

in Control

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Summary

To achieve significant transformation in the outcomes achieved for people, the national policy for social care should be built around the concept of self-directed support. In this paper, we argue for the following policy changes and offer various possible measures by which these might be achieved:

1. A national framework for assessment and resource allocation within which individual budget allocations are made based upon public criteria.
2. All local authorities be directed to individualise all funding streams for people receiving significant levels of social care funding by a fixed date.
3. A duty to ensure that there is supported decision-making mechanism in place that puts the individual in charge.
4. National policy guarantees people a high degree of flexibility on how funding can be spent, including the ability to purchase different forms of management or auxiliary support.
5. Care Management is reformed so that care planning can be led by the individual with appropriate support.
6. A local plan will be required to enable services to respond to self-directed support and to support people to broker their own support arrangements.
7. Judging the success of support must be based upon the social outcomes we identify with successful citizenship (e.g. income, relationships, contribution, ownership etc.)
8. There should be a coherent system of scrutiny and regulation for social care that is proportionate to the risk of abuse.
9. In each locality there must be some body capable of adequately representing and powerfully championing the interests of all disabled people, which fully involves local disabled people.
10. The purpose of social care and the fundamental legislation upon which it is based must be reformed around the concept of enabling active citizenship.

Introduction

The early work of *In Control* has identified a number of areas where national policy could helpfully change in order to enhance the ability of disabled people to lead their own lives and make full contributions as citizens within the UK. This paper sets out our early thoughts about possible changes.

Of course, there are many ways of achieving the same goals and any final policy changes must be congruent with other changes to the social care system. We have therefore tried to distinguish the primary goal together with some of the possible means by which that goal might best be achieved.

The overall objective is to encourage national policy that ensures that all disabled people can be citizens, rather than just clients of the social care system. Human service organisations should not define the status of the disabled person. Instead the disabled person should be seen as a full citizen. Moreover achieving citizenship means enabling people to acquire six keys to citizenship:

1. Self-determination	The ability to control your own fate and make decisions for yourself.
2. Direction	A unique sense of purpose by which to identify your role within your community.
3. Money	The means to independently meet your needs without being dependent on others.
4. Home	A place of your own in the community where you are seen to belong.
5. Support	Being able to offer others the chance to help and be useful to you.
6. Community Life	To make a contribution to the community by your meaningful presence and participation.

All disabled people can achieve all of these keys to citizenship; but many aspects of our existing social structure will need to change and improve if they are to enable disabled people to achieve their rightful place as citizens. Improvements and changes will be necessary across the social system:

- Education
- Health care
- Employment and training
- The benefit system
- Transport
- Housing

But *In Control* is primarily concerned with the most fundamental challenge for human services: **to shift power and control over services directly to disabled people so that they can become active citizens.**

If human services mean to help rather than to hinder people's achievement of citizenship, then it is necessary to change the fundamental power relationship that presently exists between human service professionals and disabled people. Today's human services have been built around the Professional Gift

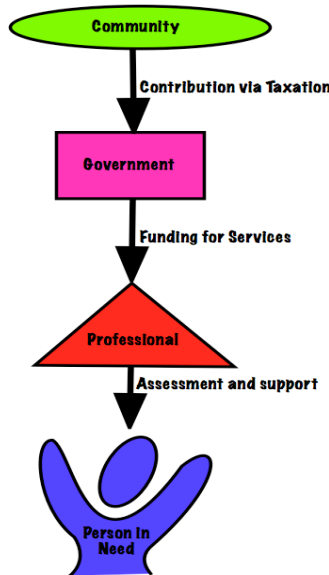
Model of service delivery, which assumes that needy individuals will be given what they need by the professionals who understand those needs. Operating within this paradigm it seems natural for human service professionals to be *In Control*. However there is a significant risk that operating in this way will lead to the individual being treated as an object of professional help

However this does not need to be the model we use to deliver human services. Increasingly systems of support are shifting away from professionally dominated systems towards self-directed support, where disabled people themselves control how they live and the support they need. The emerging paradigm is the Citizenship Model of service delivery. In this new paradigm the individual is at the centre of defining his or her own life and his or her own place in the community. Critically, resources are no longer given to professionals so that they can provide services on their terms; instead the individual's needs entitle them to the resources necessary for them to live their own life. The services they receive are negotiated between them and any professionals they choose to use.

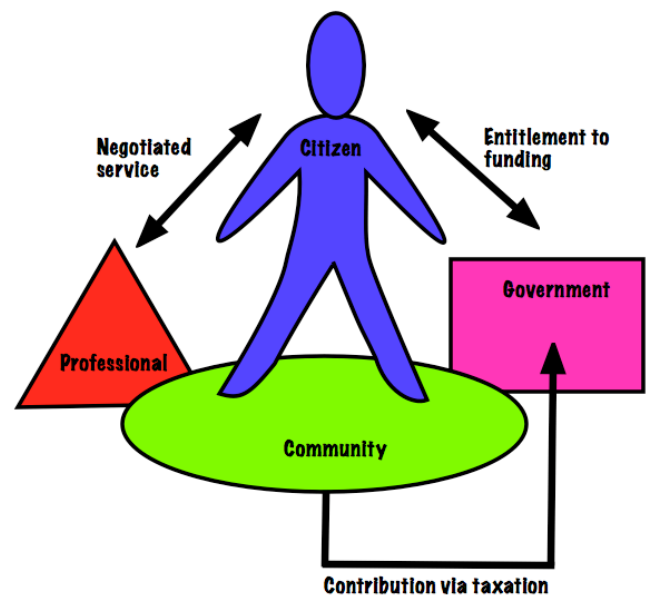
Clearly achieving such a significant paradigm shift will not be easy to achieve and there are further complexities to explore when there are duties of care towards the individual or where the individual needs help with making their own decisions. However *In Control* has already identified many of the major steps necessary to make the shift. It has published a detailed model of good practice together with early data and discussions as open-source materials at:

www.in-control.org.uk

Finally it is worth saying that while *In Control's* starting point has been to design a system of self-directed support will work for people with a learning disability we have always worked to ensure that this system is extendable to all people who use social care



systems:



- Older people who need help
- Disabled people with a physical impairment
- People with sensory impairments
- People with mental health problems
- People with brain injuries
- People with a learning disability

Further work will be required in order to develop a new system that works for effectively for all people who need help in order to live their lives with dignity and respect. But at this point we can identify no compelling economic, social or moral obstacle to extending the concept of self-directed support to all people who need help because of an impairment that would otherwise significantly put at risk their active participation in the community. Whether that impairment is there at birth arises from sickness, accident or old age is not relevant.

John Dixon, Director of Social Services in West Sussex, one of the *In Control* sites says: The project is showing that even people with complex learning disabilities can gain a significant and valued measure of control over their care. This has considerable implications for the development of the Adult Social Care Vision. Success with this service user group in achieving self-managed care through Direct and Indirect Payments implies ready transferability to other service users such as older people. Such success is of course dependent on the availability of expertise (such as from social care staff) in helping service users to navigate their way through the care pathways. It is also worth noting that in our local experience the cost of such self-managed care arrangements is no greater than (and indeed frequently less than) those they replace.

Simon Hart Director of Social Services in another of the sites, Gateshead, says: The learning and experiences from the Programme will allow opportunities across all adult social care to make services more flexible and give greater choice. We recently met with a national group of care management leaders and commissioners who unanimously shared our view that the key elements of *In Control's* model are transferable.

Sam Newman, senior manager in Devon says: I have spoken to a number of senior people here in older peoples services, both policy and practice. No one can see a good reason why self-directed support should not be transferable to older people's services.

Fair Allocation of Individual Funding

At present, although average spending per person is not inconsiderable there is no clear entitlement to funding for the social care that disabled people need to live their lives and most funding is locked into inappropriate block services. The problems created by this situation are many and are documented *In Control's Discussion Paper: Resource Allocation*. In brief they are:

- A rationing system that encourages crisis, poor planning and institutional responses

- A confrontational and defensive relationship between the authority and the individual
- Inappropriate services, poor community development and frustration at the quality of support
- Significant cost inflation, especially in new placements for people with 'challenging behaviour'.

The model of self directed support assumes that there would be clear and achievable benefits from moving towards a system where each disabled person with a significant and on-going impairment received a clear and public entitlement to a capped level of finance.

POLICY RECOMMENDATION 1: There is a national framework for assessment and resource allocation within which individual budget allocations are made based upon public criteria.

The achievement of a model of self-directed support would require all social care systems to move towards a system of totally Individualised Funding. A modern system of social care must enable people to speedily change how they are supported, to change service provider or to move home without putting at risk their basic entitlement to support.

POLICY RECOMMENDATION 2: All local authorities are directed to individualise all funding streams for people receiving significant levels of social care funding by a fixed date.

At present *In Control*, working within the existing policy framework, is helping to achieve this goal. But there are several **alternative** means by which national policy could help make this shift happen more effectively, some of which are set out below:

1. All local authorities work to a shared national resource allocation framework that relates level of need to level of funding but allows for local variations in pricing. (This could involve amending Fair Access to Care to provide a framework for rationing resources as opposed to rationing merely some 'access' to those resources.)
2. Direct Payments policy should therefore be incorporated as one important element of a universal system of Individual Funding.
3. A system of low-level community grants is established to help people get support in ways that build community and meet their needs. (cf. Small Sparks, Seattle) This would be focused on the large group of disabled people with real but less significant impairments.
4. The integration of local authority, ILF, relevant benefits and health funding

into one form of 'disability support' funding

Supported Decisions and Representation

The early experience of *In Control* leads us to conclude that the citizenship of people with some significant cognitive impairment is undermined by the systemic failure to put in place appropriate systems of supported decision-making. This is a problem for almost all of the groups of people receiving social care.

Within a model of self-directed support all the services provided to disabled people (excluding obvious exceptional mental health services) must be subject to the agreement of the individual. Where people need support to reach agreement a representative would be appointed independently from the local authority. (This can include, family, friends or other independent support e.g. advocacy. This should not be a paid representative in the majority of cases.)

POLICY RECOMMENDATION 3: There is a duty to ensure that there is supported decision-making mechanism in place that puts the individual in charge.

The *In Control* programme has set out the process and principles by which any such representative could be appointed in the **Discussion Paper: Supported Decisions**. There are several **alternative** means by which this might be achieved:

1. Local authorities are directed to assess everyone they serve in terms of their capacity to agree their own support package and to put in place an appropriate system of supported decision-making.
2. Department of Health sets Direct Payments within a broader policy framework for Individual Funding and make clear that the goal is for decisions about support to be made as close to the person (self-directed support).
3. Local authorities are held accountable for their success in ensuring that people have effective supported decision mechanisms and are supported to develop and share models of good practice.
4. Rules around Indirect Payments, the use of Trusts or other intermediaries are clarified in such a way that appropriate representation is seen as both possible and reasonable and that any checks on the process are proportionate to real risk.

Freedom and Control

If Individual Funding can be controlled by the person (or the best placed person) the value of that funding is still proportionate to the flexibility with such funding can be used. It is critical that national policy supports the freedom of

disabled people to develop the most appropriate services for themselves and does not impose unhelpful policy restrictions. Direct control of support is much more effective as a means of assuring quality and avoiding risk and hence the regulatory burden on disabled people and their families should be proportionate to the real risks.

In Control is an experiment in a different style of 'welfare state'. It is broadly contractual in way that has been much talked about but rarely implemented. There is a clear balance of mutual responsibilities and rights being struck. It is also based on an assumption of capacity - that often people themselves can generate better support alternatives than existing professional services.

The *In Control* model requires that disabled people be free to convert their resource entitlement into the most appropriate form of support. In turn the state has the right to learn from people how successful support is provided and to terminate arrangements that are manifestly failing to help people meet their needs or putting people at undue risk.

POLICY RECOMMENDATION 4: National Policy guarantees people a high degree of flexibility on how funding can be spent, including the ability to purchase different forms of management or auxiliary support.

It is also important that the existing presumption that care is planned by professionals for disabled people is reversed. Instead we must move towards a situation where disabled people themselves, with support where necessary, are defining how they will receive support and are able to change how they receive support as their situation changes or as new opportunities arise. The present system is incapable of responding with an appropriate degree of flexibility required.

POLICY RECOMMENDATION 5: Care Management is reformed so that Care Planning can be led by the individual with appropriate support.

There are several **alternative** means by which this might be achieved:

1. All authenticated self-directed support arrangements can be excluded from the requirement for national regulatory control.
2. Department of Health confirms that all forms of Individualised Funding can be used flexibly as long as they are being used to meet defined needs - they do not need to be spent only on traditional forms of 'care' and can be used in ways that enable people to meet their needs in the way that seems most effective to them.
3. The monitoring and accountability measures that local authorities impose on disabled people must be proportionate to the real risk of abuse and must be either equal to or less onerous than the procedures applied to traditional service providers.

4. The responsibility of the local authority to assure the safety of vulnerable adults is separated from their responsibility to commission community care services.

5. Enable people to use their Individual Funding mechanism to carry other sources of funding outside the immediate field of social care.

Service Development

While some change and progress may flow from purely structural reform there will still be a need to help services improve and better respond to individual need. Particularly when present expectations are often set by their present poor experience of existing services. Moving to a model of self-directed support implies change in a number of areas:

- New forms of individual support being provided by existing service providers
- Growth in informal support
- Growth in self-employed support
- Refocusing Care Management
- Development of different forms of support brokerage
- Use and development of various auxiliary services

There will be a continuing leadership role required in local communities as this period of change gathers pace. Strategic direction and leadership will be required in order to move to a situation where most funding decisions are individualised but where there is an effective infrastructure that empowers individual decision-making.

RECOMMENDATION 6: A local plan will be required to enable services to respond to self-directed support and to support people to broker their own support arrangements.

Moreover, once a system of self-directed support is in place there will still be a need for a coherent system for checking the quality of services and of terminating arrangements that are manifestly not working. This means that existing systems of auditing, inspecting, regulating and care managing services need to work to a common framework; and that the burdens placed on those who are regulated and scrutinised are both reasonable and proportionate to real risk.

POLICY RECOMMENDATION 7: There should be a coherent system of scrutiny and regulation for social care that is proportionate to the risk of abuse.

At the heart of any system of regulations needs to be a revised vision of the goal of social care. In fact the word 'care' itself may not be the most helpful, suggesting that the person who is 'cared for' is passive, not an active citizen. Instead we need to shift the focus of monitoring and management to the goal of active citizenship and the proxies for that goal must be outcomes that are social valued.

POLICY RECOMMENDATION 8: Monitoring of success or failure in support must be built around the social outcomes we identify with successful citizenship (e.g. income, relationships, contribution, ownership etc.)

Strategic overview

While most social care funding should shift into the control of disabled people themselves it is not the case that there should be no strategic thinking about the needs of disabled people by local communities. Local communities must be supported and held accountable for their success in welcoming disabled people as full citizens. Not only that, but disabled people themselves should play a leading role in setting the strategic role and holding the local community to account.

An interesting model is provided by the US model of 'Governor's Boards on Developmental Disability' or the present system of Partnership Boards could be extended or revised to take on specified strategic functions. This would also enable local communities to explore how disabled people can best access the wide and diverse range of other social and community resources that simply do not fall under the ambit of social care. It would help ensure that disabled people are no longer perceived as the 'responsibility' of social service departments.

POLICY RECOMMENDATION 9: In each locality there must be some body capable of adequately representing and powerfully championing the interests of all disabled people which fully involves local disabled people.

In addition there will still need to be a national framework that evaluates local performance and supports collaboration, learning and support between local communities. However this framework must also be based on a new form of monitoring; one which places active citizenship at the heart of the agenda. For instance local authorities could be monitored positively on their performance against the following:

- Disabled people in employment
- Disabled people controlling their own support
- Disabled people who own their own home

- Disabled people who have full tenancies
- Average income level of disabled people
- Wealth of disabled people
- Disabled people who have life partners
- Disabled people who have children

and negatively against the following:

- Disabled people using residential services
- Disabled people in residential services away from their home

POLICY RECOMMENDATION 10: The purpose of social care and the fundamental legislation upon which it is based must be reformed around the concept of enabling active citizenship.

Conclusion

In conclusion it might be worth making three final points. First the process of change from the existing institutional based services towards self-directed support will require thoughtful piloting and implementation. It is vital that an effective balance is struck between local diversity within a clear national framework. There must be clear national standards, timescales and systems in place within which local communities are able to use their discretion.

It is also important to distinguish the structural changes, with which this paper has been primarily concerned, from the wider cultural change that will be required to deliver the best possible version of self-directed support. Cultural change will not take place without:

- Leadership
- Training
- Exemplars of good practice
- Communication

Finally the transformation of the culture of social care services must take place in the context of a new public understanding of the purpose of social care. Ultimately these services and resources impact on nearly every member of the population at one time of their life or another. It is vital that the underlying ideas and system changes are effectively communicated to the

whole population in a way that builds understanding and support for the principle of self-directed support.