Individual Budgets: Transforming the allocation of resources for care

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Abstract
This article challenges local authorities, Primary Care Trusts and other funding bodies to reflect on the efficacy, and on the justice, of the way they allocate funds for individual care. It describes how greater cost effectiveness is being combined with better care in a number of authorities where a new approach is being piloted. The article follows up a contribution to the Special Issue of Journal of Integrated Care in December 2004 which focussed on user empowerment, and it aims to take thinking beyond the implementation of Direct Payments.

Key Words: In Control; Direct payments; Resource Allocation System

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Introduction
It is a rare idea that can unite Social Service Departments, politicians and the lobby groups that represent disabled people, but the idea of *Individual Budgets* might just be one such idea. In a previous article for the *Journal of Integrated Care* I described the system of Self-Directed Support that has been developed by *In Control* to replace the existing system for delivering social care (JIC December, 2004.). In this article I will explore just one critical element within that wider model for Self-Directed Support: that it is better to tell disabled people up-front about the resources to which they are entitled.

I will set out my case in three parts. First I will argue that a system of up-front funding would be better than the present system of allocating resources to disabled people. In the second part I will show how such a system might work and I will describe the methodology that has been developed by *In Control*. Finally I will consider how such a significant shift in thinking and organisation might be achieved at both a local and a national level.

Resource Allocation Now
The present system for allocating resources operates broadly as follows: (1) An assessment of need is carried out; (2) which is then followed by a care plan which describes how those needs will be met; (3) the care plan is then priced and the price of the care plan is equivalent (4) to the resource allocation (see Figure 1). Yet the prevalent Resource Allocation System has a number of perverse consequences; consequences that tend to seriously undermine the quality of the final outcome, particularly in the context of our existing system.

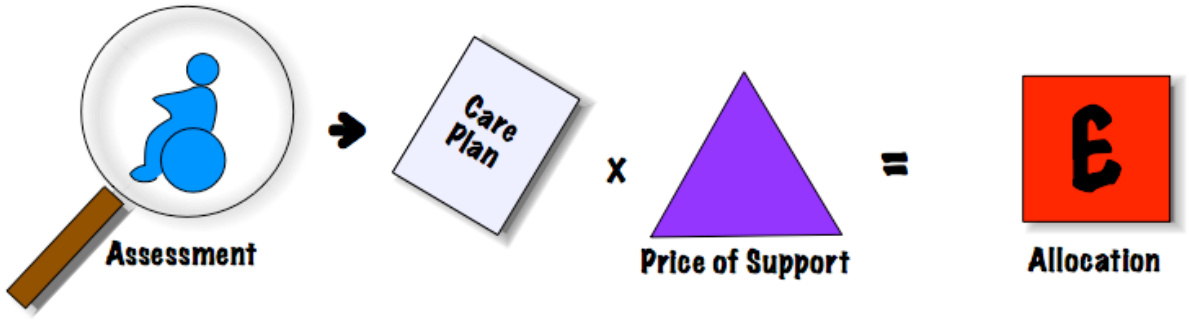

Figure 1 Prevalent Resource Allocation System

The first negative consequence is that the system is open to a high degree of purely subjective variability which results in an inequitable distribution of the available resources. How needs are presented, interpreted and understood will vary for both the individual and the assessor and there are few fixed points of reference. The system provides no guidance as to what counts as a fair level of resource for any given level of disability and even the recent creation of *Fair Access to Care* only serves to complicate eligibility, while offering no principles for distributing the actual resource levels more fairly (Department of Health, 2003).

The second negative consequence of the prevalent system is that it undermines the possibility of any effective person-centred planning for the business of care planning must remain in the hands of the local authority because they need to maintain control over the rationing process (Valuing People, 2002). Yet *In Control* has proposed that, instead of Care Managers developing Care Plans for people, people are supported to develop person-centred Support Plans for themselves. This change is more than semantic. Support Planning involves the integration of information about the individual, their gifts and preferences, information about community and relationships together with information about the formal or paid supports that people may need (In Control, 2004a). But no meaningful or creative planning can be done without information about the available level of funding; instead of planning, the process tends to become corrupted into a form of bidding and there are no incentives for the individual to plan in ways that make best use of their own gifts or the opportunities created by their community.

A third negative consequence of the present system is that it struggles to manage costs or expectations. There are numerous ways in which this is manifest. Firstly the failure to offer any clear entitlement to support leads to some people and families struggling to breaking point. The resulting support solutions are often both more expensive and of a poorer quality. Secondly, individuals and families have no incentive to seek best value for money when seeking their own preferred provider. Perversely this can sometimes lead to the local authority being pressurised to purchase expensive institutional services because the family believes price is an indicator of quality. More generally there has been little effort to set out for individuals, families or providers a sense of what the local authority thinks is ‘reasonable’. One side-effect of this process is that where service providers can offer a sufficiently specialised service, or offer a scarce service, they can largely dictate the price of services. This has led to significant inflation in the cost of so-called: ‘individual placements.’

Finally the present resource allocation system fails to deliver any meaningful entitlement to disabled people. If people have a real right to support (or perhaps a right to Independent Living) then we should be able to measure the social implications of meeting those rights. Currently these rights (beyond the right to an assessment) are ambiguous and it is not clear in law that disabled people are entitled to any significant level of support to live their lives. This is patently unjust; and while local authority commissioners do not bear the responsibility of resolving this problem alone, it is clearly important to disabled people that we start to use a resource allocation system that will deliver affordable entitlements.

It is for all these reasons that *In Control* has sought to identify an alternative resource allocation system which could replace the existing system. The key principles that we believe should underpin this system are as follows:

1. The principles that determine how resources are to be distributed must be open to scrutiny, enabling self-assessment and an equitable distribution of resources.

2. The system must enable people to know what they are entitled to before they have to begin designing the support solution that they need to meet their needs.

3. The system must place a reasonable and manageable burden on the community and on the system of public finances and must not encourage waste, inefficiency and cost-inflation.

4. The resources that are allocated to disabled people should be treated as real entitlements from which flow both responsibilities and real freedoms.

The goal for *In Control* is to develop and pilot this different approach over the coming months and years and work with authorities, providers, disabled people and national policy makers to ensure that the system can move towards an approach where people can assess their own needs, develop their own support plan and ensure that the support they receive is properly integrated with the natural support that the individual has or can expect from the community (see Figure 2)

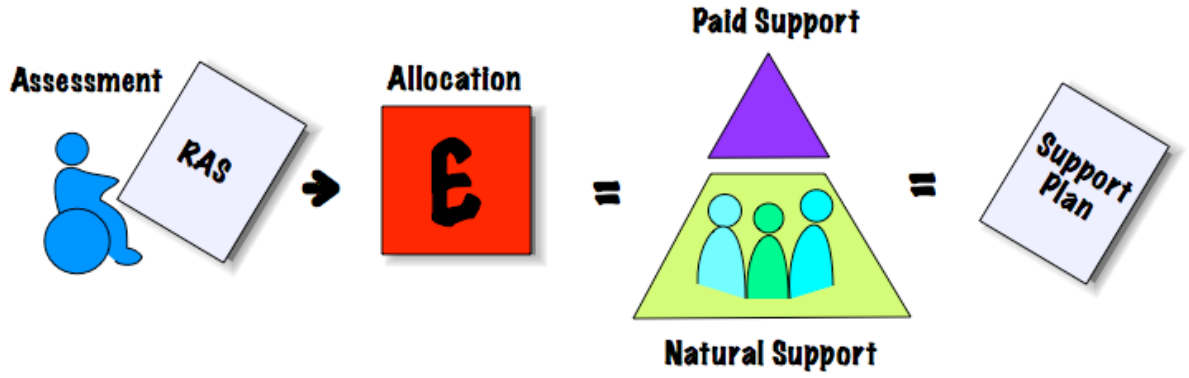

Figure 2 In Control's Resource Allocation System

Practical Illustrations

The idea of a system that functions in this way is not just an impossible dream. It is worth remembering that many international systems already use systems like this to apportion resources (Moseley, 2003); the UK courts already make awards to people who have acquired a disability on this basis and our existing disability benefit system already functions in this way (Disability Alliance, 2004).

In fact this approach has already been used sporadically in existing social care services. For instance Inclusion Glasgow, a supported living service provider, used this approach to help people leave long-stay hospitals into individually designed community services (Scottish Executive, 2000). It identified a fair level of Individual Funding that would be tied to each individual it served and then it designed a service around that known level of funding. This led to an efficient, creative and person-centred discharge process for over 40 people leaving hospital, all within the same cost levels being used to set up large group-living environments.

For example “Patrick” is someone who left hospital in 1998 with a reputation as one of the most challenging individuals within the hospital system (Duffy, 2003). His autism, his partial-sightedness and his severe learning disability plus twenty years of institutionalisation had left him deeply isolated and with highly dangerous and unpredictable defensive behaviours. Had he left hospital in the typical way he would have been moved into a challenging behaviour unit with individual placement costs exceeding £150,000 per year.

Instead Patrick, along with his family and Inclusion Glasgow, spent time developing a person-centred service that would enable him to live in his own home in the community. The recurring annual cost of the planned service was £60,000. The reason that such a service was possible and affordable was that the service design made best use of the existing funding; included in that design were the following features:

- Patrick’s family set up a Trust so that he could buy his own home using DSS mortgage interest relief.
- Patrick’s house had four bedrooms so that he could have flat-mates and also receive visits from his family.
- Patrick’s house was sited near his sister who then acted as his appointee and could oversee the service offered to her brother.
- Patrick’s house was sited so that he could get easy access to the sea-side and the country-side, as enjoying country walks is one of Patrick’s most important pleasures.
- Patrick gets help from flat-mates who live with him, can offer back-up help when needed and can introduced Patrick, gently, to other people and activities.
- Patrick is supported by a small team of paid staff who are recruited and employed just for him and who work to policies and procedures tailored to meet his needs.

- Patrick's service is overseen and managed by a co-ordinator who can work with Patrick, his team and his family to revise and change the use of the agreed finance.

These innovations do not simply flow from the Individual Budget, rather the funding entitlement sets a constraint that enables creative service design. The existence of a known financial constraint creates an environment of trust and realism within which those planning can move on to consider how to get the best possible support arrangement for the individual. In particular this method of planning encourages people to look beyond traditional services and to see how the individual gifts and community relationships of the person can function in the final support design (see Figure 3).

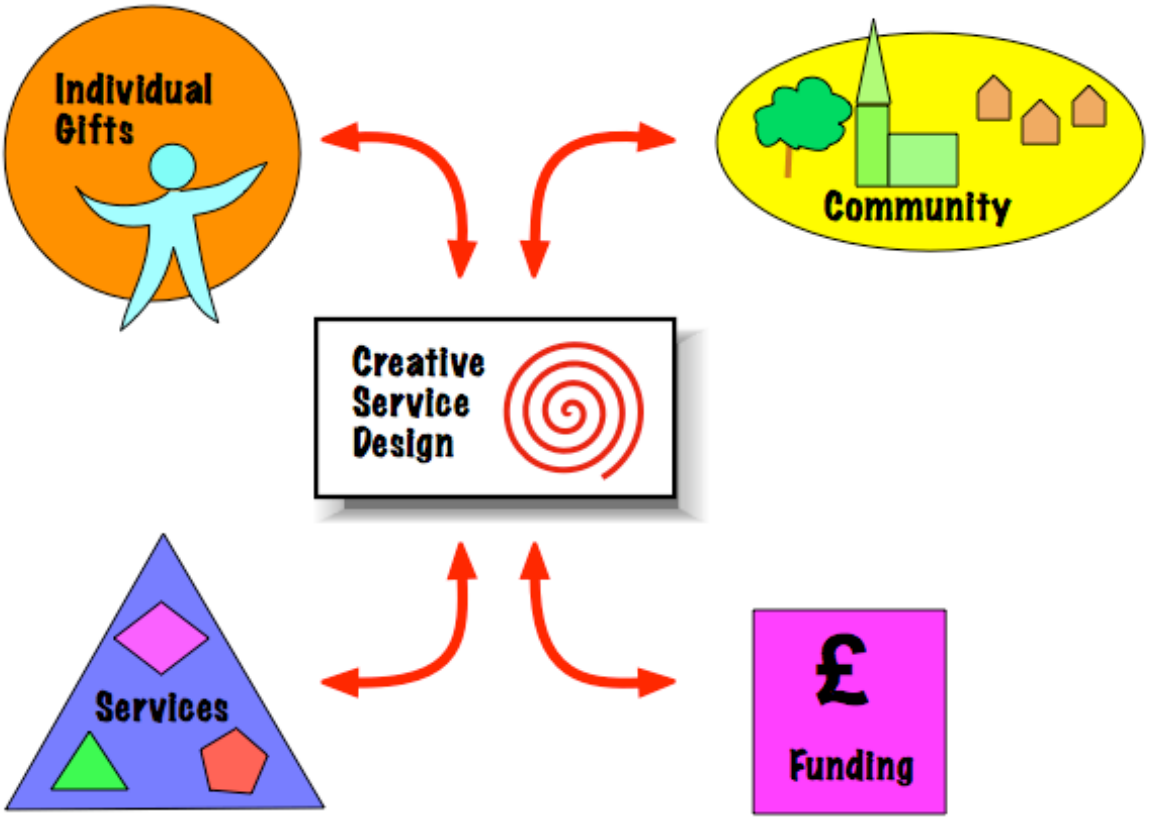

Figure 3 Creative Service Design

Other examples make the same point in numerous ways. "The Smith Family" received funding for each of their two sons with MPS III, a serious and disabling disease that leads to challenging behaviour and an early death. They were thus able to support their sons to return home for £30,000 per child, 50% of the cost of the previous NHS service (Paradigm, 2002). This community-based service worked more successfully because:

- The difficult behaviour of the boys diminished at home when they were with the family that they loved.

- When a larger and more appropriate home was purchased, with a subsidy from within their funding, the family could function effectively and offer support.

- Appropriate and tailor-made adaptations were possible within the home (hoists, special chairs, and soft-play areas) many of which were not available within 'specialist' accommodation.

- The family benefited from choosing and controlling their supporters rather than depending upon a home-care services that they could not control.

- The family were able to replace residential respite by hire purchasing a mobile home by the sea that offered flexible and positive respite to the whole family.

Again, it was these design factors that led to a successful service. In the context of successful individual design then flexible Individual Funding can be used to much greater effect than when it is limited to the delivery of traditional health or social care services.

A third example is provided by "Paul" whose family manage his support now he has returned home from a specialist autism college (Duffy & Sanderson, 2004). The residential college cost £120,000 per year, but Paul is much more successfully supported now for £70,000 per year. His present service is much less wasteful than the previous institutional service, for now it enables him to work, to get about his local community, swim, play golf and join local clubs. Paul leads a full and active life as a contributing citizen; none of this appears to be possible where resources are left locked in block services.

A New Resource Allocation System

At the end of 2003 *In Control* began to explore how this approach could be developed in a more systematic fashion. It began its work in Wigan and this has led to the development of what is now known as *In Control's Resource Allocation System*. Presently 7 local authorities are experimenting with this approach and information about measurable outcome improvements will be available in 2005. At present this work has been focused on the needs of people with learning difficulties, and detailed cost comparisons with other groups have not been made.

The methodology that *In Control* used to develop its *Resource Allocation System* is based on the simple principle that any new system must be broadly consistent with present-day allocations, in other words it would be unacceptable to give people significantly less than they would presently receive under the prevalent model. *In Control* therefore developed a process for converting the existing resource allocation system into an explicit system in the following way (In Control, 2004b):

- The local authority identified the price of the major service elements that were typically purchased by care managers, including in-house services.

- The local authority identified the typical service packages that were made available to individuals (e.g. receiving a place at a day centre plus some respite together constitute a common 'package').

- By examining the price and distribution of the prevalent individual packages the local authority can determine the funding levels that it needs for its system.

- By reflecting on its present allocation practice the local authority will then be able to map assessment criteria on to the given funding levels.

There have been several interesting findings from carrying out this process so far. First the distribution of funding packages tends to be highly clustered and hence the number of funding levels required to match present allocations is very low (typically six). Also the actual funding levels seem to reflect the relative generosity of different localities and the history of commissioning practices, rather than the underlying economies of the locality.

The mapping of assessment criteria against funding levels has also been less difficult than one might expect. Three independent criteria were proposed:

- Level of need: expressed as low, medium or high

- Family situation: expressed as whether living in the family home or not

- Complexity: expressed as either yes or no

These criteria gave rise to twelve possible permutations, that is to twice the number of levels of funding, so some funding levels were mapped on to several assessment criteria. In addition *In Control* worked with Care Managers to identify possible indicators that might help determine the judgement about an appropriate allocation. When all of this work is put together it gives rise to *In Control's Resource Allocation System*, two examples of which are given here (see Table 1 & Table 2).

Table 1 RAS for Adult Social Care Needs (within family home)

Level	Funds	Conditions	Possible indicators
1	£1,500	Low Level Need	Can keep themselves safe Can meet own personal care needs Can travel independently Can manage money with some help Can sustain involvement in activities
3	£15,000	Medium Level Need	Needs supervision or support most of the time Help is typically in the form of prompts or guidance Can be left for small periods
3	£15,000	Medium Level Need and Complexity	The person's behaviour creates extra risks There can be no gaps in support
3	£15,000	High Level Need	Needs support for 24 hours a day
4	£30,000	High Level Need and Complexity	Extra medical needs Difficult behaviour Family situation is fragile

Table 2 RAS for Adult Social Care Needs (outside family home)

Level	Funds	Conditions	Possible indicators
1	£1,500	Low Level Need	Can keep themselves safe Can meet own personal care needs Can travel independently Can manage money with some help Can sustain involvement in activities
2	£5,000	Low Level Need and Complexity	Reduced ability to sustain involvement Possible mental health problems Needs regular help with bills and reading Possibly subject to bullying
4	£30,000	Medium Level Need	Needs guidance and direction Needs help cooking Can dress get dressed Can carry out personal care Does not need 24 hour support
5	£50,000	Medium Level Need and Complexity	Difficult behaviour Self-injurious behaviour Night-time epilepsy
5	£50,000	High Level Need	Need for some waking support at night Possible complex health needs
6	£75,000	High Level Need and Complexity	Very challenging behaviour

One interesting further finding is that the assessment criteria, although seemingly relatively simple, do seem adequate for the job of assessing need, at least by current standards. In an exercise involving Care Managers from three separate authorities the Care Managers identified 116 people. Of that group 90% fitted easily into the proposed levels, 8% were marginal between the proposed levels and only 2% did not seem to fit well.

Furthermore one area that has explored using *In Control's Resource Allocation System* on a system-wide basis is Bradford. Bradford has applied the *Resource Allocation System* in a hypothetical form to 300 people known to care managers. Interestingly the aggregate of the Individual Budgets was 80% of the actual expenditure on the same group. This seems to reflect what many practitioners have believed for some time, that while many people are still excluded from support or receive very inadequate levels of support some people are actually over supported, often to their own detriment.

For *In Control* at this point the initial learning is highly promising. It seems as if we may be able to design a system that lets disabled people know, up-front, what they are entitled to receive. It also seems as if this can be done within existing resources and in a way that is broadly correlated with existing practice. However *In Control* is

only at the mid-way point of its own initial piloting of this model and further analysis may give rise to additional challenges or complexities.

A New System of Self-Directed Support

Of course just because the present system is broken it does not mean it is easy to replace it with something better; particularly when not only services, but also disabled people and their allies have learnt to adapt to the existing system and any alternative can appear threatening. So I will end by considering some of the likely implementation challenges and opportunities that we can already foresee.

The first and biggest challenges is that the idea of an Individual Budget is taken out of context and treated as merely bureaucratic solution to problems in the delivery of social care system. It is only if Individual Budgets serve to genuinely empower disabled people that there will be significant benefits. For *In Control* this means that the Individual Budgets must be combined with:

- Systems of representation and supported decision-making
- Support Planning and support to plan, where necessary
- Genuine flexibility in how resources can be used and freedom from bureaucracy

To this end *In Control* has designed a wider system of Self-Directed Support which seeks to achieve these objectives. Without such a system Individual Budgets may become just another bureaucratic system for managing the lives of disabled people. Perhaps no worse than what we have now, but certainly little better. Moreover *In Control* has worked hard to think through how delivering these systemic improvements can be done within existing resource levels. A shift towards up-front budgeting actually releases energy from within the existing system, allowing individuals, families, service providers and care managers to work more effectively and faster.

There are also a series of transitional challenges in moving from the present system to a system of Individual Budgets. The majority of existing funding is spent on in-house congregate services or under contract with external service providers. Any move to Individual Budgets will involve unpicking the *funding* for these services (which is not the same as unpicking the services – many people may continue to purchase these services for themselves). It is important not to exaggerate the difficulties here; for at one level these are simply management problems which can be resolved by good planning and leadership. But it will mean that the process of introducing Individual Budgets may have to be phased and that there may be some transitional costs.

Some of these transitional costs may be met by unlocking the wastage in the present system, but this will only be achieved if the future system has clear benefits built into it for disabled people. It is perhaps interesting to compare this issue to the closure of the long-stay hospitals, where so-called ‘dowries’ were an essential component of managing change. *In Control* is perhaps proposing a feminist version of that process, instead of dowries (funding handed from the father to the husband) Individual Budgets puts the individual in charge of their own destiny.

There are also a range of issues that will have to be faced over the long-term if Individual Budgets are accepted. First, what counts as a fair level of funding will not be static over time, this raises critical issues about how the level will be fixed from year to year. Second, the model could be made national or local, and there are costs and benefits to each alternative. Third, there are unresolved ethical dilemmas, in particular there is the fact that people living in the family home are treated less well than those living outside the family home, and if the model were extended to people in other care groups then other disparities would be revealed. These are not insoluble problems, rather they are existing problems which may simply come into sharper focus; nevertheless they will need careful thought.

There are also some very interesting opportunities here too. *In Control's Resource Allocation System* has been designed to capture the allocation of social care funding. Yet for disabled people there are many different forms of overlapping and distinct forms of funding that could be combined more effectively in a proper system of entitlements. In particular there are disability benefits, the Independent Living Fund, Supported People funding and funding for disability that is presently spent by Education, Health and Employment. An effective system will transfer much of the power and authority over these sources of funding into the hands of disabled people themselves.

- Even if Individual Budgets are restricted to social care funding there are a range of practical benefits that local authorities and NHS commissioners could realise now by shifting towards this system. In particular:

- It will enable local authorities to distribute resources more fairly and to avoid some of the challenges that they face when there are no clear criteria for a fair distribution of resources.

- It will enable local authorities to commission more effectively, using cash-limited sums to create person-centred services in partnerships with individuals, families and service providers.

- It will enable better strategic planning by local authorities who can plan for the future and identify significant misallocations of funding in the present system.

Already there are a number of local imperatives that can be refashioned around Individual Budgets to deliver better, more person-centred outcomes, within realistic funding limits:

- Replace the assessment and care planning process for Direct Payments

- Enable better planning for those returning home from long-stay out of district placements

- Provide a framework for Day Service Modernisation

- Enable re-commissioning of existing residential services

- Form the basis of family-led services and better transition planning

Many of these initiatives are being piloted by *In Control* or by other authorities at present and it is too early to speak definitively of success. But the direction of travel seems clear and the possible advantages enormous. Certainly we have already shown that there is a realistic alternative to the present system, one that promises a different kind of contract between disabled people and the public authorities that have been funded to support them.

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