Self-Directed Support: Re-Framing Inter-agency Partnership Working
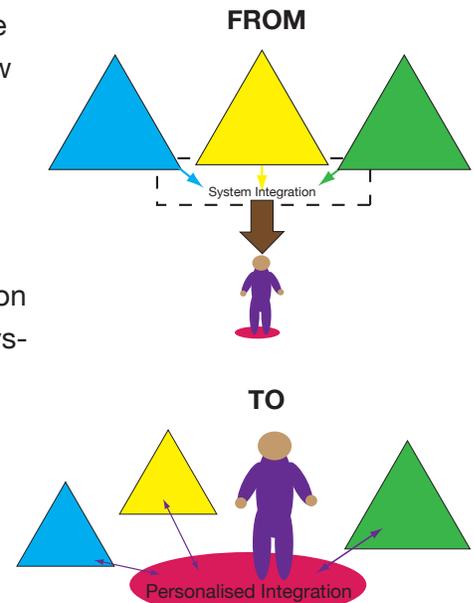
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While interagency partnership is often explored from the perspective of the health and social care system, we approach this issue from the perspective of the citizen. In particular, we focus on those citizens who have significant impairments and need significant levels of support in order to achieve independent living. We will argue that, from the citizen's perspective, the goal of achieving system integration between different agencies (e.g. between health and social care systems in the UK) can seem either redundant or unhelpful. Instead, what seems to matter more is a personalised integration of supports, that can only be achieved with the active participation of the citizen (Duffy, 2004). The ability to achieve personalised integration is a function of systems that put power and control in the hands of the citizen, enable full access to the widest range of services and opportunities, and develop the communities that can take advantage of these opportunities. Although these issues are common in many developed countries, our focus here is mainly on the UK and the US (since these countries both have a relatively long history of piloting and to some extent, evaluating new initiatives in this area).

On this understanding, current efforts to promote the system level integration of service delivery agencies may even be an obstacle to genuine progress, locking people into a narrower range of options. If this understanding is correct then the energy that has been focused on system integration could instead shift to moving the whole service system to operate and respond to self-directed supports, thus enabling citizens who require personal assistance to be in control of their own lives and to assume a share of responsibility for achieving personalised integration.

In this framework, partnership efforts must become sufficiently courageous and competent to accomplish three difficult things:

FROM

System Integration

TO

Personalised Integration

This paper's vocabulary reflects the way of thinking embodied in the Independent Living movement. We understand **impairments** to be persistent characteristics that affect a person's functioning. Impairments may be evident at birth, they may result from an accident, they may come as a consequence of chronic disease. From this perspective, older people do not require social care because of ageing, but because they acquire impairments in old age. Some impairments require reasonable adjustments to a physical or social setting or individually tailored equipment if the person is to function comfortably and competently there. Some impairments require that the person has effective personal assistance some or all of the time in order to function comfortably and competently in settings that matter to them, whether home, work, leisure or civic life.

On this view, **support for independent living is the key task of social care and a key purpose of health care**. No one is excluded from independent living because of the amount of assistance they require. Independent living does not mean doing everything for yourself; it means having control of the resources you require to enjoy the same substantive freedoms everyone expects in order to live the life you wish to lead (Disability Rights Commission, 2006). Such resources may include environmental modifications, equipment and supplies, help with transport, assistance in learning individually chosen skills, and personal assistance. Restrictive definitions of personal assistance are unhelpful. It is best understood as "whatever it takes – that a capable, ethical and well supported assistant can sustainably do – to enable each unique person with impairments to live in a way that makes sense to and for him or her" (see Lyle O'Brien and O'Brien, 1992).

Disability is the disadvantage that people with impairments experience when they encounter barriers to independent living and other opportunities that would otherwise be available to them. Creative action in collaboration with disabled people to remove barriers to full participation in ordinary life and mainstream services is an urgent necessity (Cabinet Office, 2005).

1. Guide themselves by adopting the way of thinking exemplified by the British Government in *Improving the Life Chances of Disabled People* (Cabinet Office, 2005). This document focuses not on ill health or individual impairment, but on the social and political changes needed to ensure that disabled citizens have the same 'life chances' as non-disabled people. Guiding by this star will enable the hard work of uprooting policies and practices based on the presumption that need for assistance diminishes the responsibilities and rights of citizenship. It also allows rethinking historical distinctions between health and social care in a way that more clearly distinguishes treatment for ill health from support for everyday life.

2. Embrace the spirit of the UN Convention on the Rights of Disabled Persons, the Americans with Disabilities Act, and the UK Disability Discrimination Act, all of which prohibit discrimination against disabled people. All services that wish to comply will learn how to capably perform their particular tasks in a way that is accessible to all people with impairments. In the long term, this is an even more important outcome than collaboration among service agencies.

3. Mobilise people who commission social care, people who manage and offer social care, and people who rely on social care to learn the ways of thinking, roles and practices necessary to realise fully the benefits of the strategic direction set in the UK policy documents *Improving the Life Chances of Disabled People* and *Our Health, Our Care, Our Say* (Department of Health, 2006).

The roots of self-directed support

In 1964, Ed Roberts, whose post-Polio impairments included quadriplegia and the continuous need for a ventilator to support his breathing, overcame administrative rejection and enrolled as a student of political science at the University of California, Berkeley (Shapiro, 1993). The University housed a small group of students with quadriplegia, who called themselves The Rolling Quads, in a hospital on the assumption that their substantial impairments required nursing care. Their desire for an ordinary life under their own control, informed by the politics of feminism and civil rights, led to the formation first of the Disabled Students Program at the University and then, in 1971, to the founding of the Center for Independent Living (CIL). The CIL, an organisation led by disabled people, organised peer support, advocacy, equipment design and repair, referral to accessible housing, and referral to attendants that people with disabilities could hire with social service funds.

Ed Roberts and other physically disabled activists around the world framed removing the barriers that create disability as a civil rights issue, contested the right of medical and social service practitioners to define their needs or control their lives, lobbied successfully in some places for the capacity to hire and direct their own personal assistants, invented a range of effective supports to allow them to successfully control their own lives, and created advocacy and support organisations governed and staffed by disabled people. The way they lived reversed the common understanding of disability that confined people who need personal assistance to their family home or to residential and hospital care.

International examples

Within the UK there are at least 3 different approaches to self-directed support (the Independent Living Fund, Direct Payment and in Control's system that includes the concept of an individual budget).

Within the USA there are numerous initiatives and there are significant variations within these models, not only between states, but also at the level of the county. Moreover there are many such systems in other countries:

- Germany's Social Insurance scheme enables people to take their funding as cash.
- France's Prestation Spécifique Dépendance gives cash to disabled people for support.
- Austria has an individualised funding programme called Cash Allowance for Care.
- There are several Canadian initiatives, for example the Individualised Quality of Life Project in Ontario.
- There are some Australian programmes, for example Future for Young Adults in Victoria.
- New Zealand has an Individualised Funding programme.
- In Sweden the Personal Assistance Act created a system of direct funding for support.
- In the Netherlands there is a system of personal budgets ('persoosgebondenbudget').

To date, most schemes tend to have a limited focus: some serve older people while others are just for younger adults. People with learning difficulties are often excluded altogether. This tendency to limit approaches to service-defined labels has the impact of reinforcing traditional, system-focused models of care delivery.

(See, for example, Robbins, 2006; Glasby and Littlechild, 2002; Halloran, 1998)

The elements of self-directed supports

Mrs W is an 82-year-old woman who lives alone in a mobile home. Though she is eligible for placement in a nursing home because of physical and sensory impairments consequent to multiple chronic diseases, she wants to remain in her own home. For years she had been dissatisfied with the assistance received through a block-funded home health care agency, so she eagerly enrolled in a program that offers her control of an individual budget allocation because she values the opportunity to hire her own workers and determine her own priorities. Now, she hires people she knows and trusts to help her according to her directions. She spends a portion of her $100 a week individual budget to buy over-the-counter medications and health care supplies which are not covered by her health insurance. She has also fixed her roof, cleaned her carpet, and had her windows washed. "I couldn't have done any of this myself. I didn't have enough in the bank." Now, she says, "I just feel better. I get what I need to get done without much fuss."

Mrs W participated in **Cash & Counseling**, a demonstration conducted in three US states between 1999 and 2003 to test the logic of Independent Living with older people and people with developmental disabilities. Cash refers to the person's ability to direct the expenditure of an individual allocation of funds and Counseling refers to the assistance with planning, problem solving and managing paperwork available to the person and his or her caregivers. The demonstration was evaluated using a random assignment experimental design whose findings support the program's logic and justify its extension. In comparison to control group members, those who directed their own supports (or whose support was directed by a personal representative, usually a family member) experienced significantly greater satisfaction with their lives and with the assistance they received, and their caregivers reported significantly less burden. Workers reported greater satisfaction with their jobs and with the way they were treated. Involved professionals judged that participants and their representatives ably directed their assistance (Health Services Research, 2007). Though this project was modest in size and restricted in scope, it exemplifies the necessary elements of self-directed supports.

- INDIVIDUALISED ALLOCATION
- DISCRETION
- ACCESS TO NEEDED HELP

The program elements that support Mrs W's positive experience are straightforward: she has an individualised allocation of funds, based on her assessed need for some forms of personal assistance; she has discretion in how those funds are spent (for example, she can choose to save by using somewhat fewer hours of assistance and use the savings to repair her roof); and she has access to help, as she requires it, with planning, problem solving and paperwork.

Adopting self-directed support introduces a new system architecture. Typical service architecture responds to population needs by investing in blocks of service – various types of residential care, day care, home care – and specifying requirements that providers of these services must meet. People who use such services are one of a group assigned to services to correspond to their assessed need as judged by service system staff variously called case managers, care managers or service co-ordinators. Self-directed support follows a different design principle: each person who requires personal assistance and those who know and care for him or her are co-producers of the supports a person needs to live as well as he or she can. Money allocated for personal assistance is one resource that a person can combine with other available benefits, resources available to any citizen, and naturally available support to compose a life that makes sense to him or her. Uniform policies govern eligibility and allocation of personal assistance funds; resulting arrangements are various and shift as circumstances and resources do.

This system architecture is analogous to the architecture that allowed IBM to build Blue Gene, the world's fastest and most power efficient computer as of 2004 (Gara et al., 2005). The design principle spells SMASH: Small, Many, and Self-Healing. The system gains its advantage from a very large number of very simple processors working in parallel. This allows the system as a whole to be self-healing: if one path fails, others carry on with the work. Applied to social care, SMASH suggests that the system will increase its effectiveness when it encourages individuals and their allies 1) to make sense of their own changing circumstances; 2) to act within the smallest possible number of system imposed constraints to pursue goals that they define as desirable; 3) to learn from and connect with others as they choose. This requires that system managers refrain from predetermining such mat-

ters as how many people will live together or what range of supports, activities and therapies will be available to members of a served group.

Benefits and common objections

The social space opened and supported by discretion in directing an individual allocation with help available enables Mrs W. to mobilise the resources available to her to live a life that makes sense to her as she incorporates impairment into her life's narrative. As she notes, these resources combine in richer and more complex and interesting ways than those available to her from typical service provision. In addition to her allocation and what it buys, her resources include trust in those she chooses to assist her; the self-efficacy she feels in exercising her decision-making powers to select goals and engaging her capacities to work toward them (Bandura, 2002);the security evoked by a sense of fit between the assistance she prefers and the assistance she receives; the continuity she experiences with familiar places and people; and the satisfaction she derives from saving and spending to improve her living circumstances and her modest material legacy.

Seasoned service managers may react to this apparent good news with caution. Workers might exploit Mrs W's trust. Mrs W might make bad decisions that lead to a deterioration in her health. Mrs W might increase risk by saving on hours of help; and anyway, if she can manage with fewer hours of assistance, shouldn't her allocation be reduced? Mrs W might live in a run down place with awful neighbours she would be better away from. Auditors or elected members might view Mrs W's roof repairs as an illegitimate use of public funds. Mrs W herself might fiddle the program and find a way to buy cigarettes and lottery tickets with the funds. And anyway, Mrs W is the capable exception to the dependent, incompetent, confused, and passive clientele that typically demand services. The vulnerability that people who require personal assistance cope with and their human fallibility are incontestable. However, assumptions about how best to address these realities are worth debating.

Existing services have not solved the highlighted problems: organised professional bureaucracies, whether publicly or privately operated, have not eliminated the risks enumerated above, even at the cost of substantial expenditures and demanding serious trade-

RISKS

offs in personal autonomy. Thus, costs for Cash & Counseling were somewhat higher than controls because participants were able to hire people who actually delivered the number of hours of service authorised, whereas the agencies that served control group members could not or did not deliver planned and authorised amounts of service (Dale and Brown, 2007). In the same way, the precipitous decrease in autonomy required by moving into a staff controlled residential setting is no guarantee of competence in even the most basic, health and safety related tasks: about half of care homes and nursing homes in England fail when assessed against standards designed to assure that people receive the right dosages of the right medications at the right time, and this despite focused inspection effort, guidance, support and training (Commission for Social Care Inspection, 2006). As a final example, an organisation operating a licensed and inspected, not-for-profit care home defrauded the state of New York by improperly billing for more than $800,000 in undelivered professional services over a five-year period, despite one of the world's most elaborate and expensive accounting requirements and fraud detection units (NYS Commission on Quality of Care, 2001).

Worries about misuse of money increase costs: the biggest demand on the counsellors available to participants in Cash & Counseling, and the most common cause of delay in initiating services, was the paperwork required to hedge against the possibility that the initiative would be seen to be unaccountable for public funds. In fact, extremely little misuse of funds occurred (Mahoney et al., 2007). This is not an argument against reasonable accountability, but a reminder that transaction costs are driven up by managers' concerns about punishment and unfavourable media or political attention falling on them. These concerns express and increase suspicion that most users of personal assistance are untrustworthy or that public and political support for social care in community settings is so shallow and unstable that its very existence could be threatened (on the perception of low public support for social care and some of its consequences, see Platt, 2007).

Paternalism is not free: the assumption that service workers and managers know better than people and families requiring assistance remains dominant in practice, though its rhetorical power has decreased. National policy directives promise that people will soon have

greater choice, a much louder voice and greater responsibility in the services they receive - a promise that implies radical change in the mindsets, relationships and practices that define the current system (Department of Health, 2006). For this strategy to work, people who use services will need to assume new roles and accept new responsibilities, from adopting healthy patterns of exercise and eating to assuming greater self-management of chronic disease as expert patients. The health system cannot afford passive patients; neither can the personal assistance system afford passive consumers. The paternalistic mindset that assumes that people who require personal assistance are incompetent and untrustworthy until they prove otherwise drives two unacceptable and mutually reinforcing costs. It embeds a disrespectful attitude in the foundation of social care and normalises practices that mindlessly compromise people's rights, such as the routine shunting of people into residential care for lack of investment in sufficient alternative supports (Disability Rights Commission, 2006). It too often encourages, or even requires, the passivity that justifies it. This results in losses of opportunity and life quality, the extent of which is unknown and unknowable (Deming, 2000).

Uncertainties should be resolved with many small bold tests: environmental pressure on social care grows inexorably. More people survive for much longer with impairments that require personal assistance. The ratio of younger earners to older pensioners decreases. The supply of people who choose to work as paid personal assistants declines. More families live at a distance or pursue work lives whose time demands make caregiving increasingly difficult. Fewer neighbourhoods have norms that support informal care. Service providers, from GPs and social workers to postal carriers, juggle greater demand and more requirements, most predicated on the assumptions that more can be done with less and that better quality will follow automatically from imposing more demanding targets from above. In public services, reorganisation has itself become a significant transaction cost when the adjustment time of involved people is accounted. Many people remain uncertain about the entitlements and duties of citizenship, but there is a sense of disappointed expectation and resentment around many public services. Public money seems overcommitted, family members seem overcommitted, service staff seem overcommitted. In this environment it is uncertain how many Mrs Ws there are, how ef-

fectively and accountably they or those who know them will be able to self-direct necessary assistance, how much they will be able to mobilise other resources, and how much of what kind of publicly funded assistance they will need to accomplish all this. Uncertainty can rationalise going on as usual or taking tiny, timid steps. It should signal the urgency of bold actions that can generate deeper knowledge and greater capacity. The test of partnership working is the motivation the partnership draws from its participants to take and learn from bold steps that respect and support citizen capacities.

Learning from experience

Andre is in his mid-twenties and capably does government office work that has been customised to make the most of his abilities, which are shaped by substantial cognitive, physical and language impairments. He greatly enjoys swimming, the outdoors and travel. He lives in his own home, which he shares with a married couple who work as his paid assistants and their daughter. Like the other 1,250 people served by his County's Developmental Disabilities Program, Andre has an individual budget, which in his case is directed for him by his mother, who is his legal guardian. She has chosen to take primary responsibility for hiring, training, scheduling and supervising his personal assistants, and co-ordinating with the employment support organisations that assists Andre on the job and with his healthcare providers. Both Andre and his mother are helped to deal with program requirements by an independent service broker (in this case a friend who volunteers his time), and supported by a circle of unpaid people whom they have chosen and trust for counsel and for occasional practical help.

Andre's experience demonstrates that the elements of self-directed support – discretion over an individual allocation with necessary help – can sustain complex and intensive personal assistance for a person whose cognitive and communication impairments require a substitute decision maker. His county, a participant in a US national demonstration project aimed at implementing self-determination as an option for people with developmental disabilities (Bradley et al., 2001; Rossiter and Harkins, 2005), shows that a whole local system can be transformed to and managed through self-directed support.

Andre is not typical of the people who use personal assistance services in his county, though the innovations that have grown up to support him have influenced expectations among people who rely on services and practices among service agencies. He is among the most impaired of the people the county serves and his family and support circle are among the most active, both in day-to-day management and in the amount of scheduled unpaid assistance they offer (about 5% of the total number of people the County serves choose to self-manage service budgets as Andre's mother does; others negotiate with service providers to organise and manage more of what they require, while many people simply select the offering that suits them from among available service providers). Most people who require as much assistance as Andre does live with one or two disabled roommates with the assistance of a supported living program. Most people and substitute decision makers direct their budgets by selecting the service organisations with whom they and their brokers negotiate their individualised support plans. Some substitute decision makers disapprove of changes that service providers who know and also care about the person think would be desirable, and some people have conflicts with family members about what they want to do. Some families are disengaged, especially when a person was placed in residential care as a child or young person, and some are unable to be involved much (often because they are themselves experiencing impairments as they have aged or because they are providing unpaid care to other family members with impairments). A few families attempt to exploit the system and have been replaced as substitute decision makers. And a small number of family members are neglectful or abusive of the person, often because they are themselves affected by addiction or mental ill health, and come to the attention of protective services or the courts.

Andre's county has myriad quality issues to engage and faces the same sorts of environmental pressures that any other overcommitted system does. There are also ethical questions that come more sharply into view with self-direction. The supply of good quality services is stretched and a number of people would prefer service from a provider who does not have spare capacity to accept them. Some believe that it is wrong for family investment to count for as much difference in living conditions as it does for people like Andre. Some are suspicious that substitute decision makers, especially parents, will not take

adequate account of the person's own interests and desires. Some advocates for particular approaches to service are concerned that self-direction offers too little protection against what they see as undesirable practice or too little incentive to provide what they believe people really need. Self-directed supports do not dissolve quality issues or resolve ethical questions. Indeed, the contrasts that emerge as people make different decisions about their lives and the ways that personal assistance fits in make some of these issues and questions occasions for learning.

What Andre's county has done is shift the context for development. The elements of self-directed support provide the mechanism, but the change springs from a change in mindset. Most social care systems act as if they assumed that the typical people and families who rely on them for personal assistance are incompetent, self-interested to they point that they will exploit the system in any way that is open to them, and inferior in the exercise of judgement to social care staff. The system that assists Andre begins with the opposite assumptions and manages the conflicts that arise from occasional poor judgement, excessive self-interest, incompetence, neglect and abuse as exceptions that deserve intensive attention from County staff. These staff have more time to discover and attend to exceptions because most people and their families are managing the services they use to their satisfaction and within applicable rules.

From option to operating system

In his late 30s, Gavin's mobility, swallowing, speech and vision became significantly impaired consequent to Multiple Sclerosis. As he made his self-directed support plan, he stated his purpose: "living my life my way, with the love and support of my family and friends." Gavin's family and friends provide sufficient unpaid natural support to allow him to spend significantly less than his full allocated individual budget. He buys paid personal assistance, laundry and ironing, reflexology, and a season football ticket (an expenditure that generates four hours a week of free personal assistance in season, which is worth more than 2.5 times the cost of the ticket). A colleague handles payroll at a cost of "one Thai green curry per month." (See a video version of Gavin's support plan at www.picturethispartnership.org.uk)

Gavin and his family and friends organise his support in a locality that is learning how to transform its social care system by implementing in Control, a comprehensive way to generate self-directed supports that functions like an open source operating system does for a computer network. Most other approaches offer self-directed support as one option for clients approved by the system and restrict clients to particular means (e.g. people can only direct particular services or buy from pre-selected providers; people must use an approved broker to prepare a plan or use a fiscal intermediary to manage their funds). in Control is comprehensive in that it re-orients the whole system to self-directed supports by making all funds for assistance liquid and specifying a sequence of necessary steps to implement support, each of which citizens can choose to perform in a variety of legitimate ways in order to access and expend their individual budget. in Control is like an operating system in that it is a set of policies, practices and tools that allow local authorities to convert policy demands for greater personalisation and choice into practical means to meet citizen demands for support legally and flexibly. in Control is open source in that it publishes its policies and tools on its web-site, invites use and revision, and incorporates improvements as they are endorsed by its Editorial Board (an expert group representing its sixteen partner organisations).

The **7 steps** to being in control of my support

The variety of individual capacities and preferences in a local population calls for many options. People unable to make or communicate judgements without assistance can be represented by a personal agent. There are at least six ways to hold and disburse funds. People who want assistance in making a support plan and negotiating for services can engage a broker. People who want to hire and supervise their own staff can do so; people who want to purchase a service that packages assistance can do so.

Gavin's contract with the social care system is based on a shared appreciation of the rights and responsibilities of citizenship, not on a professionally controlled definition of the appropriate service response to his system defined needs. Accountability for public funds demands that his eligibility for social care be officially certified, the amount of social care funding allocated to him be administered through a fair and

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transparent resource allocation system (Step 1 above), and that his expenditures be legal and open to audit. Within these limits, he and his family and friends are free to set goals, prioritise resource use, determine means, and pursue a life that make sense to them. In doing so he creates social exchanges based on mutual regard (Thai curry for payroll services), economic exchanges (laundry and ironing by someone local), and links to other publicly funded resources (Access to Work employment support funding). Gavin is not a consumer but a citizen, co-producing the supports required to "live my life my way". in Control supports him to experience assistance in the context of his individual interests and struggles rather than to compromise individuality and choice in order to receive the assistance that someone at a professional distance deems good for him.

Developing a shared understanding of citizenship calls for a shift in mindset by those who require assistance as well as those who manage and provide social care. Many people hold an unexamined assumption that need for assistance suspends the responsibilities of citizenship and puts the person in the passive role of client, one taken care of by state agents who should be responsible for doing what is best. This belief is in tension with people's desire for autonomy, a tension which in Control seeks to resolve by rooting all of its efforts in a clear understanding of citizenship.

This understanding identifies six interacting keys to citizenship which put support in context (Duffy, 2004). Support is one key for every citizen, and assistance funded by an individual social care budget is one possible means of support for eligible citizens with impairments. The six keys to citizenship are:

- **Self-determination** - making our own decisions, being 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.
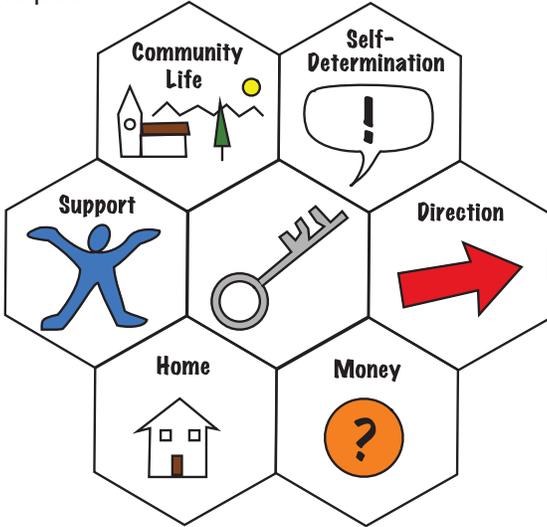
- **Community life** - playing an active part in our family, our circle of friends and our community.

These six values of citizenship specify the outcomes of an adequate system of social care. These outcomes are most likely when all the actors in a local system continually improve their ability to reflect these principles in their interactions with each other.

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 fulfil 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. Right to Self-Determination - I have the authority, support or representation to make my own decisions.	*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.*
4. Right to Accessibility - I can understand the rules and systems and am able to get help easily.	*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.*
5. Right to Flexible Funding - I can use my money flexibly and creatively.	*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.*
6. Accountability Principle - I should tell people how I used my money and anything I've learnt.	*The disabled person and the government both have a responsibility to each other to explain their decisions and to share what they have learnt.*
7. Capacity Principle - Give me enough help, but not too much; I've got something to contribute too.	*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.*

A new frame for partnership

To date, partnership working has usually been conceived as a partnership between agencies who are expected to find ways of actively collaborating in order that the different services they offer are better integrated. The citizen is, probably rightly, supposed not to be interested in the organisational boundaries that define those agencies nor the precise definition of their core roles. However it is challenging to expect those agencies to collaborate when, by definition, their core business will be distinct (e.g. local authorities responsible for social care will, whatever the overlap, be focused on different citizens, different needs, different professional groups, different accountabilities.) The rhetoric of partnership cannot put together what politics and organisational design have put asunder.

In contrast, self-directed support offers a different way of approaching this problem. Instead of focusing the task of partnership at the level of the agency, it suggests that the primary focus must be on a partnership with the citizen. The primary reason why this approach may well be more effective is that most support is already offered by family, friends or members of the wider community. The primary focus of integration for the citizen will be upon integrating resources or support from agencies with these community supports, but this can only happen at the level of the citizen and requires the citizen to have meaningful control of the resources that the agencies provide. In fact, one can sharpen this point further and argue that organisational simplification, integration or alliance may even risk reducing the possible leverage that the citizen has over the citizen. The ideal of a 'one-stop shop' supposes that the shop has something you can buy and something you want to buy; but if what you want cannot be bought or what is on offer does not suit you, then limiting the offering of agencies will limit and distort the citizen's options.

As a result, the energy that is currently deployed to achieve system integration may be better used to strengthen the citizen's ability to achieve personalised integration. This will enhance genuine partnership working in at least four ways:

A shared understanding of citizenship and the principles for organising support that flow from understanding the needs for the deep changes necessary to respond to a turbulent environment shaped by

changing demographics, developing technologies, and changing political, economic, and social conditions. The practical sense of citizenship that animates in Control provides a foundation for the dialogue necessary to establish this orientation.

Recognition of the power of designing systems that contain complexity in small, multiple, and self-healing units of action can reduce the load on more hierarchal forms of organisation, especially when much necessary coordination can be exercised by units as small and connected as the people and families who require support and their allies. The experience of self-directed support suggests that much more is possible in this direction than has so far been realised.

Re-drawing those dysfunctional boundaries that generate the demand for integration while, at the same time creating disincentives to it, would considerably ease the strains on partnership work. Most notably, the UK's distinction between health and social care breaks down as soon as people move away from acute care and begin to cope with impairments to functioning. The political issues in redefining boundaries to put all of the non-acute health and social care resources available to support people with impairments into a unified entitlement to self-directed supports are daunting. The likely improvement in citizenship outcomes make it worth struggling for.

Many of the greatest benefits to citizens with impairments will come within the boundaries of Departments, levels of government, and agencies rather then across them. Mainstream services and markets that are accessible and willing to learn how to make reasonable adjustments to the requirements of citizens with impairments are easier for people to join up for themselves than they are for managers to join up by command at distant points. This shortens the agenda for partnerships by reducing the number of inter-organisational boundaries to contest and defend.

Within the UK, the journey towards a meaningful, citizenship-based account of integration has only just begun. Early initiatives have come from the world of social care and particularly from those people involved in the Independent Living movement. One sign that these changes can begin to influence the health care system is the recent announcement of a joint health and social programme in Barnsley which they call Every Adult Matters. Their vision is to see "people

maximise their aspirations for control and independence over their health and well-being supported by flexible, responsive, preventative services." (Barnsley Council and Barnsley PCT, 2007) This kind of approach may be the first sign of a radically more realistic approach to partnership working.

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