will only become reality if the work is done by a care manager – who, in many instances, will be the same person who did the assessment. The net effect is that there is a strong incentive to make sure that the assessment process leads towards a plan that is easy to implement, and involves low risk. Ironically, this also means that unnecessarily costly solutions, notably residential care, when low-cost options such as befriending or sitting services might have sufficed (Williams and Robinson, 2000a).

3.1.4 Difficulty in conceiving creative solutions

Creative solutions tend to be avoided because they imply increased work or risk, but the built-in bias of the system against creative solutions is more fundamental. Central government guidance on care assessment has repeatedly stressed the importance of defining needs in a way that does not anticipate the form of service required to meet that need (for example, Social Services Inspectorate 1991, par. 3.53). In practice this is very difficult. Even if the assessment procedure itself avoids mention of service options during the assessment of need, the assessing officer is likely to be thinking in terms of solutions. The mentality of systems, categories, procedures and formal lines of accountability is the intellectual base from which the professionals operate, just as much as the office is the physical base from which they come visiting. When they are in role, it is the lens through which they see the world, and the people they aim to assist. Confined within that paradigm, they cannot fully relate to the complexity and uncertainties of people's lives and hopes. However good their intentions and skills, they are trapped in their role and power and, equally, the people they work with are fixed in the identity of 'case'. This is not a situation that is likely to yield bold, exciting plans.

The Social Services Inspectorate, reporting on a 1999 study of independent living arrangements for younger disabled people in ten representative councils, remarked that -

Most care plans moved too readily to becoming service plans, with a lack of specification of intended outcomes and with referrals mainly to existing block-purchased services with limited flexibility and tailoring to meet the needs of the individual.

(Social Services Inspectorate, 2000)

While there were no doubt a number of reasons why this was found to be the general picture, it is nevertheless exactly the outcome that is to be expected from a process so riddled with conflict of interest.

Historically, disabled people lobbied for Direct Payments as a mechanism to escape from being 'cases', and to take control of their lives. Unfortunately, it does not allow people to escape from the assessment and care management process. The Guidance (Department of Health, 2000) requires that the option of a Direct Payment is only discussed when needs have been assessed and eligibility for services have been assessed. In addition, the size of the Direct Payment has to be evaluated in terms of cost-effectiveness. It does not necessarily have to be equal, or less than, the cost of a care package (though this seems to be a common rule of thumb) but if it costs more then it should result in proportionally better outcomes (*ibid*). Thus, logically, assessment of cost effectiveness can only be made if the whole process of assessment and care management has been completed.

An assertive, independently-minded disabled person may be able to hold onto their own ideas while the care management process is completed and, once they have taken hold of their Direct Payment, set up the support arrangement they had wanted from the outset. They may find, however, that the amount they have been allowed is not sufficient: it is the care manager (or their line manager, or panel) who will make the judgement about cost-effectiveness. They may also find that there are conditions attached to the Direct Payment – for example the way in which the whole amount must be subdivided to meet each area of need. These restrictions could scupper their plans.

Many other people – particularly people with learning difficulties – will be less immune. The assessment process will shape their ideas about what their needs are, and how they should be met. As a result, if they obtain a Direct Payment they will gain control over spending, but the kind of support and lifestyle which results will reflect the assumptions built into the assessment process, and the care manager's knowledge and values. Moreover, it is the local authority that decides whether a Direct Payment is appropriate. There are reports (for example, Holman and Bewley 2000) of the various ways in which people can be denied access to Direct Payments. People may not be told that the option exists – sometimes, it seems, because care managers are not aware of DPs. Direct Payments may be mentioned but immediately dismissed as unsuitable, or the care manager can simply fail to follow through with the necessary detailed information or further action. In addition, the plan itself can be tilted so that the option looks unappealing or impractical. For example, there is a common but completely unjustified assumption – another example of the way in which creative possibilities are reduced to standardised packages – that DPs are only used to employ personal assistants. Some people with learning difficulties do not appreciate the distinction between control and independence; and because they know they cannot achieve independence, assume that they cannot have control.

3.2 *Service provider agencies and their staff*

Service providers usually have an immensely important role in the lives of the people they support. And because they are so important, they are also very powerful. In spite of this, service providers often stray outside their role of delivering the assistance that they are paid to provide. As soon as they do so, their role acquires conflicts of interest.

This most clearly happens during the process of individual planning, and especially at individual planning meetings and reviews, where questions are being asked (or should be asked) about the value and appropriateness of the service. The participation of support provider staff in these meetings, including those that are 'person-centred' is usually taken for granted. Provider staff often take a lead role in the meeting. It is also not uncommon for *all* the participants at these meetings, apart from the person who is the subject of the review, to be provider staff, without so much as a representative from the local authority purchasers to bring a different perspective.

The agenda at these meetings ought to focus on questions such as –

What does this person want from life?

Is the service that is now being delivered relevant to what the person wants in life?

Is this the right agency to be delivering that support?

Is it the most effective way that the money can be used to help this person achieve what they want?

Does the service represent efficient use of public funds?

The ability of staff to answer these questions objectively is seriously compromised:

- **They have a vested financial interest in defining what the person needs and wants in a way that justifies the continuing involvement of the service.** If they do otherwise, they will lose business – and making a habit of it would threaten the agency and their own jobs.
- **They have an emotional investment in believing that their support is valuable to the person, and that the kind of service they offer is appropriate.** Staff understandably want to believe that what they do is worthwhile. And, while they may be able to accept that the person – perhaps as a result of their skilled help - has now outgrown the need for them, it is likely to be very difficult to countenance the possibility that their service was never a good way to meet the person's needs.
- **Their ability to imagine the person outside the context of the service may be impaired.** Within a service setting, people will tend to demonstrate the skills they are expected to have and, conversely, appear to have the needs that the service meets. For example, if people are escorted or transported whenever outside their group home, their potential ability to travel by bus will not be revealed or developed. As a result, provider staff may adopt a conservative, resistant attitudes towards proposals to move the person to a situation where higher practical or behavioural skills are required.

- **They have an incentive to overvalue their service, and to protect their income.** It is natural that staff will be reluctant to accept that what they offer might be achieved in a less costly way. It is even more unlikely that an organisation, without some form of external pressure, will objectively examine its own operations and admit that it is over-pricing.

Reviews that are controlled by provider staff tend to shift the focus, so that they become a review of the individual's learning and behaviour, perhaps against targets set at the last review, rather than the performance or relevance of the service provided. A recent study found that many families see the service review as a continuation of annual school reviews (Williams and Robinson, 2000c) meetings do take this form it may be due to a misunderstanding by staff about the purpose of the meeting, rather than a deliberate diversionary tactic. Nevertheless, it does conveniently allow the staff, and their agency, to avoid difficult questions about their competence and value.

Of course, provider staff do have a place in the process of individual planning and reviews. As with the community care assessment, no amount of information about skills and behaviours will reveal what a person wants to achieve in life. On the other hand, it is likely to be important, once the long-term goals have been set, in identifying the skills, supports, and other resources that will be required to achieve those goals. This information may be gathered in preparation for the meeting (by service provider staff or other specialists), or as a follow-up task. It does not necessarily mean that the staff have to be present at the meeting.

In addition, it needs to be recognised that sometimes provider agency staff are the people who have the greatest knowledge of the person with disabilities, and are the best people to help them identify and articulate their aspirations. In that case, and subject to the wishes of the person, they should be at the meeting. However, their contribution derives from their personal knowledge and commitment to the person, not their status as an agency worker, and this should be reflected in the manner and content of their contribution.

It cannot be said, for these reasons, that provider staff should never attend individual planning meetings, but the common assumption that they have an automatic entitlement to attend must be abandoned. So far, nothing has emerged from *Valuing People* that makes this point. Arguably, it is implicit in the principle of person-centred planning. On the other hand, agency staff and others who wish to influence the outcome of the individual planning process may now invoke the principle of partnership to justify their intrusion.

3.3 *Standards and quality assurance*

There is a third, more subtle area where, as a result of the way responsibilities are allocated within the present system, the activities of professionals may move into conflict with the rightful choices of individuals with disabilities. These are activities concerned with setting and maintaining standards – mostly obviously the work of the new National Care Standards Commission in monitoring the delivery of supports, but also many other activities, from the in-house quality assurance work of provider agencies to the targets set for Valuing People implementation (Dept. of Health 2001b).

There can be no doubt that some minimum standards would be universally endorsed. Everyone, for example, would surely agree that people should be protected against physical and sexual abuse by support providers. However, central government initiatives have, in the last few years, increasingly required that standards of service (as delivered by social services assessment and care management staff as well as support providers) should be closely defined and monitored. In some instances – notably the Care Standards Commission, which is still developing its sets of service standards – the full implications are not yet clear. Nevertheless, the trend is not only towards strong monitoring systems, but also to higher, more specific standards. The problem with this is that the higher the standards are set, the less likely it becomes that they will match every support recipient's notion of 'quality'.

For example, it might seem progressive, and entirely safe, to require service providers to promote the social inclusion of their users. There may, however, be some users who want to be left in peace and quiet. If so, their personal definition of service quality will not match the standards imposed on the provider. The Valuing People Implementation Guidance (Dept. of Health 2001b) offers a different kind of example. Person-centred planning is a feature of the new policies: a planning method that is intended to be shaped around the wishes and needs of the person with learning difficulties. Yet the new Partnership Boards are charged with the duty to develop frameworks for introducing person-centred planning. The frameworks have not yet been published. They may deal partly with the process of implementation, but it seems all but inevitable that they will also dictate the format of person-centred planning. A policy with the good intention to give greater control to the user will, in some respects, take it away.

It is not suggested that these conflicts will always work to the disadvantage of the disabled person. Good workers and agencies can achieve great successes in spite of poor systems, just as surely as the best systems will be undermined by incompetence and carelessness. There are, of course, care managers and service provider staff who have helped people achieve the lives they wanted, and who worked with commitment and creativity. On the other hand, the existence of so many role conflicts may in part explain why the commitment and creativity, and the excellent outcomes for users, are not evidently commonplace. As discussed earlier, in mainstream civil and commercial systems, it is accepted that it isn't enough just to *hope* that the people who work in these systems will somehow manage to deal even-handedly with conflicting interests. Conflict has to be addressed in the way the system is designed.

So how might we design a system for the funding and delivery of social care that holds to the same principle?

4 *A rational model for funding and support delivery*

4.1 *The principles of a rational system*

Over several decades, social care policy has gradually come to acknowledge that most of the needs of disabled people are exactly the same as those of other citizens, and that those needs can, and should, be met by accessing mainstream resources. People with intellectual impairments are, generally, no longer put in separate communities, but instead helped to live within ordinary communities. Integrated leisure opportunities are slowly replacing segregated clubs, supported employment is being developed as a better alternative to day centres. People who use wheelchairs may need to have adaptations to the house where they live, but it is far better if the house itself is obtained from ordinary housing stock.

It has yet to be recognised, however, that the principles on which the social care system is based should likewise be taken from the mainstream, with adaptations where necessary. Civil and commercial systems incorporate several centuries' worth of learning and refinement. If the design of social care started from the template of mainstream systems, that learning would be transferred – in much the same way that access to ordinary housing stock means that disabled people are more likely to have a home that meets the general build standards and facilities that empowered consumers demand.

The process at the centre of community care assessment and care management is concerned with the use of money to purchase services to meet the particular requirements of one individual. In many ways this is the same as the process by which citizens make private purchases of goods or services in the commercial marketplace. (In some ways it is very different, and adaptations will be required. These will be discussed later.) The elements of the mainstream system might be summarised as follows:

- The **person making the purchase** freely decides how much they want to spend, within the limits of their total financial resources. They are accountable to no one for their decisions except, possibly, to other people such as family members who share ownership of the money.
- The purchaser needs **information** to make the choice. Shopping is a way to get information about products. Information about both products and services will be available from advertising, brochures, etc. Advice may be available informally from people who have made a similar purchase. If successive purchases are made for the same type of product or services, the purchaser's experience will also inform their decision.
- In addition, the purchaser may also have the option to get information and advice from a **person or agency that has specialist knowledge**: financial advisers or travel agencies, for instance. This type of role, as previously noted, is especially vulnerable to conflicts of interest, and is generally subject to close regulation. The regulations will usually be set by

government, but oversight may be passed to a separate body with appropriate powers (the Financial Services Authority, for example, in the case of financial advisers).

- The products or services are offered by **companies in competition with each other**, usually subject to regulation to make sure the competition is genuine. They compete both in terms of price and also the features and quality of the product/service – it is for the purchaser to judge the right balance between cost and quality.
- Companies are not free to put any product or service on the market, however. An immense raft of legislation exists to set **standards that must be met**. The purchaser also has statutory rights if the service or product is not satisfactory. Many large retailers will refund purchases without question, but this is far in excess of their statutory obligations³. The regulations and entitlements are concerned with minimum standards, notably safety. They do not guarantee that the product will meet the particular requirements of the purchaser: the CD should play, but the purchaser has no legal redress if they don't like the music. It is up to the purchaser to select the product that will satisfy their individual needs; or, in the case of custom-built products and services, to specify the requirements in the contract with the supplier.

Much of this seems just as applicable to the process by which people who need support services obtain them from providers (or individual employees). However, some differences have to be taken into account:

- **Public money is being used to make the purchases.** It has to be rationed out in a way that corresponds to the reasonable requirements of each individual. As the money has been levied through tax, and will always be less than the amount that would be ideally be available, there is also a need to ensure as far as possible, that it is used efficiently. Both these are, inescapably, responsibilities of government.
- **Information to guide purchasing decisions will not be so readily available.** There are no shops to browse through social care products, and social care agencies will never advertise on primetime TV. The consumers of support services are, in commercial terms, a niche market spread thinly through the population as a whole. One of the valuable functions of self-advocacy groups and parents' organisations is to provide opportunities for members to share their experiences of services, but outside such groups there are few casual opportunities for customers to swap notes about the merits of different agencies. And, because a contract for a social care provider is likely to be relatively long-term, individual users will only slowly gain knowledge through repeated purchases. For all these reasons, there is a need to reinforce and supplement the methods by which disabled people, as the purchasers, can obtain reliable information about the services that are available.

¹ The statutory rights require only that goods must be of 'reasonable quality'; 'fit for the purpose'; and conform to the description on the packaging, sales display, and given by the seller.

- **Support services often play an exceptionally important role in the lives of the people who are dependent on them.** There are very few examples of situations where non-disabled people are so closely reliant on personal assistance, except perhaps the servants of the wealthy – and even that is not comparable to the situation of a person with learning difficulties who is left waiting and hungry at home because they need support to go to the shops. Minimum standards, imposed by government, can help to ensure that agencies are competent, well organised, and reliable. However, the more effective incentive to deliver competent services is likely to come from contracts that clearly specify the service required, and give the customer – the disabled person – the opportunity to take their business elsewhere. Both these elements exist in mainstream systems, and only need to be strengthened in the context of social care. Some service recipients may need assistance in negotiating the contract, and holding the provider to it. Help of this sort must be provided by someone solely concerned with the individual's requirements. While this role may contain elements of advocacy, and in some circumstances be taken by someone who is identified as advocate, it is largely a technical service operating within the system though independently from other players (Dowson 1995). It should be added that adequate overall funding is also critically important, not only to enable providers to deliver high quality support, but also to support the growth of a competitive market that offers real choice to consumers.
- **Some people who require assistance will have difficulty deciding and/or expressing what they want, in life and from services.** There are people, notably some people with very severe learning difficulties, who cannot clearly state what kind of life they would like to have. Yet even people with the most limited communication abilities can still convey some information about their preferences, if only by displaying happiness or contentment in some circumstances, distress in others. Other people can then develop a practical plan that is consistent with these preferences. (Beamer and Brookes 2001) This will only work, however, if the people involved know the person well enough to 'hear' their views, and are free of any conflicts of interest that might lead them, consciously or unconsciously, to disregard or misinterpret the person's wishes. Private consumers often get help from family and friends with purchasing decisions, so the main implication for the design of the social care system is not primarily to move away from the mainstream model. It is, rather, to desist from the current assumption that this kind of help should normally be provided by service providers or representatives of the agency that allocates funds. But sometimes the level of help will represent a transfer of control from the individual to family, friends, and/or advocates. This must be addressed in the design of the system. The right of disabled people to have control of their own lives should be safeguarded. When people *necessarily* take some decision-making responsibilities on behalf of the disabled person, their role should be acknowledged and valued; but it should also be subject to constraints, and open to scrutiny, to ensure that it operates in the best interests of the individual.

- **Some people may have the capacity to decide what they want, but not the ability to implement the plan or manage the arrangements once they are in operation.** In fact this is also true in ordinary commerce. There are project managers for private building work; and solicitors to carry out conveyancing for house purchase. Banks, through direct debit payments and account statements, assist financial administration. The context of social care only requires that assistance of this sort is available, and made – like its mainstream equivalents – accountable to the customer.
- **People may make choices that are not in their own best interests.** This is, of course, true of consumers in any market. There is no good reason to suppose that disabled people as a whole are any less able to make sensible choices about their lives and needs than other citizens. Nevertheless, the system has to take account of the reality that some people, mainly as a result of intellectual impairment and/or limited life experience, will make major life choices that are impractical or would involve excessively high risks. The consequences for people who are especially vulnerable may be very serious. If people get help in decision-making that is trustworthy, they may be more willing to take advice. In some circumstances a formal transfer of decision-making control may be appropriate. But if a role that is expressly intended to provide assistance to the individual in making life decisions or choosing supports also contains a hidden purpose of control, role clarity will be lost. The power to veto the person's choices should rest elsewhere. The social services authorities have statutory responsibilities for protection and control, and are likely to be blamed if a vulnerable person is seriously harmed. Moreover, the risk to the individual is often closely linked to financial cost: for example, implementing a series of plans, each one predictably turning out to be a mistake, is expensive. So, logically, the power of veto should rest with the agency that agrees funding; but, like the funding itself, should be open to negotiation.

The list highlights the differences between the contexts of mainstream consumer markets and social care. Yet the modifications required for social care are not that large. For the most part, it is a matter of strengthening the roles and relationships that exist in the mainstream, to make doubly sure that they are effective.

4.2 *An alternative structure: Individualised Funding*

There have been initiatives in many countries to develop systems for social care funding delivery that accord with these principles. These countries include Canada, where the model was firstly clearly defined in the 1970s, and implemented in the 1980s (Roehrer Institute, 1991); the United States, where experimental systems – known as Self-Determination programmes – have been developed during the last five years in almost every state (Moseley, 2002); and Australia, where it is also implemented in several states. UK Direct Payments also, of course, conform to some of the principles. In addition, Direct Payments systems exist in Sweden, Norway, Finland, the Netherlands, and (on a small scale) in Italy, though these are mostly limited to personal assistance for people with physical disabilities.

Other programmes, such as the Independent Living programmes in many countries, and 'consumer directed services' (chiefly for elders, and people with mental health needs) in the United States, also have relevance.

These programmes do not all include every element, and there is considerable variation in the way the principles have been implemented. One or two do not appear to have been motivated by a concern for the rights of disabled people, and have obvious flaws. The funding and service delivery system described in this section is not taken directly from any of these programmes, though it is close to the original conception, developed in British Columbia. It is intended to provide the structure that conforms most closely to the principles of role separation and clarity set out in the previous sections, making use of the lessons that have been learned from different versions that have been implemented.

Figure 4 shows the overall structure and processes. Solely for the sake of clarity, the diagram and the description of the IF model makes use of the terminology associated with IF: *There is no suggestion that these terms need to be adopted in practice.*

The system would operate as follows:

4.2.1 *Social Services Departments*

The main role of the social services department is to allocate funding in response to requests from individual disabled people. Each decision about the amount of funding (except where approval can be given immediately) is made through a process of open, face to face negotiation, by which the requirements of the individual are balanced against other requests from other people, and the overall budget amount. Negotiations are based on a costed plan, developed by the individual. When a meeting is required for the negotiations, it is usually the disabled person who presents the plan. Negotiations also deal with any issues concerning risks and benefits, and the Department has the option to refuse to fund a plan if the risks are excessive.

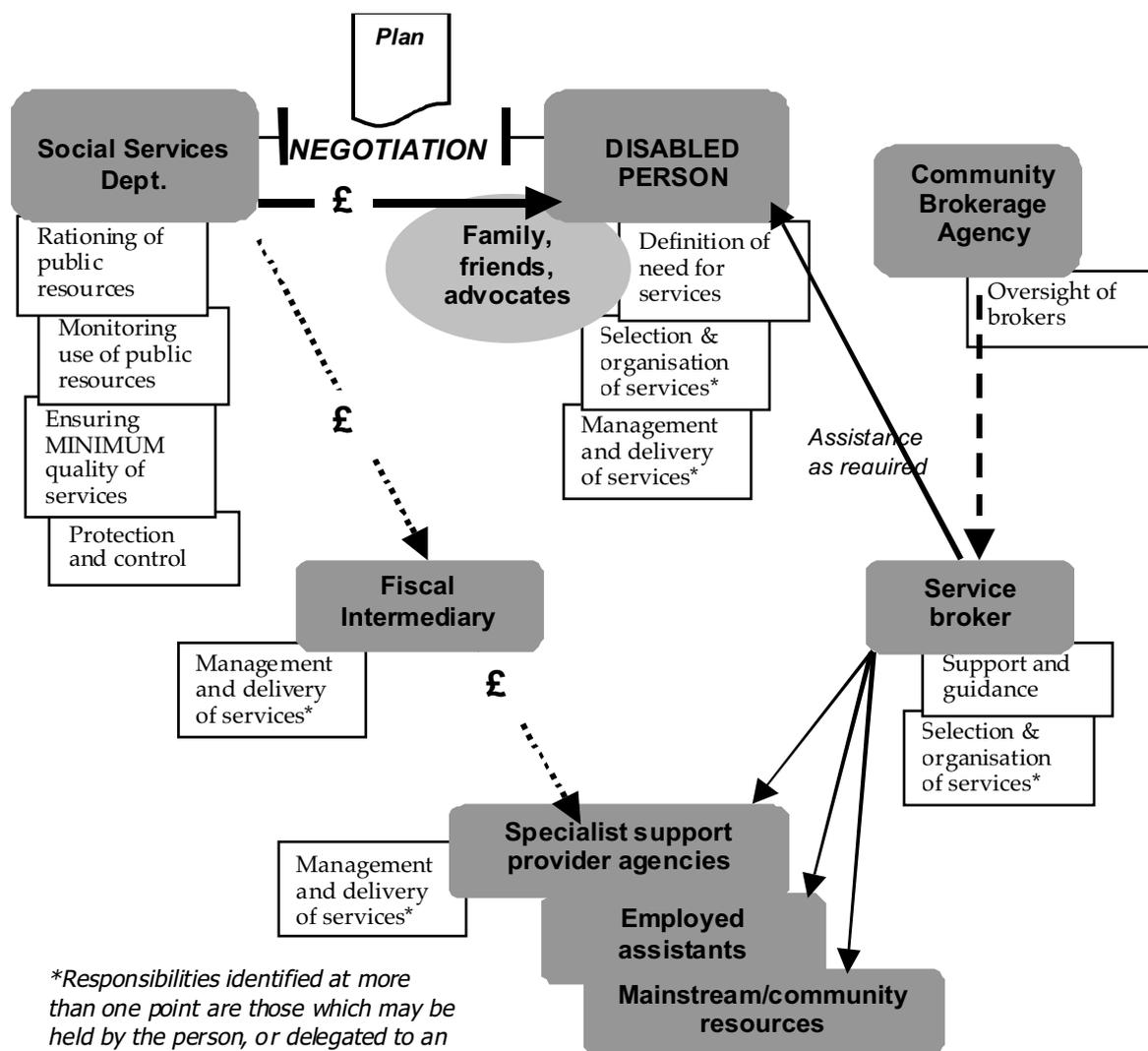
The plan presented by the individual to the Department will include a description of their impairment and any other difficulties, as part of the basis for the funding request. There will also be other information available, such as receipt of benefits, to confirm the person's disability. Sometimes the Department may still wish to gather information for itself, but this need only concern factual information. *Thus the plan developed by the disabled person, combined with the negotiation process, has replaced the community care assessment.*

To guide its funding decisions, the Department also has information about current and predicted demand, and has developed and published the guidelines that it uses to decide whether the proposed use of funding is reasonable. Within (and occasionally outside) these parameters, the decision is based on the merits of the plan.

The Department also has responsibility to monitor the use of the money by recipients, but in a way that balances the likelihood of misuse, and the cost and intrusiveness of monitoring, against the savings likely to be achieved.

The Department will need to retain the capacity to organise and deliver some services quickly. Some people may prefer to continue to receive services through the assessment and care management process, and/or to use in-house services. The Department would therefore continue to operate these services.

Figure 4: The structure of a full individualised funding system, showing allocation of major responsibilities.



4.2.2 The disabled person

In most instances, the disabled person has control over the development of the plan – which is based on their life aspirations – and over the choice of support providers. They have the option to employ their own support workers, but have to show in their plan, and in negotiations about the plan, that the legal and practical responsibilities will be met. If support-provider agencies are involved in the plan, the disabled person will have specified the service they would be required to provide, and asked for (and possibly negotiated) a cost. The costs in the plan will reflect the outcome of negotiation. The plan may also involve the use of mainstream commercial or community facilities.

If the person needs and wants assistance with any of these tasks, they have the option of help from a source that is independent from the social services department, and from service providers, and is accountable to the disabled person. This assistance is itself a service, which means that the disabled person chooses who will provide it, and contracts with them for help with the tasks which the person selects.

People may choose to receive the money for their supports, and administer it themselves. Here again, however, the plan would have to demonstrate to the Department that this was realistic. Alternatively, they can make arrangements for the money to be administered by a bank, accountant, or a specialist agency. (See 4.2.5, below.) These sources of help can supply information about actual use of funds that the social services requires, but they provides a service to the person: they do not serve as an arm of government, and do not have a control function.

Exceptionally, when a person is very severely intellectually disabled, the plan will be developed and submitted on the person's behalf by a small group of people operating as a legal trust or 'microboard'¹ – a legal entity which exists solely to manage funds and services for one person (Holman and Bewley, 2001). The plan would have to demonstrate that transfer of control was necessary; the extent of control that had been taken; and evidence to show that the trust was able to act in the person's best interests (e.g. by virtue of its membership). This kind of arrangement will be most effective if it is underpinned by legislation that provides for graduated levels of Guardianship, based on each individual's capacity.

4.2.3 *Independent planning assistance and support co-ordination.*

These two functions are usually combined in a role that is often termed 'service brokerage'². As mentioned above, brokers provide technical assistance to the disabled person. They are selected and contracted by the disabled person; perform only those tasks that they are contracted to provide, and are accountable only to the disabled person. Brokers may work with family members or others, but their primary duty is to serve the interests of the disabled person.

The cost of this assistance is met, ultimately, by government funding. However, the money provided to people to obtain their brokerage assistance is separate from the funding allocated for support services, and is provided by a route that preserves the independence of the brokers from the social services department.

4.2.4 *The Community Service Brokerage Agency*

A mechanism is needed within the IF system to –

- safeguard the quality of brokerage services;
- ensure the independence of brokers;

¹ Information on microboards can be found at the Canadian site, <http://www.microboard.org>

² The term 'service broker' is used in this paper because it has become the most familiar name for this role. It must be stressed that the role is not exactly comparable with the role of broker in purely commercial or financial contexts; and even within individualised funding its interpretation varies.

- provide information to people requiring brokerage services, so that they can make a choice about the broker they wish to use;
- enable funds for brokerage costs to be made available at a level that is appropriate for each individual.

These requirements are met by an agency that, in the terminology of individualised funding, is called the Community Service Brokerage agency.

This agency is controlled by disabled people, possibly with the participation of some family members and other people with relevant skills who are not linked to the social services department or service providers. This is to ensure that the quality of brokerage services truly reflects the requirements of the people who use them, and that brokerage remains independent from government. Because the agency is concerned with general oversight, co-ordination and information, it has sole responsibility for these duties within a given locality.

Brokers may be directly employed by the Community Service Brokerage Agency, or operate as individual brokers or in brokerage agencies, receiving fees for services provided. These alternative arrangements have their own advantages and disadvantages, and are discussed in more detail in section 4.3.

4.2.5 *Assistance with financial and employment responsibilities: the fiscal intermediary role* ¹

Fiscal intermediaries, in the terminology of IF, are the individuals or organisations which are available to assist people, if required, in the administration of their funds, and also – if required – to act as the legal employer of personal assistants. They provide a *function* within the individualised funding system, and may or may not take the form of a specialist agency. Fiscal intermediaries provide a service to the disabled individual, and their involvement should not lessen the control that the individual has over their funding. To ensure this, there may be a contract between the fiscal intermediary and the disabled person.

4.2.6 *Service providers*

Services providers deliver services under contract specified by the disabled person. It is possible that a personal assistant or contracted agency worker will attend meetings when the person's satisfaction with services, or future plans, are being discussed; but this is not assumed.

Service provider agencies will want to ensure that their own commercial interests, organisational security, and the needs and rights of employees, are preserved. These are factors that they will consider when developing their own policies, and when discussing and negotiating contracts with disabled people.

¹ 'Fiscal intermediary', though a rather clumsy term, is an accurate description, and does not invite confusion with any other role. It originates from the U.S. tax system.

Frequently Asked Questions about service brokerage

◆ **Do people have to have brokers?**

No. Service brokers provide a service to the individuals who require support services, and it would be totally contrary to this principle to insist that every person must use a broker. And if a person does want some help from a broker, the contract they agree with the broker will set the terms and scope of the help provided. Some people, for example, may want help in thinking about their own futures and the kind of supports they will require, others may only want help in finding and organising the supports they need.

◆ **Isn't it the same as care management?**

It may look similar, because it is concerned with the same processes: deciding what supports someone requires, finding providers, writing a costed plan, and so on. At a purely technical level, some of the tasks involved are very familiar to care managers. But, unlike a care manager, the service broker's sole concern is to provide assistance to the individual. This is a fundamental difference, and it completely alters the mentality that is required, as well as the practical working methods. In contrast to the care manager, the broker operates in alliance with the person, outside the bureaucratic framework of the local authority. The broker has no authority to act without authorisation from the disabled person, and always reports back to the person about any activities undertaken without the person's participation. And although the broker should, of course, offer their advice, it is no part of the broker's role to veto, ignore, or re-interpret the person's wishes. It can be very difficult for care managers to become service brokers, because it requires them to shake off old, often unquestioned habits, and some re-training is essential.

◆ **Isn't it the same thing as advocacy?**

Service brokerage does involve elements of advocacy, to the extent that brokers sometimes work to help people express and assert their views. For example, the broker may support the person (if requested to do so) at the meeting with social services to negotiate the funding allocation. However, the emphasis of the role is on delivering a service, and one that requires technical knowledge and skills. Moreover, the brokerage role, though completely independent from the other 'players', nevertheless provides a function that is part of the system, whereas the advocacy role in social care is often

'outside' the system. So, while brokerage may have elements of advocacy, and some advocates may be able to give help with planning and organising supports, the focus of the roles is very different. Since both are of value, it makes sense not to confuse them.

◆ **Can parents be brokers for their disabled son or daughter?**

Parents may be able to help their son or daughter to think about their wishes for the future, or to find the services they need. But they don't need to adopt the label 'service broker' to do this. Parents who want to acquire the label, sometimes at least, see it as a way to gain more official recognition for the important part that they already play in their son's or daughter's life. A better solution would be for the system to recognise and respect the contributions that parents make.

There is, of course, no reason why a person who has a son or daughter with disabilities should not become a broker for other people. However, they would – like anyone else – need to complete some training first.

◆ **Why should we import the brokerage model, when we've got our own support schemes already set up in the UK?**

'Service brokerage' is a handy, internationally recognised term; but it doesn't much matter whether or not the term becomes officially adopted in the UK. Clearly, there are already many schemes in this country which broadly aim to deliver the same kind of assistance (often combined with the fiscal intermediary role). The arguments in this paper in support of service brokerage do not imply disrespect for the value of those schemes, let alone suggest that the schemes should be wound up and replaced by people called service brokers. Rather, the arguments are, in essence, in support of two principles: firstly, that the function contained in the brokerage role, and in UK schemes, is an integral component of an IF system, and needs to be available in all localities. This will not happen while it depends on purely local decisions to offer low priority, short term grant funding. Secondly, it is argued that the logic of role separation and clarity points to a set of organisational and funding characteristics that must be present, whatever the role is called. It is important to review the UK schemes, which have developed in many different forms, against these criteria.

4.3 *Organising and funding service brokerage*

The IF system has to incorporate a way to fund the brokerage function (whether or not called 'service brokerage'), which preserves its independence from the government and service providers. As it is, in itself, a type of service, it should ideally allow and respond to the choices of customers. On the other hand, it plays a special role in the system, as the route that many people will use to gain access to support services, which implies special arrangements for funding and monitoring. Two organisational models favour either side of these requirements. The third is an intermediate option that offers the strengths of each, with fewer disadvantages.

OPTION 1: *A single agency (covering a locality) that receives funding from the local authority. It employs all the service brokers. The agency is controlled by consumers, in order to preserve its independence. People who require brokerage assistance may choose their broker from those employed by the agency.*

Advantages:

- ✓ single point of access;
- ✓ secure resources, and employment security for brokers;
- ✓ direct oversight of brokers' work.

Disadvantages:

- X consumer choice limited to salaried brokers, all of them from the same agency;
- X consumer choice will have little effect on the 'market' of brokers available;
- X a fixed cost, regardless of actual demand for brokerage services;
- X the agency may reach the size where it become bureaucratised and remote from the lives and wishes of the people who use its services.

OPTION 2: *People are given an allocation of funding that they can use to purchase brokerage services. They are then free to purchase brokerage from individuals or brokerage agencies that offer their services in a competitive market.*

Advantages:

- ✓ when the market has developed, it will give consumers a wide choice of brokers, and evolve in response to consumer demand;
- ✓ overall cost will reflect the actual level of demand.

Disadvantages:

- X difficulties in safeguarding quality of brokerage services;
- X lack of job security for brokers;
- X availability of brokerage cannot be assured;
- X no mechanism to provide independent information about available sources of brokerage services;
- X there is no way to allocate brokerage costs in proportion to the amount of brokerage that people will need, because they will not have a broker to help them negotiate for it – a 'chicken and egg' problem.

Option 3: *In this option – the 'mixed model' – a small community brokerage agency, controlled by disabled people, receives funding from the local authority. The community brokerage agency directly employs a small number of brokers who provide a minimum guaranteed resource, but brokerage is also available from a market of individuals and agencies providing their services on a fee-for-service basis. The community brokerage agency sets and monitors standards of practice, and provides information services for people who require a broker. In addition it can stimulate community development work, on a larger scale than is feasible for individual brokers. The in-house brokers also help people to make an initial request to the state agency (i.e. council) for the funding they will require to pay for the broker they choose from the open market.*

Advantages:

- ✓ ensures minimum level of brokerage resources;
- ✓ independent monitoring of brokerage standards;
- ✓ open market of brokers, which will be shaped by consumer choices;
- ✓ low system overhead for brokerage services;
- ✓ clear access route to brokerage services, with assistance if required in obtaining brokerage.

Disadvantages:

- X limited job security for independent brokers.

4.4 *Parents and self-determination*

The role of parents in supporting the self-determination of their sons and daughters, especially those with learning difficulties living in the parental home, has long been an area of difficulty. Can the Individualised Funding model reduce these problems?

Many adult disabled people depend on their parents as the primary source of support. The state depends on them as well, because the budgets for personal social services are based on the assumption that parents will continue to give this support without charge. In spite of this, parents are sometimes seen very negatively: as over-protective, interfering, and outdated in their views, and hence as a threat to the self-determination of their disabled sons and daughters.

If parents do tend to conform to this stereotype, the reasons must be complex. However, the reason that parental attitudes are such a major issue is more straightforward: here again, it is a problem of conflicts of interest. On the one hand, parents are in a position to shape the person's choices, or (especially if the person has severe learning difficulties) to speak on their behalf. On the other, their own needs – emotional, and often financial – are tied up with the choices the person makes. When parents are support providers, they will encounter the same conflicts as other providers. As advocates, they may not be focused exclusively on the person's views and rights.

While parents play such a critical role in supporting their sons and daughters, and in sustaining the social care system, there can be no easy way to re-structure the system to remove this conflict. In some respects, the conflict may be accentuated in a DP or IF system because, with the withdrawal of the state and service providers from the individual planning process, more responsibility may fall on parents to help their son/daughter to plan for the future. However, a good IF system can ease some of the conflicts, and address those that remain.

A recent research project in Swindon (Williams and Robinson, 2000a; Williams and Robinson, 2000b) found that, in reality, the parents of people with learning difficulties almost universally downplay their own needs, in favour of those of the person from whom they care, and the real conflict is far more often between the whole family and an inadequate service system. Since the occurrence of disability is random, there is no reason to suppose that the parents of disabled people are inherently more protective or reactionary than others. On the other hand, parents will have had their attitudes influenced by their dealings, over the years, with health and social care professionals. If parents feel that their opinions, based on many years' knowledge of the disabled person, are being over-ridden by a professional whose involvement is fleeting, it is to be expected that they will go on 'stubbornly' putting forward their own views. They have good reason to doubt the advice of professionals who, by their accountability and mentality, are distanced from the realities of life as an unpaid carer. It is understandable that parents, like their disabled son or daughter, will be left feeling resentful about allocation decisions that have been made behind closed doors, with no evidence that anyone argued their case. The services that are being delivered have often only been acquired with a struggle, and carers know that, if the services fail, they are the ones who will have to fill the gap that is left. In those circumstances it is entirely rational to take a conservative attitude towards change.

An IF system would clarify the roles of the professionals, and hence make them more trustworthy. The requested level of service might not be agreed, but at least the decision-making would be open, and the council would have to give reasons for its decision. Assistance in developing and implementing plans would be provided by someone with no hidden agenda. And though the plans might not work out, and services might still fail to deliver, there would be security in the knowledge that the funding remained, and could be used to find alternative sources of support. There are some instances being reported from IF programmes of individuals and/or their families voluntarily returning excess funds. This hints at a new spirit of partnership based on the recognition that the recipients of IF and the state have a common interest in using the total funding as fairly and effectively as possible. As noted in the evaluation of the New Hampshire programme (New Hampshire DDSS, 2001), however, recipients will be reluctant to return funds unless they are confident that the state will be equally willing to respond if costs subsequently rise.

Although the current DP arrangements raise the concern for parents that they will become service managers, at least some have found the experience very positive. As one parent in the Swindon project said,

The direct payment has helped me to be a parent again, and not just a carer.

The possibility of conflict between the interests of the disabled person and their parent(s) would, of course, remain. However, it could be further reduced and checked by various measures:

- Professional training and practice that underpins the principle that the disabled person's rights and requirements are the primary concern. ('Person-centred' methods may be in favour, but it is evident that care managers, social workers, and other professionals still often only have a relationship with a person with learning difficulties through the parents, who act as intermediary.)
- The increased use of 'circles of support' in which the views of the parents are supplemented by those of other people who are committed to the disabled person. In some areas of the UK, a direct payment can be paid to an individual through their Trust only if that board includes at least one member who is not already a close friend or family member. This is a useful check on the power which a family could assume.
- Further development of the principle that carers have needs and rights that should be acknowledged by the system, but kept separate from those of the disabled person.
- Legislation which clarified the powers of parents, and others, to make decisions on behalf of the people with intellectual impairments whom they support. (See Section 5.4.2)

4.5 *The effectiveness of individualised funding*

The IF programmes that are now in progress in several countries are valuable 'learning laboratories', exploring the operational choices, challenges, and responses from stakeholders. However, they do not offer a definitive answer to the question, 'Does IF work?'. There are a number of reasons for this:

- Most of the programmes have become operational in the last three or four years, and evaluation findings are only beginning to reach the public domain.
- The largest number of projects are in the United States, and these are jointly identified by their aim to further the goal of people with learning difficulties, rather than by the adoption of IF. All do, to some extent, involve the individualised funding method to transfer control to the disabled person, but the model is interpreted variously (Moseley 2002). The mechanism for allocating funding varies, with implications for the degree to which the funds are based solely on the requirements presented by the disabled person or their representative. In some programmes the brokerage role may be taken by people who are employees of provider agencies or the funding agency, while in others the broker is seen more as a 'mentor' – a non-professional person linked to one individual. In a few programmes, the primary emphasis is on systems-level change: cultural change in state and provider agencies, a greater leadership role for disabled people and their families; loosening of the regulations governing the use of funds for services. The existence of these variations may, in time, provide very useful indications of the strategies for self-determination that are most effective. However, combined or diffuse findings from the US experience as a whole tend to hide these distinctions, and 'level out' the impact that IF can have.

- Some of the elements of IF schemes can be developed without implementing the whole IF model, and it can therefore be argued that observed positive outcomes are the result of those elements, rather than the consequence of implementing a coherent IF system. These elements include person-centred planning methods and broad cultural change in support of self-determination. In particular, it may be difficult to separate the benefits gained by handing control of support purchase (as in UK Direct Payments) from the effects of other components, and of the implementation of the whole IF model.
- Evaluation has to address the question of the aims of individualised funding (and DPs), and a number of more technical issues. Self-determination may be seen narrowly in terms of control of support, or as having control of one's life as a whole; and assessed either in terms of actual decision-making control, or the disabled person's sense of their own self-determination. If choice and control are seen, not as ends in themselves, but as the means to a better quality of life, and/or to greater social inclusion, these outcomes must also be measured. The impact on overall costs may also be a factor in judging the success of IF, and may be skewed, for better or worse, by the way in which people were selected for inclusion in the program.

While these are all reasons to be cautious in interpreting the information that has emerged from evaluations, it can nevertheless be said that the available findings are overwhelmingly positive. The Self-Determination Program in Monadnock, a county of New Hampshire, was a relatively early pilot of IF which acted as a spur to similar developments across the U.S.A. Independent quantitative evaluation (Conroy and Yuskas, 1996) examined changes in the lives of 38 of the 43 participants, all of them people with learning difficulties, over a period of eighteen months. The results were 'positive, encouraging, and unprecedented'. In almost every aspect of their lives (i.e. not just in purchasing decisions), respondents reported a significant increase in personal choice. The services and supports provided to participants were also found to have become more individualised. Data from personal interviews with 27 participants who were able to give their own responses found that these participants were more satisfied in all the nine dimensions of life that were examined. No significant increase was found in the amount of community-based activities, and none of the participants (about half the group) who did not have a 'circle of support' at the start had acquired one after eighteen months. However, the circles that did exist on average more than doubled in size.

The evaluation also found that, while challenging behaviours had decreased, the participants did not demonstrate that they had acquired new skills. This led the evaluators to remark that –

... the old way of thinking, the 'readiness model', would require people to "learn and earn" the right to make their own life choices. ... The Monadnock emphasis was on changing the support system, not the person.

All these gains – achieved in eighteen months – were accompanied by a reduction in overall expenditure on support services of between 12.4 and 15%. This was reportedly¹ the result of greater use being made of informal (i.e. zero cost) supports and lower cost mainstream options in place of specialised support services.

The evaluation established that, as a group, the characteristics of the participants were similar to those of non-participants. Thus there was no reason why the same benefits could not be realised more widely. However, the evaluators acknowledged that the strong, values-driven leadership in Monadnock might have been a factor in the results.

Since the evaluation, the self-determination programme has been extended across all regions of New Hampshire, and a further evaluation was published in 2001 (New Hampshire DDSS, 2001). By the time of the evaluation, 170 people had participated in the project. A 'before and after' survey was completed with participants in three of the twelve regions, and showed significantly larger numbers of people making decisions about their lives.

The results are not, however, as marked as those for Monadnock. Although all the regions implemented some form of individualised funding, they were allowed to interpret the model as they wished, for example in the sources of help made available to assist people in planning their supports. The 2001 evaluation also used questionnaires to study how far the values of self-determination were embraced by staff in the regions, and found that while the values were strongly endorsed by managers, other staff were less in agreement. It appears – though this is not explicitly stated in the evaluation – that the qualities of the Monadnock programme which produced such remarkable results 'faded out' as the programme was extended. Unfortunately, it is not possible to discern whether the critical qualities concerned leadership and values in themselves, or the way in which IF was implemented.

Findings from evaluation (Roehrer Institute, 2000) are also available for an IF project in Ontario, Canada. The Individualized Quality of Life Project was launched in 1997, became operational early in 1998, and continued until autumn 1999, when a final set of data was collected for the evaluation. 150 people received IF within the project, covering three groups of people with learning difficulties: young children living with parents; young people in transition from school; and adults living with ageing parents. Evaluation, by means of case studies, surveys, and focus groups, concentrated on the quality of life outcomes for participants.

As in the Monadnock project, the evaluation sought evidence of change when the programme had only been operating a matter of months; and yet, here too, the outcomes are very clear and positive. Summarising the outcomes in terms of the goals of the project, the evaluation report states that –

- For the majority of the participants, the project strengthened **self-determination**. This occurred as a result of the development of a vision for the person's life as a valued member of their family and community; greater decision-making control about supports; the far greater recognition and value that people obtained in personal relationships within their family and beyond; and increases in personal skills.

¹ Only the amount of savings is given in the evaluation report. An explanation of the cause of the savings was given in personal correspondence with a senior figure in the Monadnock program.

- *Community participation* increased for a significant majority of individuals, in many forms. Over 50% increased recreation involvement since participation in the project began, and almost 60% of adult participants had seen increased educational, vocational, and employment participation (though mainstream employment remained restricted to a small minority).
- *Access to needed supports* improved substantially over the course of the project.

It may be argued that the current UK Direct Payment system has the potential to deliver similar results. However, the evaluation identified independent planning supports as one of the key factors to success. While some families were not concerned about the source of planning support, and others were content to continue to receive it from a service agency with which they were familiar, many found that independent support was very important. In particular, it assisted the development of a clear vision for the person's future, and this was instrumental in improving community inclusion and improved relationship. The evaluation concludes:

... the importance of developing a clarity of vision for a person's future, and of developing a detailed, specific plan to realize this vision, cannot be underestimated in understanding the successful outcomes in this project. It seems likely, though this evaluation did not test the hypothesis through comparative research, that provision of independent or third-party planning facilitation is a key ingredient in fostering such visions and plans. There are no accountabilities or interests that more independent planning facilitators must take into account, other than those to the individual and family.

(Roeher Institute, 2000)

While the findings of these few evaluations do not do justice to all the IF innovations that have been taking place, they are strongly supported by the more anecdotal information that is emerging from many programmes. The impact of implementing IF in differing ways is not yet quantifiable, but that are strong indications that a clear structure which avoids role conflict, especially in the provision of planning supports, is very important.

4.6 Individualised funding and larger goals

At the level of the individual, a Direct Payment offers a way to escape from dependence on social care providers, either by setting up personal assistance arrangements 'outside' the system, or by using control over funding to invert the usual power relationship with providers. At the systemic level, DPs and IF have the same appeal for advocates of the rights of disabled people. Changing the fundamental structure of the system looks a much better strategy for improving the position of disabled people than trying to persuade and educate the professionals to deliver the services that people want.

¹ Most DP provision in mainland Europe, for example the Swedish scheme under the 'LSS' legislation, is concerned solely with personal assistance.

Many disabled people may require nothing more from the system than the funding (of an adequate size, and without too many strings attached) to organise their own personal assistance¹. With the benefit of personal assistance they can live in ordinary housing, access ordinary community resources for leisure and education, and find employment. Once established in the community, and with the ability to initiate their own relationships, full community inclusion will follow.

But for many people the route to citizenship is not so clear. Even if they are enabled to employ personal assistants, or make their contracts with provider agencies, and are physically located in the community, inclusion is not a reliable consequence. Public prejudice may bar their access to community resources, and personal relationships may not develop spontaneously. If they are not able to be assertive, and have no one else to argue their case, they may still find that many day-to-day decisions are made for them.

For these reasons, the case for implementing IF has to be tempered with a recognition that it is not a quick-fix solution which can replace all the other strategies that have been developed to promote the rights and inclusion of disabled people, especially people with learning difficulties. John O'Brien, who has warned against a simplistic faith in IF, identifies it as one of six building blocks that "interlock to form a foundation on which people with disabilities and their families can strive to build a life that offers real opportunities for security, dignity, and contribution". Three of these operate at the level of the system, three at the level of each person:

Systemic level building blocks:

- Responsive and flexible assistance (*the provision of the full range of assistance and assistive technologies, in a way that respects the individual, enables community participation, and adapts to changing individual requirements*)
- Individual funding (*an adequate level of public funding, provided in a way that allows the person to negotiate the support arrangements*)
- Transition of existing services (*organizational learning and redeployment, as a continuous process but especially in transition*)

Personal level building blocks:

- Person-centered planning
- Community development
- Personal support (*the friendship and family relationships which provide shared life experiences and pleasures, practical help, and confronting challenges and threats*)

(O'Brien, 1999)

O'Brien also argues that, in placing the focus solely on IF, the resources available to assist people towards citizenship are narrowed to public funding, which will inevitably be inadequate. Strategies that address all the building blocks, however, make use of the far greater resources that lie beyond the social care system, in communities and mainstream facilities.

These arguments should not be used as a mandate by social services departments or service providers to interfere in people's lives where they are not wanted. Some disabled people will not want help, from professionals at any rate, in

achieving community engagement. Some people may not even want to do anything that conforms to the local Partnership Board's definition of person-centred planning. Nevertheless, it is undoubtedly true that other strategies need to be employed alongside IF. O'Brien suggests that change at the personal level reinforces systemic reform: as disabled people become more involved and visible in their communities, public attitudes will change; and this will create a climate where progressive disability policies, and higher levels of expenditure, will be more acceptable.

Equally, as O'Brien states, an IF system reinforces the other building blocks. IF systems not only change the actual control which people have over their lives, but enhance the status of recipients as people who are able to take control. IF allows people the freedom to establish themselves in the community, in circumstances that are not stigmatising. If fully implemented, it enables people to make their own plans, supported by their own friends and, if required, by professional help that is independent.

Person-centered planning provides a variety of helpful ways for people with disabilities and their families and friends to consider critical questions about desirable futures and to guide action. As the service system adopts some of its techniques and language, it is important to encourage people with disabilities and their families to maintain the capacity to plan independently of the service system.

(O'Brien, 1999)

The independence of service brokers from statutory agencies, and their primary allegiance to the disabled person, means that they are closer, in both accountability and outlook, to the community than to the professional system. As a consequence they are well placed to carry out community development work to assist the inclusion of people they are assisting. An IF system also places an obligation on service providers, ultimately driven by commercial self-interest, to deliver supports that will help people to achieve the lives they want.

5 *Setting the individualised funding model into the UK context*

It is beyond the scope of this paper to discuss the full range of issues that each of the stakeholder groups would need to address in the transition to a comprehensive IF system. Some are already being considered in the context of Direct Payments, and others have been explored by IF programmes in other countries¹. However, some major issues need to be highlighted.

5.1 *Individualised funding and welfare benefits.*

In contrast to most European schemes, IF allows disabled people to purchase whatever assistance they require, from whatever source they prefer, subject only to constraints agreed when the funding is allocated and any safeguards that exclude particular provider agencies. This is especially important for people with learning difficulties, whose need may not be for solely for personal assistance, but for access to mainstream opportunities. However, if people need money from the state to access ordinary community services and facilities, it may simply be the result of poverty.

IF is not an appropriate answer to poverty. There are costs which result from disability – or, more accurately, from a disabling society – that are predictable from the sort of short clinical assessment that is used to determine eligibility to disability benefits. Likewise, unemployment calls for income maintenance assistance, not individualised funding. The essential function of IF and Direct Payments (and, in the final analysis, of state-funded social care itself) is to provide the necessary flexibility to respond to costs that are closely associated with the particular needs and preferences of each person. These cannot be met in an efficient and equitable way through standardised welfare benefits – even those that have different bands of payment. However, this flexibility necessitates a lengthy process of assessment or negotiation that is costly to the state and intrusive to the individual, and limits any principle of rightful entitlement. Therefore IF should be used only to supplement, not to substitute for, an adequate system of benefits.

5.2 *Independent Living and Direct Payment Support Schemes*

In many areas of the country there are already schemes that assist people to obtain and use Direct Payments. They describe their services by a variety of names, and have differing origins, but nevertheless fit broadly into the roles that, in the IF model, are most often called service brokerage or fiscal intermediary services.

¹ For discussion of implementation issues from an international perspective, see Dowson and Salisbury 2000 (i); Dowson and Salisbury 2000 (ii); and additional documents available at <http://members.shaw.ca/bsalisbury/> and <http://members.shaw.ca/individualizedfunding/>.

These organisations have grown in the context of UK policy, and to a large extent reflect the views of disabled people about the kind of help that they require. It would be absurd, as well as insulting, to try simply to impose a 'foreign' model and terminology on these schemes. If Direct Payments provision were expanded into a coherent IF system, the main impact for these organisations should be to underline their importance. As key components of such a system, they should not be considered, as they often are at the moment, as interesting but minor innovations on the edges of social care.

However, if the logic that underlies the IF model is correct, then it has implications for the characteristics and exact roles that these organisations should play. The historical association between Direct Payments and personal assistance and the involvement of care management prior to receipt of a Direct Payment, means that the work of these schemes does not, typically, place much emphasis on the early stages of planning – on dreams and overall goals. More typically, they are involved in the later stages of finding supports and implementing the plan. They are, therefore, delivering some of the services that are termed as service brokerage in individualised funding systems. Moreover, there is usually only one scheme in each locality: the local authority is unlikely to fund more than one. Those schemes that are outside social services usually emphasise their independence. All these characteristics suggest that the organisations are performing the distinct role of the community brokerage agency. If that is so, however, it would be important to ensure that –

- a. **They are truly independent from social services**
This requires funding provided on terms that do not allow undue pressure to be exerted by social services; and a board overwhelming composed of people who have no links with social services or support providers. More subtle links must also be avoided, such as management staff who have moved across from social services, and continue to feel a strong pull of loyalty towards their old colleagues.
- b. **The agency is controlled by people who are representative of the people being served.**
This might mean having a formal system of representation in which, for example, some members of the board are nominated by the local People First group. But the critical requirement is that the composition of the board must reflect the range of people being served and, in particular, their differing forms of impairment.
- c. **The agency is empowered to perform its role in supporting and safeguarding the quality of service brokerage.**
This requirement is straightforward if all brokerage assistance is to be delivered by the staff employed by the agency. However, if it is the intention to allow a market of independent brokers to develop, the community brokerage agency must have the authority to act as gatekeeper for brokers, and to set the required standards of competency and practice.

Research, and informal reports, suggest that some of the existing schemes are not genuinely independent, and/or not representative of the full range of social care users (possibly for the good reason that they were set up to serve a more limited group). As *Valuing People*, acknowledges –

Most local councils operate support schemes, but often these are focused on the types of support people with physical disabilities may need. Schemes must be accessible to people with learning disabilities, so that they too have the right support to manage a direct payment and remain in control.

(Dept. of Health, 2000)

Alternatively, these schemes might have the option to become part of the service broker market, releasing them from the special obligations of the community brokerage agency. They would nevertheless need to ensure that they were truly independent. A further option would be to establish themselves as specialist fiscal intermediary agencies, which may be where their activities and skills are already concentrated

The double role of some schemes in providing both service brokerage and fiscal intermediary services raises an issue which merits further discussion. There is no major conflict of interest between the roles, but there are arguments for keeping them separate:

- Whereas assistance in planning requires a firm values system, an understanding of the issues facing disabled people, and a knowledge of community and specialist resources, the work of a fiscal intermediary is ultimately only concerned with accountancy and (sometimes) with employment legalities.
- It extends the influence that a single agency or individual may have over one person's life to a degree that may not be 'healthy'.
- There is some possibility of conflict of interest, which could cause the advice given at the planning stage to be biased in favour of using the same agency's fiscal intermediary services (as a way of gaining business); or possibly in favour of plans that imply minimal fiscal intermediary services, in order to avoid cost or inconvenience to the agency.
- It implies larger organisations, with greater risk that they will become bureaucratic.

The last of these arguments applies most strongly if the agency is either the single monopoly brokerage provider in the locality, or if it has the special role of the regulator of the brokerage market. The organisation's priority concern with the needs and rights of disabled people, and its cultural location in community rather than services, could be undermined by a large, bureaucratised staff group.

Local implementation of comprehensive IF arrangements should be based on discussions with local organisations representing disabled people and carers. Direct payment support schemes, and similar organisations, would need to identify the role they wish to take within the IF system, and the changes they would have to make to their structures, policies, and personnel. In order to ensure that all groups and disability sectors had an opportunity to be involved in the new system, some organisations will need time and funding for training.

5.3 *Implementation issues*

The development of individualised funding in the UK must ensure that the essential principles are retained, while also taking account of the existing framework of policy, and practice – and, in particular, preserving the strengths of the Direct Payments provision.

The potential of the existing Direct Payments provision has not yet been realised. The escalating growth of DPs is evidence that, even without enhancements to the system, the take-up is not yet approaching its ceiling. Many councils have plainly been slow to develop the systems and staff skills required to support Direct Payments. Similarly, many service provider agencies have not yet seen Direct Payments as a business opportunity as well as a way to support the user outcomes that they invariably profess as their aim.

At the level of central government, what is needed first is a shift in emphasis, to put Direct Payments provision into the position where councils and providers will be more obliged to respond to the opportunities and challenges. From these foundations, some enhancements can be made within current regulations: for example, the contributions of DP support schemes as brokerage sources or fiscal intermediaries can be clarified and strengthened. It would be helpful, however, to have guidance from central government on the limits to such developments imposed by current regulations. In particular, it is not clear whether the duty of local authorities to carry out community care assessments of need can be delegated. Full implementation would require some changes in the regulations, and probably in primary legislation. These are identified in the recommendations at the end of this paper.

Thus implementation could occur through a gradual process which allowed the stakeholders time to address the implications, and to work together to develop pilot schemes. The learning from this process would inform guidance, and lead to some standardisation around best practice. However, it is *not* suggested that this should lead to a final phase of wholesale implementation. The right of disabled people to self-determination should extend to the choice of whether or not to take the level of control over their supports that IF allows. The future of care-managed services should depend on the collective exercise of that choice.

5.4 *Associated policy issues*

Although, in operational terms, the proposed IF system can be established as a separate and parallel arrangement, it has connections with wider policy issues. This section briefly identifies three issues.

5.4.1 *Partnership working*

As acknowledged in the Introduction, the arguments presented in this paper run contrary to the philosophy of partnership working that is central to the Government's thinking, in *Valuing People* implementation (Dept. of Health, 2001b; Dept. of Health, 2002) and in many other areas. This is not to suggest that there is no place for partnership. At some levels of contact between certain kinds of organisation – health and social services management being the obvious case - the closest possible collaboration may be in the best interests of those who require assistance. If

partnership meant nothing more than good lines of communication and mutual respect, then there would be very few circumstances where it was not desirable.

But it is clear that the government does see it as much more. The draft guidance on partnership promotes partnerships characterised by a shared culture based on common values, aspirations, and priorities, and backed up by good personal relationships. Moreover, this sort of partnership working is advocated for every level of operation, and across all relevant public, provider, and voluntary organisations, including advocacy organisations. Partnership is set to feature in every activity, from strategic planning to individual planning: the soy sauce ingredient in the *Valuing People* cookbook.

This unqualified endorsement of partnership in every situation is the cause for concern. There is no case offered in either *Valuing People* or the draft partnership guidance for the ubiquity of partnership: it is merely asserted that -

Effective partnership working by all agencies is the key to achieving social inclusion for people with learning disabilities.
(Dept. of Health, 2001b)

In the language of performance management, partnership is an enabler, not a desirable outcome in itself. Yet government policy does not advise that the extent and kind of partnerships should be determined by their value in supporting worthwhile outcomes. Nor is there evidence of recognition in national policy that partnership has its disadvantages and dangers. Getting a service or an interpretation of policy from a 'one stop shop' is an excellent convenience if the service or advice is good. If, on the other hand, the response is unsatisfactory, the only hope may be to find someone inside the system who is sufficiently independently-minded to take the matter further. Many people who use services do not fully understand the difference in professional roles, or the line-management hierarchies. To them, 'the welfare' can already seem monolithic. Partnership working will move the reality closer to this perception.

While the draft guidance emphasises the need for partnerships to stay focused on the needs of people with learning difficulties, this is a weak defence against the powerful influence of group identity. In most partnership situations, the professionals will greatly outnumber the people with learning difficulties and family members, and spend much more time working together than in contact with people who receive services. They will often share class identities, and sometimes ethnic and gender characteristics, that separate them from the consumers. Notwithstanding the advice in the guidance, partnerships all too easily become ends in themselves. Who will be willing to speak in support of the unjustly treated consumer, if it would rock the Partnership boat?

The ultimate risk is that the pursuit of excellence will be sacrificed because it threatens the partnership. Instead, a culture will develop in which mediocre services are viewed as the best that are achievable, and poor services are tolerated.

For all the reasons outlined in this paper, role separation and clarity need to be retained. The conflicts that are inevitable and proper between stakeholders must be kept external to the roles, where they can be seen and addressed. Partnership – of the kind envisaged in policy – blurs roles and, when inappropriately applied, conceals conflict. So, while partnership has an important place, it should not be established when it will -

- allow an excessive concentration of power;
- internalise and thereby hide inevitable conflicts;
- incorporate organisations which can only be effective if they remain independent;
- deny recipients of services the opportunity to receive independent 'second opinions';
- prevent recipients of IF/DPs to conduct independent negotiations with potential providers.

5.4.2 *Substitute and supported decision-making*

Individualised funding systems permit people to make decisions about their own lives. If this includes people whose ability to make such decisions is in doubt, it will test the way in which the law, social care professionals, and family members step in to assist or over-ride those decisions. The introduction of Direct Payments for people with learning difficulties quickly encountered problems in this area, and though the latest guidance on Direct Payments (Dept. of Health, 2000) has softened the relevant definitions of consent and capacity, it remains a confused and difficult area. A full IF system would be hampered by the same problems, and one of its key advantages over Direct Payments – accessibility to people with severe intellectual impairments – would be weakened.

Changes in English law have been under active discussion since a Law Society discussion document published in 1989. (Law Society's Mental Health Sub Committee, 1989). Following a series of consultation papers and a further six years' work the Law Commission published their report with a draft Bill in 1995 (Law Commission, 1995). The various Governments have been slow to take these issues forward. A green paper, *Who decides?*, was published in 1997 but despite a huge response has never progressed. Incapacity legislation has existed in Scotland for many years, but is unsatisfactory, notwithstanding an updated Act passed in 2000.

The issues are extremely complex, and beyond the scope of this paper. Nevertheless, it is widely accepted that the present position in law is unsatisfactory. Many people who could make decisions for themselves have choices forced upon them by support staff or parents. Unlike other citizens, people with learning difficulties may have to prove their competence before they are allowed to have autonomy (Simpson, 1999). In other situations, where there is some reason to doubt a person's ability to make a wise decision, staff or parents who decide on their behalf are

acting in a legal grey area. Once people have become labelled as incapable of making decisions, they may find it very difficult to recover their right to make decisions – because, having been so labelled, their views are likely to be discounted.

Progressive thinking strongly favours finding ways to help people to make choices for themselves, and so retain self-determination, and to reduce the need to make decisions for people: supported decision-making, rather than substitute decision-making. Values Into Action, in conclusions drawn from its own research, argues that the limiting factor on self-determination for people with learning difficulties is not the degree of intellectual impairment, but the quality of support:

If some people can be supported to have choice and control, then everyone can. What we need are supports, attitudes, and a legal system that enables, rather than hinders, self-determination.

(Beamer and Brookes, 2001, p.75)

Valuing People strengthens some of the elements of the support that is required, including advocacy and person-centred planning (if it is correctly implemented). Other elements, such as circles of support, independent living trusts, and independent planning supports, may also be used within current policy. They would, however, be able to operate more effectively in a full IF system.

Although every effort should be made to support every person to make their own decisions, there will be situations where the connection between the decision made, and the information clearly available from the person, is extremely tenuous. The more that decision-making relies on interpretation and extrapolation (“they seem more contented in this situation, therefore we judge that they would like to live in circumstances where this situation arises often”) the more uncertain it becomes that the process is really one of supported decision-making, and not substitute decision-making. There is a persuasive case for ‘pushing the boundaries’ of supported decision-making, and insisting that it is achievable for everyone. It challenges the policy-makers, courts, and people working with individuals, not to give up on the goal of self-determination, and to resist the ‘easy option’ of substitute decisions. In the context of policies and practices that have been far too quick to dismiss people with learning difficulties as incapable of making their own decisions, this may be an important position to take.

It has disadvantages, however. If substitute decision-making is occurring, but is not distinguished from supported decision-making, then there is no way that it can be kept within proper limits. As a result, there is little to prevent the boundary being pushed in the other direction, with the arena of substitute decision-making gradually extending into areas where supported decision-making is unquestionably achievable. Acknowledging that *some* people cannot make *some* decisions for themselves is not easy for advocates of self-determination, but it clears the way to assert most emphatically that people *can* make other decisions.

If this is true, then there may be a case for legal recognition of the need for substitute decision-making in certain situations. This would be helpful in underpinning individualised payments that are agreed by the social services department on the basis that certain decisions may be made by a circle of support, or trust members, on behalf of the individual. However, substitute decisions should –

- Be limited to specific areas or levels, reflecting the abilities of the individual concerned, and leaving as many choices as possible within the control of the individual, with support.
- Take as much account as possible of the individual's known wishes.
- Be made with the involvement of someone who is independent from family and service providers, and whose role is to advocate the person's rights and wishes.

5.4.3 *Quality assurance and individual choice*

Section 3.3 identified a potential conflict between the imposition of standards by government, or by the National Care Standards Commission, and the right of individual disabled people to decide what kind and quality of supports they want.

Even the most efficient free markets require some regulation, and there are additional reasons (outlined in Section 4.1) not to trust that a market of social care providers will always deliver what disabled people want. So there is undoubtedly a need for government to set some standards. Equally undoubtedly, government and its proxies should involve disabled people, as representatives of the users of services, in setting the standards.

But consultation and user involvement are a poor substitute for individual customer choice. Car manufacturers research customer preferences, and organise focus groups, but it is sales, not surveys, that matter in the end. Moreover, if services are truly to be person-centred, then they will not be standardised. A dynamic organisation that provides services tailored to individual requirements will follow the market, learning quickly from the pattern of demand and finding better ways to meet it. Too much regulation can hinder this process, in social care as in other markets.

Within service provider agencies, exercises in 'user empowerment' and 'participation' all too easily become the soft option– a comfortable, progressive-sounding alternative to the challenge of offering a decent service¹. Customers, on the whole, don't want to be consulted: they just want what they want.

A balance needs to be found between the central imposition of general standards, and the application of choice by individual consumers of social care. The correct balance is very difficult to define, but the government's well-intentioned concern to push through improvements in services appears to be tilting the scales far too much on one side.

¹ See Dowson et al, 1998

In addition to the focus of policy on performance, there is the lingering tendency to assume that disability necessarily leads to vulnerability, and that therefore disabled people need the protection of the state. The arguments for making more use of customer choice to define quality and pursue excellence are particularly relevant in a DP or IF system, where the consumer is also the customer, and where there are brokers or other independent agents to support negotiations with providers. However, the principle still applies in care managed service delivery, and so this is not only an issue within IF systems. Care managers could define contracts most closely, reflecting the individual's requirements. Why shouldn't the day service come not only with a promise of the hours and activities that will be delivered, but also with a money back guarantee?

6 *Recommendations*

- 6.1 Government policy should promote the development of a comprehensive system of Individualised Funding, building on the existing Direct Payments provision. Specifically -
 - 6.1.1 Community care assessment and care management guidance should be modified so that, at the request of a disabled person, a council may replace these procedures with a process of open negotiation between the disabled person and the local authority, based on a costed plan developed by the disabled person. As part of the negotiation process, the Council would require evidence that the plan was viable.
 - 6.1.2 In assessing the amount of the Direct Payment that is appropriate, the Council should be guided by the arguments presented by the person in the plan and in negotiation; by policies developed by the council on appropriate areas of need and priorities for assistance; and also by funding guidelines that indicate the approximate amount that is available, given the overall budget, for people of different levels of disability. The policies and funding guidelines should be published, and readily available, so that people can take them into account when preparing their plan.
 - 6.1.3 The outcome of the process would be a Direct Payment to enable the person to implement their plan, subject to adjustments resulting from the negotiation. Individuals should be able to choose to receive the payment directly, or for it to be paid to a third party. The third party would act on behalf of the individual. However, negotiation may include proposals by the council to restrict the powers of the third party.
 - 6.1.4 Councils should be required to establish a system of arbitration that can be invoked by a person who is not satisfied with the outcome of negotiation.
 - 6.1.5 Councils should be required to fund and empower agencies that will assist and regulate the supply of independent planning supports ("brokerage"). Each agency should have sole responsibility within a geographical area; and, in combination, the agencies should cover the entire local authority area.
 - 6.1.6 Funding for agencies with responsibility for regulating brokerage services should be awarded only to organisations that are able to demonstrate that control of the organisation is independent from the local authority and agencies that provide social care services (whether in the same locality or elsewhere); and have a management board which reflects the main characteristics of potential users of brokerage supports. It is important that the management board should include people who have learning difficulties.

- 6.1.7 Central government funding to councils should be provided to meet this new cost.
- 6.1.8 Councils should be required to establish a mechanism by which disabled people who wish to develop their own support plan can access funds to meet the costs of assistance, if they require it, from independent and accredited sources ("brokers").
- 6.1.9 Councils should also make allowance, in the amount of Direct Payments awarded, for any reasonable costs the disabled person will incur for help administering the funding and/or meeting the legal responsibilities of employing their own support workers.
- 6.1.10 The current guidance in the Direct Payments Guidance regarding 'capacity and consent' should be further relaxed, in acknowledgement of the increased availability of assistance to Direct Payment recipients, in planning, implementing, and managing their support.
- 6.2 The legal position regarding decision-making capacity urgently requires improvement, and should be changed to promote and extend supported decision-making. Substitute decision-making should only be sanctioned when all available methods of supporting the person to make their own choices have not provided a decision that can safely be considered to reflect the person's wishes; and should be limited to specific areas or levels of decision-making, preserving the individual's right to choice in other areas.
- 6.3 Guidance on individual planning, whether issued by central government or by Partnership Boards, should establish the principle that service provider staff should only participate in discussions about the person's future at the person's invitation, and should not be expected to represent the view of the provider agency
- 6.4 Furthermore, individual planning meetings (and similar formal meetings where the person's support requirements are reviewed) which are organised by the service provider, and where all the participants (other than the recipient of support) are service provider staff, should be strongly discouraged.
- 6.5 Community care assessment guidelines should be adjusted so that the assessment of needs logically follows, and builds on, the identification of the person's overall life goals and major lifestyle preferences. It should also be permissible for these goals and preferences to have been established outside the community care assessment and care management procedures, for example through person-centred planning.
- 6.6 In the development of policy intended to promote high quality services, the preferred strategy should be to oblige services to respond to the requirements of each user, and hence to the user's personal definitions of quality, rather than to impose standard definitions of quality. This applies especially to higher levels of quality (as opposed to baseline safeguards) where fixed quality standards may conflict with users' individual preferences.

Bibliography

- Beamer S and Brookes M (2001) *Making Decisions: Best practice and new ideas for supporting people with high support needs to make decisions*, Values Into Action, London
- Conroy JW, and Yuskas A (1996) *Independent Evaluation of the Monadnock Self-Determination Project*, The Center for Outcome Analysis, Ardmore PA
- Department of Health (2000) *Community care (Direct payments) Act 1996; Policy and practice Guidance (LAC(2000)1)*, London
- Department of Health (2001a) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, HMSO London
- Department of Health (2001b) *Valuing People: A New Strategy for Learning Disability for the 21st Century: Implementation Guidance LAC (2001)23*, HMSO London
- Department of Health (2002) *Draft Good Practice Guidance on Partnership Working*, Department of Health, London
- Dowson S, Hersov E, Hersov J, and Collins J. (1998) *Action for Empowerment: A method of self-audit for services to people with learning difficulties or mental health support needs*, National Tenants Resource Centre
- Dowson S (1990) *Who Does what? The process of enabling people with learning difficulties to achieve what they need and want*, Values Into Action, London
- Dowson S (1995) *Means to control: A review of the service brokerage in Community Care*, Values Into Action, London
- Dowson S and Salisbury B (2000a) *Foundations for Freedom: International Perspectives on Self-determination and Individualized Funding*, TASH, Baltimore
- Dowson S and Salisbury B. (2000b) *Issues for the implementation of IF*, The Roeher Institute, Ontario
- Holman A and Bewley C (2000) *Funding Freedom 2000: People with learning difficulties using Direct Payments*, Values Into Action, London
- Holman A and Bewley C (2001) *Trusting Independence: A practical guide to independent living trusts*, Values Into Action and Community Living
- Law Society's Mental Health Sub Committee (1989) *Decision Making and Mental Incapacity: a Discussion Document*, The Law Society, London
- Lord Chancellor's Department (1997) *Who Decides? Making decisions on behalf of mentally incapacitated adults*, HMSO, London
- Moseley C (2002) *Self-Determination for Persons with Developmental Disabilities: Final and summative Program Report*, Robert Wood Johnson Foundation National Program Office on Self-Determination, University of New Hampshire

- New Hampshire Developmental Disabilities Services System (2001) *The New Hampshire Self-Determination Project Evaluation Results*, New Hampshire Developmental Disabilities Services System
- O'Brien J (1999) *Community Engagement: A Necessary Condition for Self-Determination and Individual Funding*, Responsive Systems Associates,,Inc., Georgia
- Roeher Institute (1991) *The Power to Choose: An Examination of Service Brokerage and Individualized Funding as Implemented by the Community Living Society*, The Roeher Institute, Toronto
- Roeher Institute (2000) *Individualized Quality of Life Project: Final Evaluation Report*, The Roeher Institute, Toronto
- Simpson M (1999) *Bodies, Brains and Behaviour: the return of the three stooges in Learning Disability* ch 15 (148-56) in *Disability Discourse* eds Corker, M. and French, S. Open University Press
- Snelham N, McBride G, Gramlich S, Williams V, Myers B (2000) *Looking at people's lives: barriers to direct payments for people with learning difficulties*, Swindon People First Research Team, Swindon
- Social Services Inspectorate (2000) *New Directions for Independent Living: Inspection of independent living arrangements for younger disabled people*, Department of Health, London
- Social Services Inspectorate (1991) *Care management and Assessment: Practitioner's Guide*, Department of Health, London
- Swindon People 1st Research Team, (forthcoming) *Journey to Independence*
- The Law Commission, (1995) *Mental incapacity Paper 231*.
- Williams V and Robinson C, (2000a) *In Their Own Right: the Carers Act and carers of people with learning disabilities*, Policy Press
- Williams V and Robinson, C (2001b) *More than one wavelength: Identifying, Understanding and Resolving Conflicts of Interest between People with Intellectual Disabilities and their Family Carers* *Journal of Applied Research in Intellectual Disabilities*, 2001,14, 30 –46
- Williams V and Robinson C (2000c) *Tick This, Tick That: the views of people with learning disabilities on their care assessments*, *Journal of Learning Disabilities* 4 (4), 293-305
- Yuskauskas A, Conroy J W , Elks M (1997) *Live Free or Die: A qualitative Analysis of Systems Change in the Monadnock Self-Determination Project*, The Center for Outcome Analysis, Ardmore PA