

Reflections on **in Control**

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We write as critical friends, invited by **in Control**'s leadership to facilitate reflection on the learning emerging from their work and to contribute some of our observations to this report. **In Control**'s commitment to discovering effective ways to support people eligible for social care in ways that protect and promote their full citizenship matches our own convictions. Self-directed supports –the means that the **in Control** network are developing to reform the social care system– seem to us a robust and creative response to many of the challenges facing the government of a society that aims to improve the life chances of people who require publicly funded assistance to lead their daily lives.

We each view **in Control** from different perspectives. David works primarily in an English and European context as a policy advisor and facilitator of system change. John, a student of innovation in supports to people with disabilities and their families, has been a regular visitor from the US for nearly 30 years. Our occasional collaboration began in the early 1980's, when David led the *Ordinary Life* initiative for the King's Fund, a network that shaped the development of community supports for people with learning disabilities. In the past year, we have facilitated two

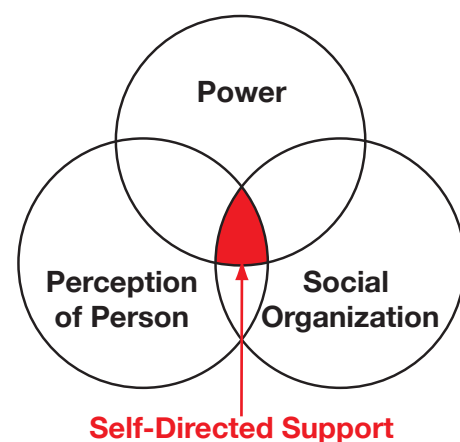
reflection days which have brought some of **in Control**'s core staff and leaders in local implementation of self-directed supports together with national policy leaders and civil society leaders. This chapter is based on what we have learned from thinking about these conversations, talking further with some of those involved in the change, and reading some of the extensive documentation of **in Control**'s activities available at www.in-control.org.uk. We aim to describe some notable aspects of **in Control**'s ways of working, as they appear to us as deeply interested observers. In doing this we have interpreted what **in Control** does in our own terms. We recognize that commentators with different interests and experiences of **in Control** would produce much different accounts. We hope that our translations add to an understanding of **in Control**.

In Control as social acupuncture

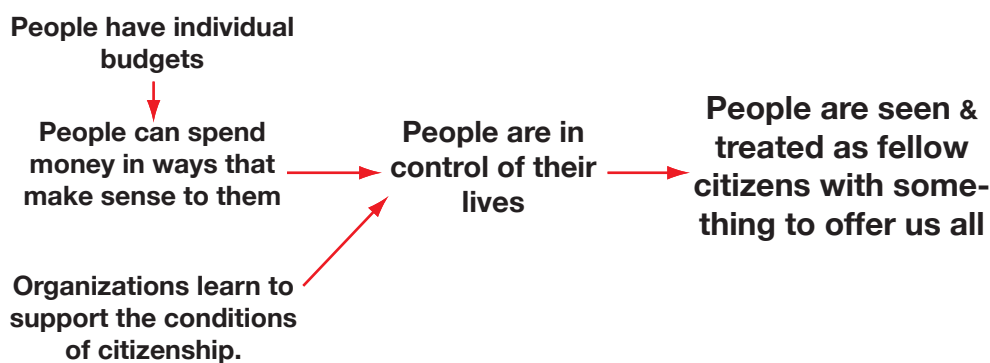
Guided by a map of the body's energy flows, acupuncturists apply very small but very sharp needles in order to achieve energy balance and thus health. Social acupuncturists seek those points in a system where highly focused intervention will yield deep change and a new balance that will better promote human flourishing.

On **in Control**'s view, the greatest potential energy to transform social care will be released when all the people who require assistance self-direct their supports. This diagnosis focuses energy on shifting the way the person requiring support is perceived, the way power is distributed and exercised, and the way social resources are organized. The person is seen as a citizen entitled to the assistance necessary to lead daily life as he or she chooses.

One responsibility of citizenship is to decide on the best use of the resources available to provide necessary support. The organizational systems responsible for allocating available public funds and offering supports must adapt in order to honor people's responsibility to decide and to become co-producers with people who require supports and community resources and mainstream services.

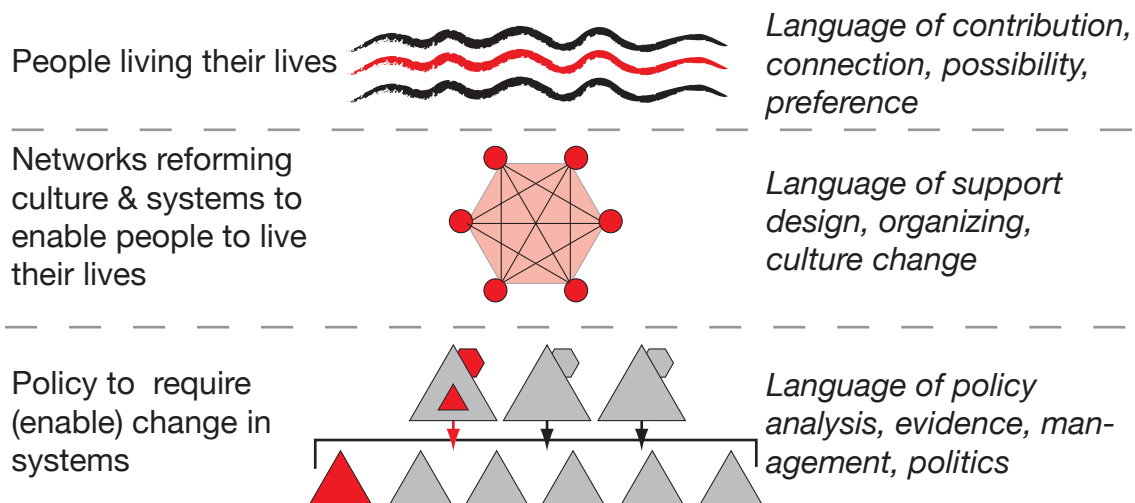


This shift aims to systematically increase the number of people who confidently engage social networks, civic associations, and publicly funded resources with the expectation that they will be able to generate adequate support to pursue what matters to them in life. While **in Control** enters through the door of social organization by establishing procedures and practices within local authorities for allocating and assisting people to direct individual budgets, its purpose is to transform the nexus of perception, power, and organization, moving from the classification, placement, and supervision of clients to recognition and active support for citizenship.



Singular focus on self-directed support as the way to support for citizenship provides a filter that informs decisions about what not to work on. **In Control** argues that the point of greatest leverage is getting a few people in control of their supports as soon as possible, learning from that initial experience, and repeating with another group, taking the shortest possible time to get the greatest possible number of people in control of their supports.

Transformation entails revised expectations, new connections, and learning through action by people who require support, people who provide support (including mainstream service providers), and people responsible for assuring that a locality adequately responds to its citizen's needs. It requires changes in culture –mindset, relationships, structures, and practices– at three levels.



Though **In Control** strives for fluency in all three languages, its messages are grounded in people's everyday lives, its materials typically connect people's stories to system design or policy recommendations, and its interventions often bring people who rely on social care and their family members into direct contact with decision makers.

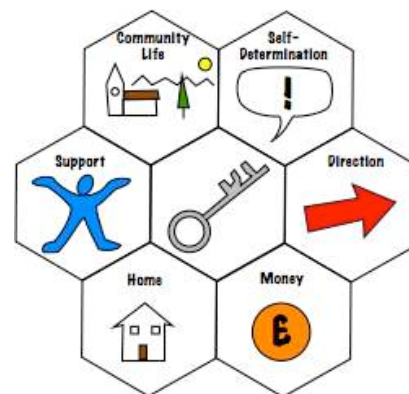
A practical moral foundation for deep change

In Control's effort to reform social care by implementing self-directed support rests on two footings: a careful review of what has worked to improve the life chances of people with disabilities; and a well developed moral argument that systems should actively promote the conditions of citizenship rather than inhibiting them. **In Control**'s approach to stimulating change permits continual updating of each of these accounts of the system's purposes, practices, and limits.

What has worked for people

In Control benefits from its core team members past active involvement both in improving the life chances of people with complex and challenging support requirements and in previous efforts to reform the social care system. Practical experience, mostly with services to people with learning difficulties, informs their understanding and underwrites their confidence in the feasibility and benefits of self-directed supports.

Assisting people with long histories of institutionalization, isolation from family and community life, and complex needs for assistance to re-establish themselves as participating citizens has demonstrated the effectiveness of designing individualized supports based on six keys to citizenship:¹



- **Self-determination** - making our own decisions, in control of our life
- **Direction** - having a meaningful life that suits us and the kind of unique person that we are
- **Money** - being able to pay our way and to decide how we will meet our own needs
- **Home** - having a place of our own, where we are safe, where we belong
- **Support** - getting help, when we need it, to do the things we really want to do
- **Community life** - playing an active part in our family, our circle of friends and our community

These six goods, which **in Control** claims apply universally, specify the why of a social care system aimed at promoting citizenship. They guide the collaborative design of supports and the evaluation of services. A system is effective to the extent that it protects or provides access to them. Clinical interventions are useful to the extent that they protect or promote access to them. Taking these keys seriously stimulates social inventiveness: for example, finding practical ways to support self-determination, direction, and control of money when people experience impairments in communication or cognition by developing methods of substitute decision making that keep decision making as close to the person as possible. Implementing self-directed supports in a local authority and a nation creates systemic capacity to assist people to strengthen the keys to citizenship in their own lives.

¹ Simon Duffy (2004). *Keys to citizenship: A guide to getting good support services for people with learning difficulties (2nd edition)*. Birkenhead: Paradigm. Keys quoted from Simon Duffy (2007). Individual service design. Download from www.incontrol.org.uk

What is right

Many people identify **in Control** with an important procedural innovation: a thoroughly specified, continually improvable, seven step process for getting, using, and learning from experience with an individual budget that



offers people great flexibility in the way they make plans, control money, and develop supports and provides local authorities with a fair and transparent method for allocating available social care money and generating a range of effective supports.

In Control is also a disciplined effort to build a community that can use the experience of shared work to reform the social care system to generate a clear understanding of the moral foundation for social care and gather support for it. This effort looks beneath ideas about good public management (as important as these may be when it comes to designing the means to deliver support). It asks what claims people who requires assistance can legitimately assert on their society. It's answers begin by recognizing people who require assistance as citizens.

Citizenship is the right ideal because it implies a vision of society where everybody is an equal member of the community, but where the natural diversity and differences between individuals are seen as positive opportunities for interdependence (not as some big problem). Citizenship also reminds us that communities must be constructed from the willing efforts of free individuals; full and active citizens build and sustain the communities they belong to.²

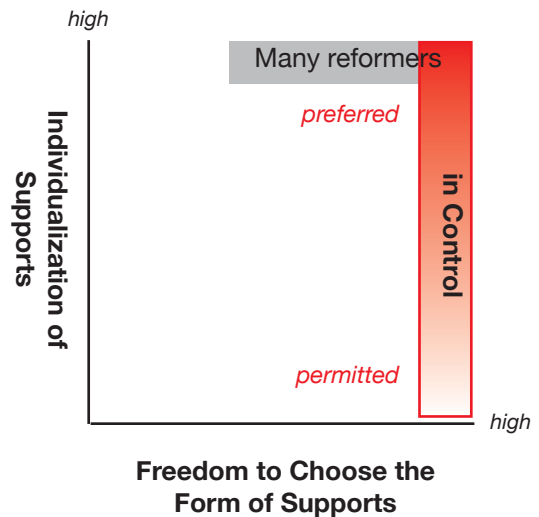
² Simon Duffy (Summer 2006). In Control. *Llais*. P. 9. (Download from in-control.org.uk)

Citizenship can be, and often is, constricted by common social care practices that demand an unnecessary and morally unacceptable sacrifice of autonomy in return for assistance. Everyone has something to offer others, but contributions can be obscured or erased by service practices that treat the heightened interdependence occasioned by impairments as though interdependence both cancelled people's gifts and was incompatible with their independence. This is wrong. People are entitled to the support they need to function as citizens (though currently this entitlement is unenforceably vague). Support should be delivered in ways that maximize autonomy. For example, citizens who require support have a right to know how much public money is available to them and the process by which it is allocated should be understandable to them. They should be free to spend their allocation in any legal way that they believe supports their living a life that makes sense to them.

This effort also asks what duties it is fair to expect of citizens who receive assistance. One of these duties is to exercise as much choice as possible about how they wish to be in control of planning, selecting, and managing their supports. Another is to contribute to mobilizing the support they require and to exercise as much creativity as they can in designing their supports. Another is to explain their decisions, reflect on what they are learning from their experience of support and share what they have found with others. To accommodate individual differences in capacity and preference, **in Control**'s approach to self-directed support offers both a thoughtful approach to substitute decision making and a menu of choices for dealing with planning, direction, and support management. (Cross reference to Chapter 2 pages on substituted decision making).

This understanding puts priority on interdependent autonomy. This priority sharpens the focus of change by pruning a number of reform ideas in good currency from **in Control**'s proposition to local authorities. An example: there are strong advocates for requiring independent brokers whose task is to conduct person-centred planning and support people in connecting with services that will suit them. **In Control** recognizes the case for service brokerage, identifies independent brokers as one of several options to support planning and locating supports and offers some support to people who want to become independent brokers, but **in Control** resists

requiring people to use brokers. This resistance is consistent with the principle of maximizing autonomy: pre-purchasing brokerage amounts to a sort of tax on people’s individual allocation and promotes one alternative to the likely exclusion of others. An example: many reformers, including **in Control**’s leaders, have seen the benefits of highly individualized services and the drawbacks of such congregate settings as registered care homes. However, **in Control** advises that local authorities should not deny people the choice of using their allocation to buy a place in a registered care home: in a trade-off between choice of preferred supports and an option that likely limits choice, **in Control** prioritizes choice of supports. A preference for more individualized and individually managed supports shows in the examples that **in Control** uses to ground the communication of its concepts and in its many investments in providing opportunities for people to learn about personalized alternatives and how to organize them.



The search for a clear and widely accepted foundation is also a search for adequate language. For example, **in Control** prefers “support plan” to “care plan”, in part because “care plan” carries the baggage of a professionally defined and controlled process for assigning a client to a pre-purchased slot.

This table succinctly summaries **in Control**’s current understanding of the proper foundations of social care.³

Principles	Meaning
1. Right to Independent Living - I can get the support I need to be an independent citizen.	If someone has an impairment which means they need help to fulfill their role as a citizen, then they should get the help they need.
2. Right to a Personalised Budget - I know how much money I can use for my support.	If someone needs on-going paid help as part of their life they should be able to decide how the money that pays for that help is used.

³ Need reference

Principles	Meaning
3. <i>Right to Self-Determination - I have the authority, support or representation to make my own decisions.</i>	<i>If someone needs help to make decisions then decision-making should be made as close to the person as possible, reflecting the person's own interests and preferences.</i>
4. <i>Right to Accessibility - I can understand the rules and systems and am able to get help easily.</i>	<i>The system of rules within which people have to work must be clear and open in order to maximise the ability of the disabled person to take control of their own support.</i>
5. <i>Right to Flexible Funding - I can use my money flexibly and creatively.</i>	<i>When someone is using their personalised budget they should be free to spend their funds in the way that makes best sense to them, without unnecessary restrictions.</i>
6. <i>Accountability Principle - I should tell people how I used my money and anything I've learnt.</i>	<i>The disabled person and the government both have a responsibility to each other to explain their decisions and to share what they have learnt.</i>
7. <i>Capacity Principle - Give me enough help, but not too much; I've got something to contribute too.</i>	<i>Disabled people, their families and their communities must not be assumed to be incapable of managing their own support, learning skills and making a contribution.</i>

The principles derived from careful thought remain inert if they are not embodied in different ways and tested and refined in action under a variety of local circumstances. So there is a further commitment to implementability that guides **in Control**'s approach to self-determination. Its models, policies and procedures meet two tests: they are affordable, that is they can be implemented within existing local authority social care budgets; and they are legal, that is they do not violate any existing laws or require relaxation of existing rules. These constraints don't apply when **in Control** provides advice. Its representatives advocate changes in law or policy that would expand the resources available for citizens to self-direct.

What is likely to transform social care

Learning from history

Despite substantial attempts at modernization –which have generated a great deal of activity to re-organize, redefine roles, and make plans in collaboration with users and carers– the social care system has proven remarkably stable in terms of what

most people who use its services experience. Despite great investment in care management and its refinements, far too few people can make basic choices about where they live, who supports them and for what purpose. A close look at past efforts and the systemic limits they reveal has informed **in Control**'s focus and strategies.

Consider, one example, direct payments. Leaders in the Independent Living movement conceived direct payments as a way for disabled people to control their lives. They designed the policy, lobbied successfully for its adoption, and organized effective ways to mobilize disabled people to gain and use them. Yet, while many have benefited from direct payment and demonstrated its effectiveness, the actual uptake is far smaller than the potential and the social care system seems to have encapsulated direct payments as one small offering rather than use direct payments as a lever to change the pattern of service. The creative energy arising from organized disabled people and channeled through central government policy is damped at the point of local implementation. The limiting system dynamics revealed in this case include these:

- Fear that direct payments will break the bank, bringing sanctions from central government.
- Fear that decreased professional oversight could be judged as a breach of the duty of care.
- Uncertainty about how inspection and regulation regimes will treat the consequences of implementing direct payments.
- A widely shared assumption that people who request and use social care are untrustworthy or incompetent.
- A mindset that defines social care as welfare or compensation rather than as assistance necessary to allow full citizens to lead daily lives of their choice.
- Defense of local services provided by local authorities or purchased in blocks.
- A history of recurrent reorganization and multiplying central mandates which creates overload and encourages a disengaged stance: "wait and soon the requirements will change".

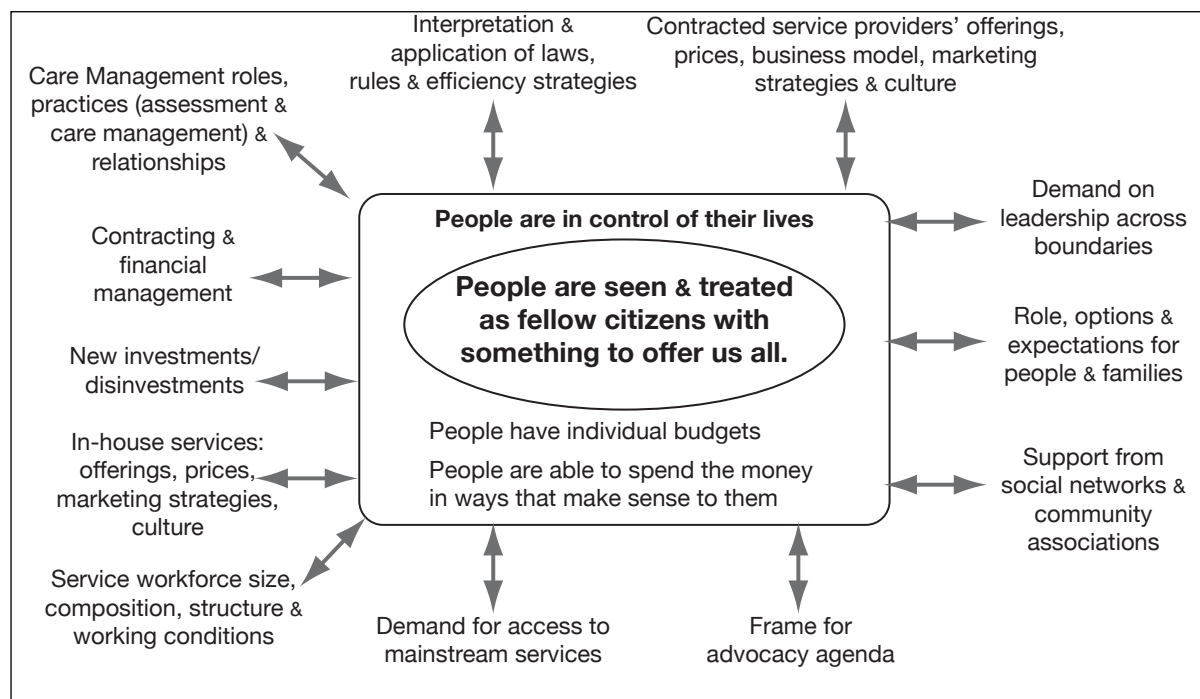
- A history of distance and ritualized interactions between local authority officials and advocates for change that leads to mutual blame rather than collaboration and drains energy from the change effort.

Several important lessons can be drawn, including these. Central requirements can founder without local leadership. Real change is more likely when mobilized citizens with a stake in the quality of supports meet officials and professionals who share a commitment to their vision, so it is important to begin by identifying, connecting, and aligning leadership from both inside and outside. If a change is to benefit citizens historically separated by different modes of service (e.g. older people in need of support and people with learning difficulties), influential members of separated groups will need to discover common interests in change and a common language. New forms of organization, for example Centres for Independent Living, must develop to do new kinds of work. Unless mindsets change and devaluing assumptions are challenged by implementing practices based on a positive view of the capacities of citizens who require support, the system will trap the change in the smallest possible organizational space, where it can affect the fewest people.

Multiple strategies

As the limits to deep change listed above have different sources, **in Control's** network deploys a variety of strategies to engage them. Some limits yield to technical problem solving and regulating uncertainty by adopting a process of testing and refining procedures and decision rules in an expert network that involves many localities. Some limits may relax at least a little by engaging central policy makers, inspectors and regulators in refining the model and in problem solving. Some limits arise from organizational culture.

The number and variety of structures, roles, and functions affected by the shift to self-directed services makes the change process complex. In Control provides a number of guides for the transformation process that outline and sequence critical change tasks.



One useful way to think about the different sorts of strategies necessary to implement self-directed support is to consider two different kinds of skilled change work: technical problem solving and containing adaptive work.⁴ *In Control's* network supports both kinds of work. Successful technical problem solving develops effective and efficient practices; successful adaptive work sets new parameters for technical problems solving.

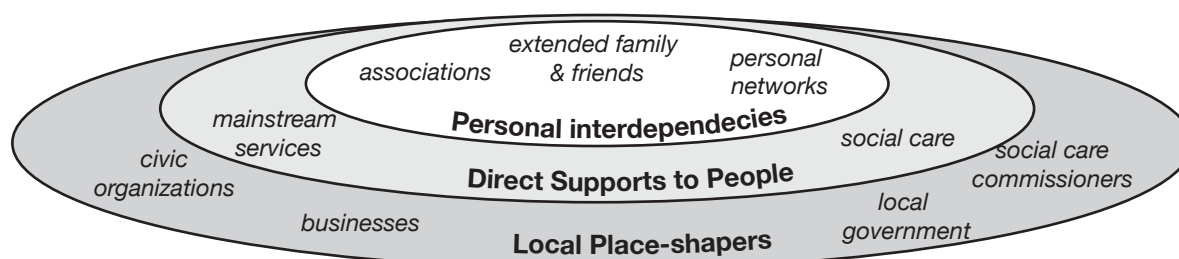
Technical Problem Solving	Adaptive Work
Manage the current system to its highest potential output within system limits.	Re-design own roles, boundaries and practices in order to learn how to thrive under changing conditions.
Address problems that can be fixed through a known or discoverable series of steps (no matter how complicated) which can be described and disseminated.	Address the political and emotional issues in identifying gaps between desired and actual capacities, what must be conserved and what must be lost, and how the costs of transformation are to be distributed.

⁴ See Ronald Heifetz (1998). *Leadership without easy answers*. Cambridge, MA: Belknap Press of Harvard University. Also see R. Heifetz (2003) Adaptive work. In T. Bentley and J. Wiliston, Eds. *The adaptive state: Strategies for personalizing the public realm*. London: Demos. Pp. 68-79.

Technical Problem Solving	Adaptive Work
Necessary learning can be done by instruction and captured in documents.	Necessary learning requires engagement in acting/reflecting under real life conditions of risk and uncertainty.
Necessary change can be accomplished through exercise of authority.	Necessary change requires mobilizing commitment among people with different perspectives, interests, and definitions of issues and goals.

In Control attends first to the point of performance, adopting a local perspective to define implementation problems and generate solutions for them that will strengthen local capacity to support citizenship.

A common insight into the nature of self-directed supports informs **in Control**'s approach. Self-directed support is a local co-production, created by interactions among people who receive supports, the various networks and associations that comprise their communities, providers of mainstream services, providers of social care, those responsible for commissioning social care, and those responsible for



local place-shaping. This view highlights the importance of intentionally managing boundaries to discover productive interdependencies at every level of local organization. People reach out to those they know and the associations to which they belong in order to enlist supports and opportunities to make a contribution. Support providers are active in assisting people to participate in local life, including its economic, civic and political dimensions and to make good use of mainstream resources. Those responsible for commissioning and providing social care look around to see how they can build alliances that will increase the whole capacity to support citizenship for people at risk of losing control of their lives.

Understanding self-directed support from a local perspective also provides a place to stand to assess the effects of central government policy and practice on local supports for citizenship. **In Control** complements local work with efforts to loosen constraints by stimulating its national partners and allies to consider changes in law, policy, and regulation; re-think the multiple flows of public money allocated for people eligible for social care; and encourage national organizations to recognize the benefits of personalized supports.

What form of organization will facilitate deep change?

A distinctive structure

In Control's structure reflects its chosen position as authoritative source of knowledge on self-directed services. Rather than structuring itself as another campaigning organization or a service improvement organization it has found sponsors among established organizations with that mission. Rather than become another consultancy, it has made partnerships with several consultancies. Partners use their capacities to work with clients who seek their assistance in a way that faithfully applies the **in Control** approach and generates learning. Partner relationships are governed by a detailed agreement which safeguards **in Control**'s distinctive position. Rather than selling customers a product, it has a low cost membership open to any local authority and a system for freely distributing what it learns.

This interdependent structure, which includes sponsors, members, and partners as well as a core team, keeps the core team small while allowing large amounts of work to be done by and in collaboration with partners and member authorities. It provides multiple links to the deliberations of central government without stretching the organization to establish an independent presence at the center. As the workload grows, the core team remains compact, exerting leverage through its partner and sponsor relationships and through mutual aid among member authorities. This allows the core team to continue to focus its efforts on the new problems that emerge as implementation proceeds while web site users and members apply, and may update and improve, documented best practices.

Boundaries for local authority membership are lower than they are for partnership. Membership has expanded from 6 collaborating authorities in 2003 to more than 90 members in 2007. To join, a member local authority pays its dues, indicating an interest in implementing self-directed services, and observes the rules for use of **in Control** materials. Member authorities

choose how they will implement ways for people to exercise choice and control over the supports they need and whether and how they will involve **in Control** and its partners. As the table

	Low	High	Total
People in control	0	870	2,102
£ controlled	0	£7,058,379	£20,406,928

1 September 2007

suggests, some members have committed very substantially to self-directed supports while others are considering their investment. Lately 10 local authorities have committed themselves to **Total Transformation**, an accelerated process of moving everyone funded by the authority to self-directed supports. This openness reflects **in Control**'s desire to form a community of learners and its recognition that community is built from the free choice of members to cooperate with one another.

Weaving into other's webs

In Control's work resonates with some of the streams of thought about how to create better public services and clashes with some others. Proposals that take for granted that current service models are adequate and frame the problem as generating efficiencies by smarter contracting for more efficient versions of today's typical services grasp the problems much too far from their roots and would create an unfriendly environment for self-directed supports. Taking support for citizenship as the center for any reform effort re-orders accounts of the economics of social care. The problem is less that existing services are wasteful of money that might be spent more efficiently than that the system as a whole is massively over-invested in ineffective services. The solution is not to look for bargains in the warehouse of typical service models, but to invest available funds in self-directed supports—an approach designed to generate innovation by enabling those who require supports to design and modify them to suit the way they choose to live their daily lives.

The themes of re-invention and co-production are growing in currency and some of the explorers of these ideas have identified **in Control** as a source of practical examples to illustrate, test, and expand their ideas. This tag cloud suggests an expanding context for self-directed support by identifying some of the terms explored in recent publications that have featured accounts of **in Control's** work. Many of these concepts are simply trial balloons in the debate on more effective public service. Some point to networks that might be informative, inspiring, or influential; or to ideas and arguments that might strengthen **in Control's** case; or may be signals to orient **in Control** to new resources. **In Control** has invested a modest amount of time in tying into some of these networks.



Strong metaphors for organizing

In Control describes itself as *a research and development community committed to self-directed support and defines its role as helping people learn about self-directed support and ensuring that learning is shared*. Three metaphors –Operating System (OS), Open Source, and Brand– guide the way **in Control** organizes itself. **In Control** wants to manage an open process by which an expanding network invents and implements the means to transform the social care system to universal self-directed support.

Operating System An operating system makes a computer useful by defining the way that the applications access and use the machine's resources in order to do the work that a person wants from the computer. In **in Control's** analysis, the social care system needs a process analogous to an operating system to mediate between Government policy and citizen experience. Policy sets requirements that local authorities must meet if citizens are to experience the benefits the policy promises.

Implementation requires local interpretation, and big changes –like those called for in *Our Health, Our Care, Our Say*– require correspondingly complex interpretations. Currently the social care system lacks effective ways to consider the variety of local interpretations and test their coherence with the policy. This lack generates a pattern of stuckness: central authorities, frustrated by limitations in implementation, push for change by further requirement and regulation; local authorities look for interpretations that minimize external pressures; citizen's see what looks to them like big promises without delivery. Some see the way out of this pattern as stronger imposition of top-down authority, reducing the need for interpretation with more and more detailed specifications. Some see the way out as letting innovation grow from the ground up by allowing even greater latitude in local interpretation. **In Control** sees another way: an explicit and regularly revised set of policies, practices, and tools that reflect most promising local interpretations of self-directed services. Compiling local interpretations not only allows sharing of inventions and ideas, it also provides a common point of reference for identifying areas where central policy requires revision or where implementation demands a more joined-up central effort because of conflicts among policies or practices.

The operating system metaphor reflects **in Control**'s simultaneous work at two boundaries: 1) in the relationship between people entitled to support from the social care system and local authorities; 2) in the relationship between local authorities and central government and its agents. At each boundary, **in Control** works to support those on both sides. This is apparent from the offerings in the website Library. There are tools and materials to inform and support people entitled to social care to play their central role directing the supports they require. There are tools and materials that structure the local system in ways that offer people choice and control over the support they need to lead their daily lives. There are policy suggestions to local authorities and submissions to influence central policy and practice. At each boundary, **in Control** functions like an operating system: translating requests from one context into another. The notable difference: the computer's operating system commands the allocation of the computer's resources; **in Control** advises and assists human actors in generating necessary support within the constraints of the systems they live and work within.

Open Source An open source approach to software development publishes the code for an application and allows people to modify it on condition that they share the modifications they make with a custodian of the application who holds responsibility for whether and how to adopt modifications.

In Control has adopted this approach to developing the means necessary to implement self-directed services. Open source implies continual improvement based on iteration. **In Control** core staff, or partners, or member local authorities, or sponsors identify an implementation problem which **in Control** core group members or partners often collaborate in solving. The results are disseminated and form the basis for the next round of improvement and revision. The Editorial Board holds responsibility for judging best practices, maintaining the integrity of the approach, and incorporating improvements. The Resource Allocation System, for example, now stands at version 4.0.

The web site, www.incontrol.org.uk, makes copies of policies, procedures, and tools freely available. The open access copyright notice reserves **in Control**'s right to the materials and grants permission to use and modify the materials to suit local conditions provided that proper credit is given and modifications are shared with **in Control**.

Brand A brand is a set of images and ideas that represents the identity of an enterprise and shapes people's expectations of it. A brand is typically communicated by a logo and a distinctive look and feel to products and their presentation.

In Control brands itself with its name, logo, and style for its materials. The name itself communicates purpose and its dual house styles –easy to read materials with distinctive artwork from *know what i mean* and materials formatted as organizational manuals, policies, and training materials tied together by a common style sheet of typeface, layout and color– define its position on the boundary between people and families who require assistance and the authorities responsible for social care. Several complex diagrams are more than informative graphics, they are iconic representations of **in Control**'s approach, turning up regularly in various contexts.

The identity that **in Control** wants to communicate through its work and its branding might be paraphrased like this, *We are the best source of information on assuring that people have choice and control over the support they need to lead their daily lives. We want the information we provide to be practical and accessible for the people who are entitled to social care and for the people who are responsible for administering the social care system. What we have learned is freely available and we encourage anyone who is serious about self-directed services to use and add to our knowledge.*

Seeing **in Control** as a brand offers ways to think about maintaining integrity and multiplying influence by building and protecting a recognizable identity which attracts increasing strength as more and more people invest confidence in it.