Independent living is what non-disabled people take for granted: living your own life, deciding what you want to do and making it happen

DEMOS

Independent Living

The right to be equal citizens

Sarah Gillinson
Hannah Green
Paul Miller

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As ever though, all errors and omissions remain our own.

Sarah Gillinson
Hannah Green
Paul Miller
May 2005

Foreword

Jim Elder-Woodward, Rachel Hurst and Tony Manwaring

Last year, we were two – and they said it would not last. This year, we are three, and it has. So much so that we three writing the foreword of this report are building on both the process of collaboration and the key arguments which informed last year's *Disablism: How to tackle the last prejudice*. In this foreword, we wish to set the context for an intervention, which we hope will have a major impact on how we all live our lives in the years to come.

Independent living is what non-disabled people do every day of their lives – it is equally the human right of disabled people to enjoy, but this fundamental right is denied to them living within a disablist society.

Independent living is a philosophy; a manifesto for empowerment, self-determination and self-fulfilment; and a way of being – it is not a 'service', a life sentence of being forced to live on your own in the community, or any of the other descriptions that are so typically assumed by those whose fundamental view of disabled people is one of 'helpless cripples' who are objects of 'charity'.

In fact, independent living may involve very substantial support being provided to individuals so that, whatever their level of impairment and whatever the expectations of those around them, they can exercise personal choice and control. Above all, it is about making *independent* decisions about how to live – empowering and informing individuals about the choices open to them and then enabling them to put their choices into practice – not about being on your own, dumped and isolated. For disabled people, as for others, it is about friendships and a sense of belonging, about removing the barriers which prevent participation and inclusion. In answer to those who might raise the spectre of deficient 'care in the community' as an argument against advocating for independent living, this is to distort what it really is, while failing to make the changes that are needed so that it can be made a reality.

A danger has already arisen that people talk about independent living and attach it to their services, because it is becoming a recognised and favoured foundation for shaping social policy and welfare reform. But much like the social model, over recent years, many will use the language, but not share the experience or respect the difference that informs a real understanding of what it does and should mean in practice.

Independent living, above all, is what most non-disabled people take for granted – living the life you want to live – deciding what you want to do, and then having the opportunity and, if necessary, the support, to get on and do it. It's as simple as that!

But for disabled people to decide what to do may not lead to the act of doing it, or doing it may not achieve that which was wanted in the first place. This is because so often the disabling barriers of society – the ignorance, prejudice and oppression expressed by non-disabled people, the lack of resources, the rigidity of organisational structures, and much more – exclude and debar, or at best modify their freedoms and actions.

And these disabling barriers are not just unique to people with physical or mental impairments. They affect everyone disempowered and discriminated against by powerful elements in society. Independent living is about redressing power in society for everyone, by making society more inclusive, more supportive, more enabling for all.

That's why independent living encompasses all aspects of how we live our lives – because the intelligence and contribution of disempowered people, including disabled people (eg people with a physical and/or mental impairment, with whom Scope is particularly concerned), cannot find full expression without challenging all the disabling barriers that have to be overcome.

If you are someone with a physical impairment and can't get out of bed, or get around, or don't have the support that you need to manage your situation on a day-to-day basis; if employers assume it will cost a fortune to adjust to your needs, and if having made all the effort to get a job and get to work you lose the benefits that you rely on to overcome the effect of impairment; if your parents are told that you are not a real human being, and professions of all kinds regard you as the problem that needs to be fixed and controlled: then it's no wonder that disabled people construct an identity which builds in what they are continually being told, that they do not have the right to full and equal lives, and to achieve their full potential.

'Time to get equal' is the overarching theme of Scope's campaign to work with others, within the disability rights movement and beyond, to build a society in which disabled people can have full equality. This report on independent living marks the next phase of the campaign, and is launched at a critical moment of opportunity within our society as a whole, as well as within the policies and practice of Scope as a long-established disability organisation.

Of course, independent living is the product of disabled people's thinking around their own situation and then organising for the right to shape their own lives. As the report recognises in the introduction, independent living is not some abstract term or set of principles, but was born out of social and political struggle. It has not happened by itself, or been given to disabled people. Disabled people have made it happen for themselves.

Despite recent legislation, as the 2004 report 'Improving the life chances of disabled people' from the Strategy Unit of the Prime Minister recognised, disabled people do not enjoy anything like the same life chances as others. We have only started on the road to full equality.

In taking further steps, it is imperative that we take advantage of the unique set of circumstances that have come together to create a real opportunity for a once in a generation 'step change' towards making independent living for all a practical reality. The Strategy Unit report affirms that independent living needs to become the central organising principle around which welfare reform and social care are organised. There are a number of factors that have come together: the combination of budgetary pressures on public finances, the left/right convergence around principles of individual choice and personal responsibility, pressure in the labour market combined with the growing consensus that successful businesses in the future will need to get better and better at managing difference, the impact of legislation so far enacted, the recent green paper on adult social services combined with the commitment to individual care budgets, and an increasing focus on the 'personalisation' of services.

Just as this is a time of opportunity, so it is also a period of real challenge. As this report argues, independent living will require a fundamental shift in the organisation of welfare and social services: there will be powerful institutional inertia to overcome, and complex issues to work through.

It will require significant reform of existing agencies, including organisations such as Scope. They will need to contend not only with established ways of doing things, but also the often fierce and protective response of parents, the institutionalisation of disabled people to which they have contributed, the ignorance of the media and the complex funding and other arrangements that sustain current models of provision. More generally, despite very big advances on the policy front, for example in relation to inclusive education, practical outcomes have been far harder to achieve. So nothing can be taken for granted, and any assumption of a benign progression to a rights-based framework which leads to ever greater inclusion of disabled people in society would be foolish indeed. Independent living will happen because it is made to happen.

Moreover, our view is that the 'window' for delivering this step change really is very small. The 'push and pull' of the various forces described above mean that a lot has to happen within the next two years or so in order that the commitments, dynamics and patterns of institutional reform have been mapped out and decisions implemented, so that the capacity to deliver independent living is embedded. If we wait until the second half of the next parliament (as at the time of writing), when the Euro referendums and other as yet unknown major issues will be taking up time on the floor, the moment may be lost.

So, given all this, the question becomes *how* best to make it happen. This report proceeds from the conclusion that – as with the previous report on disablism – there is much that we can achieve by working as we have been doing, but that there are inherent limitations from so doing which, in the context of the scale of change required, can only be achieved by working together. Last year, we acknowledged the dangers and risks of this approach: for many, these remain of overwhelming concern, but perhaps for us, having worked together at a deeper level for well over a year, while these risks have not in any sense disappeared, the reasons for collaboration become ever more apparent, and the basis on which it needs to rest, more firmly grounded.

The concept of trading zones, which was developed for the first time in the Demos work on 'disablism', is one that we have found very helpful and on which we are building. A trading zone brings together people of different experiences, from institutions with different interests and capacities, to explore ideas and actions of mutual interest and benefit, on a basis of equity and mutual respect. The 'Ezone' (equality zone) was the first such zone. It is now firmly established and, for those participating, has proved a useful 'space' to exchange and explore ideas, analysis, tactics and strategies. A statement of collaboration (see appendix C) sets out the principles which underpin the values of those participating in the zone.

More recently, we have established the 'ILzone' (independent living zone) for two main purposes: to explore how best to develop the understanding of what independent living is and to work together to create the policy framework to support its delivery. We hope to discover how best to transform existing service models, particularly within Scope, around the principles of independent living. It is in this context that we are publishing this report. The terms of reference for the ILzone are included as appendix D.

While it is within the space provided by the trading zone that we have done this, it is the concept and practice of 'co-production' that best describes how we both shape ideas together and, perhaps more importantly, work together on their implementation. As we will each confirm, this report has itself been the outcome of this process of co-production – involving not only ourselves and the Demos team, but many within and beyond Scope, above all key players who have 'lived' independent living, nationally and locally across the country. Critically, we believe that it can only be through the practice of co-production that independent living can be delivered, if there is to be a step change in practice over the next few years.

For co-production to succeed, it has to be underpinned by the values of respecting difference within a framework of diversity. This cuts all ways, and not only in relation to disabled and non-disabled people, or to organisations like ours. In the course of the co-production of this report, we have heard black disabled people say that it cannot be assumed that because they are also disabled, they are necessarily included in the local user-led organisations of white disabled people; and local centres for independent living reflecting on the variety of their experience; and we recognise the significance of national boundaries, with Scotland, so often ahead in terms of welfare reform, if anything, finding progress in relation to this agenda just as problematic as England, but in different ways.

Co-production is certainly key to vital issues within independent living, such as assisted decision-making with those with high support needs; the trade-off values between control and responsibility; and capacity-building user-led support organisations. These issues do appear in this report, but much more joint work needs to be done by all parties represented on the ILzone, if they are to be fully tackled.

The rationale for co-production also recognises that for independent living to be achieved it must begin with a person-centred and holistic determination by the individual of what they want; and for it to be delivered it requires a framework of support and enablement, which has to be directed by the individual themselves with other individuals (such as personal assistants), agencies and institutions providing the practical support. This in turn requires a reshaping of what is available on the ground, in particular through a network of centres for independent living, which has at its centre a core resource of information, advice and national representation to government etc, much like the network of citizens' advice bureaux (CABs). But, unlike CABs, CILs (Centres for Independent Living) must encourage and sustain peer support and political and social change.

The result is a map showing the relationships between individuals, agencies and systems, some of which work in harmony, but most of which do not. It follows that a 'one size fits all' approach to what independent living will mean on the ground cannot apply. There will necessarily be a variety of forms that it may take in practice.

But disabled people can't do it all on their own. First, because it requires a systemic framework, as we have just outlined. Second, because existing institutions, which often act as barriers, must be reformed – they must become part of the solution, not the problem. And third, because we go back to our earlier argument that there is a narrow window for a once in a generation opportunity, which requires a very substantial increase in capacity of user-led organisations, but which on its own cannot expect to deliver all that is needed.

Bringing all these individuals and institutions into the pattern of alignment that will be required to deliver independent living, while also reforming those institutions and creating new ones so that they can play this role, and building the capacity of disabled people and their organisations, is going to be a complex and delicate process. It requires shifts in power, as well as understanding and changes in practice. Above all, perhaps, it requires a re-engineering of the institutions of the welfare state – delivering joined-up support for the individual, so that we can all live our lives to the full.

We live in an era of huge change not only in our society but also in others – from Europe to South Africa – changes that would not have been thought possible have happened within a few years. Such change has been rooted in people coming together to argue for their civil and human rights, and creating the institutions and patterns of reform needed. It has also required a change in consciousness and practice from and by those who have held power within the old order. The tipping point for change is reached over years, but can then crystallise dramatically. We hope that this report, taken in the context of what has gone before, and the work of many others, will contribute to this process of change – and that we will therefore hasten the day in which medical condition or impairment will no longer be a critical factor in shaping whether or not we can live the lives we want.

We all have a right to independent living – the right to be full and equal citizens.

Jim Elder-Woodward is chair of the ILzone; Rachel Hurst is director of Disability Awareness in Action; Tony Manwaring is chief executive of Scope.

1. Origins

A brief history of independent living

Independent living is a philosophy and a movement of disabled people who work for equal rights and equal opportunities, self-respect and self-determination.[1]

Adolf Ratzka

Independent living was born in the 1960s in Berkeley, California. At the same time as Martin Luther King was spearheading the civil rights movement, fighting for the economic, social and political rights of black people, a group of 12 students at the University of California came to recognise their own 'right to living'.

These students, who had severe physical impairments, attended university lectures and seminars alongside their non-disabled friends but in other ways their lives could not have been more different. While most undergraduates were off exploring a new-found freedom outside family life, they were housed apart from other students in a wing of the Student Health Service, Cowell Hospital. This was the only place that was seen as being capable of meeting their needs. Most of their time was spent constrained to the University campus, partly because their electric wheelchairs did not have the range to take them out into the community but largely because the surrounding area was not set up to accommodate them. Overall, they were basically isolated and in close contact only with each other.

At the same time, the campus was the scene of some of the great demonstrations of the time in support of the civil rights of black people. At the heart of this was the struggle for self-determination. It was at this point that the closeness of the group and their shared understanding of the struggle to control their day-to-day lives became an asset. Residents of Cowell Hospital recognised in themselves and in each other the ways in which the medical and rehabilitation services they received fundamentally undermined the self-determination that was their right as human beings. As Hale Zukas put it, 'A sense of unity and self-confidence gradually developed, largely as a result of the free flow of communication and sharing of experience.'[2]

It was from this understanding – that disabled people are a discrete group with equivalent rights to other minority groups – that the first Centre for Independent Living (CIL) was born. Its activities included facilitating access to a pool of personal assistants who supported the students to get up, get dressed and prepare meals as well as helping them to navigate university bureaucracy to arrange accessible seminar venues. In short, it enabled the Berkeley students to lead full and active lives similar to their non-disabled friends. Their work was founded on three basic principles:

- Those who know best the needs of disabled people and how to meet those needs are disabled people themselves.
- The needs of disabled people can be met most effectively by comprehensive programmes that provide a variety of services.
- Disabled people should be integrated fully into their community.

These principles continue to underpin the work of CILs and other user-led organisations today.

Alongside the vital work of the Berkeley CIL in supporting with disabled people to identify and obtain the resources that would enable them to access independent living, political campaigning continued apace. The fight for political rights and the right to equal participation was seen to underpin parallel fights for economic and social rights. Without that stake in changing the society in which they lived, the Berkeley revolutionaries saw a parallel threat of the same ongoing challenge that Nelson Mandela was fighting to overcome in South Africa, against the apartheid regime:

> *Africans want to be paid a living wage. Africans want to perform work which they are capable of doing and not work which the Government declares them capable of . . . Africans want to be part of the general population not confined to living in their own ghettos . . . They want security and a stake in society. Above all, we want equal political rights, because without them our disabilities will be permanent.*[3]

Black people faced barriers to independent living in South Africa as a result of a very conscious, large-scale social and political movement, which discriminated against them on the grounds of their skin colour. Disabled people face barriers as a result of similar, often unconscious, but no less oppressive sociopolitical reactions, which discriminate against them on the grounds of their impairment.

For Nelson Mandela, as for the independent living movement, overcoming the barriers to independent living on a daily basis to access the workplace or live in the community are essentially a short-term measure. What Nelson Mandela, the Berkeley students and the independent living movement continue to fight for today is the means by which to dismantle them. This is a true recognition of the equal value of human worth, and an equal right to independent living.

This reflects Rawls' conception of Equal Liberty (the first of his two principles of justice), which places equal political participation at its heart. In part two of his *A Theory of Justice*, he writes, '. . . all citizens are to have an equal right to take part in, and to determine the outcome of, the constitutional process that establishes the laws with which they are expected to comply.'[4]

On this basis, it has been suggested that there are four assumptions underpinning the philosophy of independent living that reflect this rights-based understanding of the concept:

- that all human life is of value
- that anyone, whatever their impairment, is capable of exerting choice
- that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives
- that disabled people have the right to participate fully in society.[5]

Independent living is the means by which many disabled people want to achieve their individual goals in life, the principles by which they want to live and by which they want to be treated. It is the embodiment of a right to be recognised as an individual born to equality, freedom and dignity. The movement which began in Berkeley and continues its fight today was a movement for social change, and an attempt to end disablism – 'discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others'.[6]

Twelve pillars

Disabled people within the independent living movement have long seen the day-to-day reality of independent living as requiring 'twelve pillars',[7] or supports, to sustain it. These are:

- full access to the environment
- a fully accessible transport system
- technical aids – equipment
- accessible/adapted housing
- personal assistance
- inclusive education and training
- an adequate income

- equal opportunities for employment
- appropriate and accessible information
- advocacy (towards self-advocacy)
- peer counselling
- appropriate and accessible health care provision.

As it stands, access to these ‘twelve pillars’ is by no means a given. Here are two examples cited in the Strategy Unit’s interim analytical report ‘Improving the life chances of disabled people’, published in June 2004:

- Around 55 per cent of families with a disabled child live in, or near, child poverty; and children are almost twice as likely to experience poverty if there are disabled adults in their family.
- Disabled people are more likely to have no educational qualifications; 25 per cent of disabled men and about 30 per cent of disabled women aged 16–44 have no qualifications, compared with to about 10 per cent of non-disabled men and women.[8]

The world is simply not set up to enable disabled people the freedom to turn choices about their lives immediately into action. So, currently, the corollary of a right to independent living is the right to access the resources and opportunities that empower people to make it a reality, despite the societal barriers they face – ‘emancipatory services’ as Jim Elder-Woodward has put it.[9] The use of ‘emancipation’ (freeing someone from the control of another) and ‘empowerment’ (the freedom to act with authority) are significant. Neither say anything about how an individual chooses to exercise that freedom.

Similarly, while the support to exercise independent living is a right due to all, its outcomes have to be seized. Making choices and taking decisions about the direction of one’s life and the way in which it is lived are not passive services that can be received. Independent living has to be co-produced by the resource provider and the disabled person, who should have complete control over the direction of their life and the resources they require to live it to the full. To be fully realised, it also has to be set in an environment and political framework that allows anyone and everyone to access it.

It is also worth clarifying what independent living is not. On one hand, it clearly does not mean doing everything for oneself, without help, or living in isolation. On the other, it is equally clear that independent living is not a community care service in itself. As Jim Elder-Woodward and Rachel Hurst told us, 'It (independent living) is not about controlling disabled people's lifestyles by managing separate care for them – it is about disabled people controlling their own lifestyles by managing their own support, as non-disabled people do every day.'

Services have a role in supporting disabled people to realise and access a life lived according to the principles of independent living. But they do not to take its place.

This is a real challenge to policy-makers and 'care providers' for whom services and welfare have traditionally been based on the state fulfilling basic, biological needs. Fulfilment is described by survival – by meeting our basic needs as 'natural beings', for example food, shelter and health.[10] Needs themselves are defined by the individual's ability to fend for him or herself in a given environment. By this definition, in most societies, someone with a severe physical, sensory or mental impairment will have multiple needs but none of them will be about their social or personal development – the ability to contribute to society, live within a family or community, or fulfil one's potential. On Maslow's hierarchy of needs, it is only the physiological needs and safety that are addressed.[11] Love, esteem and certainly self-actualisation (the desire to become more and more what one is, to become everything that one is capable of becoming) are not.

This represents the antithesis of the rights-based philosophy of independent living which turns this 'welfarist' approach on its head – instead of starting with the 'deficiency' of the individual, it starts with the qualities and features of an independent life, including self-actualisation, that every citizen, regardless of impairment, should be enabled to access. To achieve this, services aim to overcome the deficiencies of society as the individual experiences them, rather than the perceived deficiencies of the individual.

This clash of approaches has been a major contributor to the oppression of disabled people. As Ken Davis from the Derbyshire Centre for Independent Living has said:

> *It (welfarism) has failed to bring us into the social mainstream, failed to bring us equality of opportunity, but it has been gloriously successful in spawning golden career opportunities for hordes of 'welfare professionals' doing good works in 'looking after' us and, in the process, of keeping us out of sight and mind.*[12]

This is not just about inadequate services, although that is certainly true – chronic underfunding of support for disabled people is the logical conclusion of this approach as the recent Joseph Rowntree Foundation report *Disabled People's Costs of Living* pointed out. Support based on the limited assessment of professionals rather than on the experience of individual disabled people themselves was found to fall far short of creating a 'level playing field' with non-disabled people: 'The income of disabled people solely dependent on benefits, irrespective of the type or level of their need, is approximately £200 less than the weekly amount required for them to ensure a minimum standard of living.'[13]

It is also about compounding society's view (in which many disabled people are included) of disabled people as inferior or incapable.

Today, policy rhetoric is changing at a national level to reflect a rights-based approach. The Strategy Unit's final report, *Improving the Life Chances of Disabled People*, includes a section on independent living which acknowledges that:

> *Historically, disabled people have been treated as being dependent and in need of 'care', rather than being recognised as*

> *full citizens . . . Independence comes from having choice and being empowered regarding the assistance needed. Without this choice and empowerment, disabled people are unable to fulfil their roles and responsibilities as citizens.*[14]

Similarly, the recent green paper on adult social care, *Independence, Well-being and Choice*, starts from the principle that 'everyone in society has a positive contribution to make to that society and that they should have a right to control their own lives'.[15]

So the vision and understanding, which in both cases was formulated in collaboration with disabled people, exists to some extent at national policy level. Making it a reality for every disabled person is another matter. Crucially, both documents acknowledge the central importance of 'person-centred', personalised or self-directed support to enable and realise the deeply personal and diverse choices that comprise an individual life. Person-centred planning is also an important tool in the implementation of the 2001 white paper *Valuing People: A new strategy for learning disability for the 21st century*.[16] At the same time, the Strategy Unit report recognises that within statutory services a personalised approach is not the norm: 'The support which society makes available to people with a range of different impairments is generally not fitted to the person. Instead, disabled people are expected to fit into services.'[17]

This is true for all the interconnecting parts of the system of support. This system basically comprises assessment and funding for, and provision of, 'twelve pillar' resources from technical aids like a wheelchair, to personal assistance. It also includes the broader policy context, of transport, housing and education for example, which set up the infrastructure that defines what extra resources are necessary for disabled people to navigate the society in which we live.

Both documents also acknowledge that successful models of personalised support already exist. Many local user-led organisations have worked with disabled people in this way since the inception of the independent living movement. They put the person at the centre, empowering them to realise their rights, articulate what they want from their life, identify what they need to make it happen and support them to obtain, manage and modify that support.

User-led organisations

In this report, the term user-led organisation is used to describe all groups working within the independent living philosophy. These might be CILs, but could also be other groups working to the same ends, but by other names.

It is important to clarify this as the term 'user-led' is open to abuse. Evidence from our research suggests that some traditional service providers have begun recruiting disabled people as a 'fig-leaf' measure. But an understanding of the philosophy of independent living and its working requirements does not come hand in hand with an impairment in either the long or the short term. We will return to potential solutions to this in the final chapter.

So employing disabled people may not be a *sufficient* condition for improving responsiveness to service users, within CILs and other organisations working to the philosophy of independent living, but many see it as a *necessary* condition for maintaining user-led integrity and to provide the best possible services. Others feel that such a policy 'may be seen as ghettoising disabled people and contrary to the principle of inclusion'[18] and that certain roles can be filled equally well by non-disabled people. This often applies particularly to 'backroom' roles such as financial administration.

Generally, there is consensus that user-led organisations must be controlled and run by disabled people, but that the employment of non-disabled people is acceptable in the absence of suitably qualified disabled applicants. Glasgow Centre for Inclusive Living (GCIL) works on this principle, although Peter Brawley, a trustee, explained that in an ideal world every position would have a disabled and a non-disabled employee. He sees this as being key in the long term to building the understanding in non-disabled 'mainstream' society that will help to dismantle disablism.

Visits to local user-led organisations illustrated the four central categories of resources on offer to support individual empowerment and ultimately inform service design. These tally with the categorisation developed by the National Centre for Independent Living (NCIL): peer support; information, advice and guidance; training; and advocacy as defined in chapter 5.[19]

The Living Options project in Derbyshire drew up the following checklist to assess an organisation's commitment to user involvement:

- ○ Does your organisation want to increase user power?
- ○ Are your staff required to demonstrate a commitment to user involvement?
- ○ If you impose limits on user power, do you make these clear to everyone?
- ○ Are your environments, processes and information accessible to disabled people?
- ○ Do you involve disabled people's organisations as well as individual users?
- ○ Do disabled people control your user involvement process?
- ○ Do disabled people control your agenda for consultation issues?
- ○ Do you provide user representatives with the same support systems as staff representatives?
- ○ Do you communicate the outcomes of disabled people's involvement back to them?
- ○ Has your organisation ever made changes against its will because disabled people wanted you to?[20]

For policy-makers, user-led organisations demonstrate more than ‘what works’. First, recognising, harnessing and spreading the success of local organisations that are working with people as peer supporters, trainers, information hubs and advocates is only part of the challenge. It poses one of the most pressing and significant questions for governments in the twenty-first century: how to navigate the point where bottom-up enthusiasm, authenticity and effectiveness meets requirements for top-down control and accountability.

Second, and most fundamentally, the very existence of these organisations and the role they currently play in empowering disabled people illustrates the need for sweeping reform of every part of the system described earlier. They highlight the shortcomings of a disablist system that makes the existence of user-led organisations so vital in navigating and overcoming it to support disabled people to be full and equal citizens.

There is no denying that reform on this scale is a major challenge, particularly if governments continue to see each component of the system as discrete and separate, and in need of an individual blueprint for reform. This report argues that we need to think about policy-making in a different way. In complex environments like this one, piece-meal, top-down policy interventions as we traditionally think of them, even if they are well meant, will almost certainly have unintended consequences. The introduction of direct payments is a classic example – instead of removing the need for support organisations, their advent has necessitated a new role, providing support and training for users to manage them effectively.

But if government acknowledged and used the interlocking, interdependent nature of the system to its advantage, reform in one area could become a motor for change. With a strong philosophy or direction for reform, it should be possible to trigger wholesale transformation by starting at any point in the system.

In the current system, we face a moment of opportunity. Consultation on Incapacity Benefit reform as well as the drive to implement the Strategy Unit report and green paper on adult social care have created the space for reform. Treated as an opportunity for system-wide change, these could transform and embed our understanding of the role of disabled people in society in a way that would shape any future reform in its image.

About the project

This report is the outcome of a Demos research project funded by Scope and BT and supported by Disability Awareness in Action (DAA) and the ILzone. During the first phase of research, we undertook a series of in-depth interviews with key members of the independent living movement, policy-makers and the Disability Rights Commission (DRC) during January and February 2005 (see appendix A). These included representatives of the National Centre for Independent Living (NCIL), the European Parliament of Disabled People, local CILs and other independent organisations such as Equalities UK and the Disabled People's Forum, Leonard Cheshire. It was these conversations that helped to clarify the above aims and identify the projects into which we could do more in-depth research.

We then visited a number of user-led organisations, including CILs, in Greenwich, Glasgow, Essex, Oldham and Birmingham, among others, during March 2005 (see appendix B). It is these visits and the conversations we have had with employees, volunteers and clients from these organisations that form the backbone of our findings. We are very grateful to all those who took the time to share their exciting and often transformational work with us; those stories we have included have been anonymised. We understand that much of what we saw was the pinnacle of existing support for independent living, and that our findings do not reflect the day-to-day reality of disabled people everywhere in the UK.

This report

This report builds on the work of the independent living movement to explore what it would mean if the whole system were oriented by a philosophy of independent living. The next chapter describes some of their transformative work to demonstrate what ‘personalisation’ looks like in practice, setting the standard for how other parts of the system should operate.

The report goes on to describe the ‘why’, ‘what’ and ‘how’ of independent living through the stories of user-led organisations, the ‘emancipatory services’ they provide and how they work with disabled people to co-produce independent living.

It then outlines what should be possible if government takes up this challenge for wholesale reform and finally suggests practical next steps for transformation.

2. Getting personal

How to put the user at the centre

> *Before, I was a snail inside a shell . . . I'm a butterfly with wings now! I started off going to the WI and cross-stitch club. Now I've applied to do voluntary work with Age Concern.*
>
> (Service user, IVS)

> *It's not so much about being able to do things, but about doing them without forward planning . . . I can just walk around here and see what's round the corner.*
>
> (Service user, GCIL)

> *True independence (for me) is asking my PA to work with me to help my child, because I'm doing it, I'm requesting it.*
>
> (Advocate, GAD)

Independent living is a very personal thing. The Berkeley students of the previous chapter were unwilling to accept the uniform blueprint that medical and rehabilitation services imposed on their lives. Each of them had a different map for their lives based on their characteristics as a person, not just as a patient.

Myriad factors combine to make up the whole person. First there are those embedded in the individual themselves, like aptitude, talent, interests and personality. Second, the values and attitudes we hold as a result of our background: family, community and education. Third, those imbued in us by the broader society in which we live, the obvious example in Western societies being the status we place on paid employment. At the same time, the person is affected and influenced by the way in which society responds to their characteristics, the choices and decisions they make and the position they hold. The previous chapter sought to illustrate what that position should be – one of equality and respect – and what it often is in a society blighted by racism, sexism and disablism – one of inferiority which places constraints on individual choice and action.

A personalised approach to providing resources for independent living has to take account of the individual characteristics that define the different things each person wants to do, how they want to do them and the barriers they face in achieving them. For disabled people, these vary according to how society responds to and accommodates their impairment as well as to their personal interests and aspirations. It also has to take account of the position that the disabled person holds in society. It has to reflect their right to independent living by treating them as equal citizens.

Charlie Leadbeater has outlined five potential ‘types’ of personalisation:[21]

- ‘First, it could mean providing people with a more customer-friendly interface for existing services.’ This might mean making service providers accessible at times that suit the user, for example NHS Direct’s 24-hour service.
- ‘Second, personalisation could mean giving users more say in navigating their way through services once they have got access to them.’ Individual education plans in schools illustrate what this might mean.
- ‘Third, personalisation could give service users more control over how money is spent.’ Direct payments are the obvious example of this, with local authorities giving disabled people the funds and power to commission their own support.

- ‘Fourth, personalisation could mean users are not just consumers but co-designers and co-producers of a service: they actively participate in its design and provision.’ Community safety initiatives like Neighbourhood Watch are one illustration of this approach.
- ‘Fifth, personalisation could mean self-organisation: the public good emerging from society.’ Services arise where they are required, designed collaboratively by the people who identify the need for them. This was precisely what the students in Berkeley achieved with their pioneering Centre for Independent Living.

In the fifth type of personalisation, the professionals who devised and delivered solutions for service users in the first type have a very different role. As Leadbeater writes: ‘They are designing the environments, networks and platforms through which people can together devise their own solutions.’ The power relationship has shifted dramatically from the ‘professional knowing best’ to the user both knowing and designing best. For disabled people, this is a complete reversal of the power relations that have characterised the support they have received under the welfarist approach of the past. A personalised approach puts the disabled person in control of what services they receive and how they receive them.

Shallow and deep personalisation

Leadbeater’s first two ‘shallow’ types of personalisation alone cannot respond adequately to the individual needs and aspirations of disabled people. They offer some variety for *how* people might access services, but make no fundamental changes to *what* those services offer the individual. Independent living places the individual’s right to self-determination at the fore and this cannot possibly be realised without resources that can respond differentially to individuals. Perhaps more significantly, these first two versions of personalisation do not respond to disabled people as equal citizens. Services are still ‘delivered’ with the state remaining a paternalistic presence.

The third type of personalisation represents a half-way house. Having control over how resources are spent sounds exactly like what the independent living movement has been calling for since its inception. But as a lone guiding principle, this approach also falls short, as disabled people's experience of direct payments has shown. Having a direct payment in an area where personal assistants are badly trained or few and far between, for example, or if the assessment for payment does not provide enough assistance, is not always an improvement on services provided by the local authority. Without a say in what services and assessment look like, the choice afforded by a direct payment remains hollow.

These first three types of personalisation don't go far enough to support true independent living because they are unable to meet both the needs of disabled people and to respect their right to be treated as equal citizens. But even if these services were designed in consultation with users at their inception to be fit for purpose, they wouldn't enable independent living for all for two main reasons. First, 'users' is a generic term. It suggests that disabled people are a homogeneous group, which could not be further from the truth. The term disguises a vast range of impairments including physical, sensory and mental impairments, as well as long-term ill health and learning difficulties. In this model, services would not provide the flexibility that independent living demands, and user panels could never be sufficiently representative of the citizens they should be engaging. Second, research has shown that traditional forms of user engagement in service design are as disabling as the rest of society and, as the Social Care Institute for Excellence (SCIE) points out, 'though some strong models from disability and survivor organisations exist they are under utilised by mainstream audiences'.[22]

The fourth and fifth (deep) types of personalisation start to describe a model that caters to the individual and respects their position in society – 'personalisation through participation' as Leadbeater calls it. As co-producers of independent living and co-designers of the support that enables anyone to access it, regardless of impairment, disabled people would be in control of what they do with their lives and how they do it.

User-led organisations of disabled people offering resources to support independent living are the ultimate example of the fifth type of self-organising personalisation. They understand the imperative to meet personal support needs – workers co-design services and co-produce outcomes with disabled people. But they also model equal citizenship in the way in which they work with clients and, vitally, in the way that they were founded and continue to be organised.

Making it happen: Individual empowerment

Personalisation through participation and co-production or 'self-directed support'[23] describes the guiding principles for how user-led organisations work with people in recognition of – and to realise – their right to independent living. At every point, decisions are owned and directed by the disabled person.

In practice, empowering the individual means working through a process of questioning that our reseach identified as having three stages. Disabled people may come to organisations offering independent living resources during any stage of this questioning process, to see if one or more of the 'twelve pillars' could help answer their question. Often organisations will be working with the disabled person on all three questions at once. This three-stage questioning process includes 'The Why', 'The What' and 'The How' of independent living:

1. *The Why?* This is about a fundamental revelation – that a disablist society should not constrain a person's right to self-determination or participation. It supports people to realise that disabled people can dream and aspire to something different – that it is their right and it is possible.
2. *The What?* This is about supporting people to identify what they actually want from their lives.
3. *The How?* This is about making things happen – identifying and accessing the resources to make independent living a reality.

The Why?

To understand that horizons can widen, people first need to realise why they should widen. Those who are disempowered within their own restricted social or personal lives often have marked narrow and impoverished horizons. They are so oppressed they have grave difficulty seeing the need or the reason to improve their situation.

Nurturing motivation and aspiration for a different life is an important and powerful first step towards independent living. This may be particularly true for those who are living (or have lived) in a residential home or in other settings where it has been assumed that they should not have responsibility for or control over their own lives. Carlo Salvatore, an advocate at Greenwich Association of Disabled People (GAD), stressed that liberating people to have the ability 'to dream' is crucial in empowering them to lead an independent life. Equally, it might mean demonstrating that a different life is possible. Miles, a peer supporter working with individuals in care homes, says that simply going into residential homes as a wheelchair user and independent man is often enough to convince some residents that they could change their own lives.

However, an aspiration requires appropriate channels to become reality: channels that are reliable, flexible, adequate and sustainable. This is the next role for organisations of all types supporting independent living.

The What?

Many disabled (and non-disabled) people do not instantly know what they want from their lives, or may only know part of what they want. For example one person we interviewed, who had lived in a home for her whole life, knew she wanted to move into the community because she desperately needed more privacy. In the residential home, staff would walk into her room whenever they wanted. Beyond this, she did not know what she wanted or what her independence should encompass.

Organisations offering support for independent living have a crucial role in working with people to help them identify and articulate what they want from their independent lifestyle. To be truly in control of our lifestyle, the ways in which we choose what to do, when to do it and with whom to do it will vary according to our interests, friends and family, and environment. Deciding on going to the cinema over going for a walk, or going on holiday with a partner over regularly eating out with friends, are only two examples of lifestyle choices that are dependent on individual circumstances of place, resources, attitude, personality and preference.

But for some, including some disabled people, the amount of control we choose to exercise over our day-to-day decisions may also vary. Interviewees were clear that it is perfectly possible to make a rational decision to relinquish day-to-day control of the payments to your personal assistant, for example, for the peace of mind that it affords. This is a trade-off for the individual to negotiate. The balance of the decision lies in a combination of the individual's own skills, characteristics and life experiences. For each and every disabled person, regardless of gender, ethnicity or sexual orientation, not only may this *framework* of independent living differ, but its *manifestation* may vary as well.

The How?

Organisations also have to recognise that the ways in which they work with people to exercise choice and control have to be as adaptable and personalised as their aims. Organisations have two key tasks in working with people to realise their vision of independent living:

- to help people identify and access the tools and resources that will enable them to exercise their choice and control over their own lifestyle; these might include a direct payment, personal assistant(s), communication equipment or adaptations to housing
- to provide support to develop skills and confidence to use those tools; the obvious example is the training in financial management that may be required to use a direct payment effectively and proficiently.

Organisations need to work differently with each person not just because their aims and starting points are different, but because every person has different ways of accessing the resources they offer. This may literally be about where different groups think of turning first for support, but also about how that support is best delivered. Race, culture and gender, as well as impairment and personality, have all emerged as crucially important factors in this.

It has been suggested, for example, that members of British Minority and Ethnic (BME) communities are often particularly hesitant to ask for support. Julie Charles from Equalities stressed that while there is strong understanding about the meaning of independent living within the core of the movement, the term is not necessarily well understood beyond. As a result, members of BME communities that Equalities work with would not necessarily go to a CIL with a query about their direct payment. This is precisely the role that Equalities aims to fill, working actively with BME communities to raise awareness about and provide the support that it is their right to access.

National cultural differences are also important. Independence is a positive aspiration in the UK, something to strive for. In some cultures though it is eclipsed by other values. Rachel Hurst told us that in many South African communities for example, ‘the business of a PA is immaterial, as a family member will automatically give the assistance’.

Women also experience and access independent living differently. People First, a peer support group for people with learning difficulties, found that women were initially underrepresented at their ‘Problem Places’; it turned out that they found the busy environment particularly intimidating and felt shy in a large group. They have now set up one-to-one or small group conversations to address this.

Personalisation requires resources that can vary between people and also vary for each person over time. Independent living is a dynamic concept; our aims change as does the amount of control we want over day-to-day decisions and how we want to exercise it. So organisations supporting independent living must be responsive to the changes in the person that their resources helped to stimulate in the first place.

Making it happen: political empowerment

To support the empowerment of individuals, user-led organisations require a deep understanding of the ways in which their users experience barriers to independent living. As a result, they are important and authentic holders of information about how local and national policies could and should be better designed. For individuals, the formal ways of feeding into design of services are often as exclusive as the services themselves.[24] So understanding, articulating and communicating user experience to local authorities and service providers is a central activity for many user-led organisations. It is also an important subsidiary activity for others.

Many of those organisations that see it as their primary purpose are impairment and gender and/or ethnicity specific. They feed in generic concerns about ways in which services treat, and often fail, specific groups of disabled people. Several organisations highlighted that this seems to be particularly the case around people with mental illness and learning difficulties. This is the ‘tailoring’ part of personalisation. They also build relationships between service users and providers promoting understanding of a particular group to improve the ways in which services work. Where they can engage more effectively, it allows providers and users to work together better to deliver the service they receive – to ‘co-produce’ them.

For organisations that see communicating the voice of a certain constituency to transform statutory service provision as their key aim, other functions emerge. This might simply be the peer support that is a function of the conversations that groups have about their concerns over statutory services. This support can be practical as well as moral – collective group expertise about local provision and solutions is obviously greater than that embedded in any individual. It is this acknowledgement that lies at the heart of People First’s technique of regularly resolving problems presented at their ‘Problem Places’ in a committee, rather than alone.

It's good to talk

North Essex Stronger Together (NEST) empowers service users through training and support, designs and participates in service provision and runs user-led mental health forums that raise key issues for discussion as well as encouraging social interaction. These forums are held every two months in different areas around Colchester, focusing on different user groups. The last forum was 'Connections for Women' attended by over 100 people mostly made up of service users and individuals from relevant support organisations.

'Connections for Women' provided a forum for people to talk, especially those who do not usually class themselves as having mental health issues, for example rape victims and those suffering domestic violence. The attendees discussed services, housing and welfare benefits and how those services could be accessed. Participants also got involved in a mapping exercise looking at where people get help from, where they start their journeys, what were the positives, negatives and possible actions.

Following such forums, findings are fed back to service providers and to other users. June Harper, the chief executive of NEST, has strong networks with local service providers and NEST produces a newsletter that is published on its website and distributed in GP surgeries, voluntary organisations and churches. Empowering other service users with the realisation that their difficulties are not unique is often as important as changing services at a local authority level.

There are also many user-led organisations that see the value of influencing the system but don't see it as their primary purpose. For example Carlo, the GAD advocate mentioned earlier, first tackles the problem presented by the individual using his knowledge and experience of local services and officials to immediately help resolve the crises that people face. But then he tries to tackle the causes of the problem. He combines the information he gains from his advocacy role about the problems that disabled people regularly face with his knowledge of local services and officials. He feeds the combined information into the redesign of statutory services.

All of the established CILs interviewed for this project included some element of consultancy work with local services as part of their remit. This was not always by design, but was an inevitable consequence of their in-depth understanding of the issues that people face.

User-led groups unlock and communicate user concerns by:

- understanding the context in which problems exist, and by being able to use language which connects with people's experience
- working in particular ways – in small groups, providing other activities to help people talk or building up longer-term relationships for example to create an environment in which people feel comfortable expressing their concerns
- creating solidarity and legitimacy – stimulating acceptance that having such concerns is natural and 'allowed', and talking with and on behalf of a group with confidence in a spokesperson's understanding.

The preliminary report *Creating Independent Futures: An evaluation of services led by disabled people*[25] details data collected from the 76 individual users and nine organisations that took part in the third stage of this project. In comparing professional/provider-led and user-led services, two key themes emerged: choice and control, and peer support. All participants were adamant that user-led organisations were far more responsive to their needs both in terms of what was on offer and how it was offered. They felt that they had a greater choice of services and, equally important, more control over how they were delivered. Peer support was also highlighted – user-led organisations were far more aware of the problems faced by disabled people and, consequently, more responsive. Peer support also helps to address the isolation many disabled people experienced, particularly in the period after the onset of impairment and/or becoming disabled.

Peer perspective

Being a service user 'certainly helps as you use the right words and give relevant examples for the situation'. Ruth, from NEST explained the benefits of being a user-run organisation: 'It gives you a bit of an advantage as you see things slightly differently.'

People First (PF) is also linked to the local partnership board, which is made up of representatives from different services and different areas of the local authority. This board offers a forum for people to speak up for themselves. The representatives on the board do not have learning difficulties, so PF members also attend to make sure that their rights and views are heard. It was felt that PF acts as a sort of translator, while trying to train people to communicate with people with learning difficulties in an appropriate way.

The next chapter looks in depth at the ways in which organisations co-design support to empower disabled people to identify, articulate and exercise their independent living choices and lifestyles. The value of this approach is not just in the increased quality and effectiveness of the support which disabled people access through these organisations (the outcomes), it is in the way in which users engage with them (the means). Putting people in control of their support enshrines their role as equal and valued citizens.

3. The *Why* of independent living

Recognising the right to an independent life

It is the very nature of disablism that makes the 'why' so important. Barriers to independent living are manifest on a day-to-day basis in the ways that society treats disabled people as a separate group, *outside* mainstream society and with lesser rights – through an inaccessible environment, prejudice in the workplace or low expectations for example. But, crucially, it also affects them as *part* of that society – disablism affects the ways that many disabled people see themselves.

How disabled people come to recognise their right to independent living is deeply personal. For the Berkeley students of chapter 1, it was a result of external social pressures alongside the peer support that allowed them to see the reality of their own situation, and to have the power to do something about it. For others, it is embedded in their personality – this was true for many of the pioneering individuals who were instrumental in setting up some of the first user-led organisations to support independent living. They just knew that the way they were being treated was not right. For some, it is a consequence of circumstance – the death of family members or carers, or the closure of a residential home provide the catalyst. Increasingly, because of the user-led organisations featured here, disabled people see the possibilities of a different life. Supporting people to come to this realisation then has to be a very sensitive and flexible process.

Russell and Miles, part 1

Russell has lived in a residential home for the past 11 years. Before he met Miles, his peer supporter, he was fed up, frustrated and unfulfilled – at the end of his tether. He was not even sure exactly what he was so frustrated about. In the home, he was never given the opportunity to articulate his concerns, so was not even able to think them through properly.

Russell was clear that he wanted his life to change. He just did not know how it could, why it should or what it would be like if it did.

Russell first met Miles when he gave a presentation about his role as a peer supporter, making it clear that he was available to talk through any difficulties at any time. Simply seeing Miles – a wheelchair user like him, leading an independent life – was the first step to liberation. Russell saw what his life could be like. The second step was just being listened to, talking through his concerns and options for resolving them – realising that independent living was not just something for others, but possible for him too to seize.

Just listen

Peer supporters often play a key role in the process of an individual recognising their rights. Listening is a key part of their role. Miles works as a peer supporter with residents of care homes. He often supports people in the move between a residential home and the community. It is not his role to persuade residents that they want to take on a more independent life; initially his role is just to listen to whatever worries people have. Before talking to Miles, Russell was aware of his frustration, but without a means of expressing it, was unable to identify its roots. Once he did, it became clear that they were linked to living in a residential home and Miles's role morphed into supporting Russell with the 'what' of independent living.

Most fundamentally, listening to someone is a mark of respect. Russell was not afforded this in his residential home. In itself, being listened to can be a vital trigger in realising that equality is a right that is there to be seized. It is liberating. As Kate, an ex-user of and current volunteer at Independent Visitors Scheme (IVS) Essex said, being listened to helps people to feel 'You're important, that's what they make you feel . . . you're a person, you're valuable, you're important!'

This is wholly 'personalised' as the peer supporter is merely a facilitator – it is the disabled person who comes to the realisation that they have a right to determine the way they live their own life, at their own pace.

The social model of disability

The social model underpins the political demands of disabled people and their organisations. Since its development in the 1970s the social model has been increasingly accepted and adapted by disability groups throughout the world. It lays its emphasis on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment. These barriers include inaccessible education, information and communication systems; working environments; inadequate disability benefits; discriminatory health and social support services; inaccessible transport, housing, public buildings and amenities; and the devaluing of people labelled 'disabled' by negative imagery and representation in the media. In the words of Colin Barnes, 'From this perspective, people with designated impairments are disabled by society's failure to accommodate their individual and collective needs within the mainstream of economic and cultural life.'[26]

It's not just you

As a service user at IVS, Kate highlighted an understanding of the social model of disability as a turning point in her life. Realising that it was society that was the problem, she felt able to achieve whatever she wanted. Almost all the organisations visited as part of this research offered training in the social model as a core service. This was compounded by the way in which they operated. Through the lens of the social model, resources to support independent living are not about 'correcting deficiencies' or filling holes in people's skill sets. They are about empowering and equipping disabled people to overcome the inherent discrimination in the ways in which society is constructed. So even if users do not participate in explicit training in the social model, it is imbued in them from their first moment of engagement with user-led organisations. Kate explained that the confidence she developed in this way liberated her to say no to things – a key component of being in control of your own life. She no longer felt obliged to do everything that was offered to her.

For the 12 students at Berkeley, recognising oppression in each other was the key to unlocking recognition of their own situation. Peer support often supports people to realise that the issues they face are not unique and that they are not acceptable. This does not have to be an explicit organisational aim for it to be effective. People First, Essex, runs a 'friendship group' for anyone with learning difficulties who feels isolated within the community. People come to the group for company, but often leave with more confidence and aspiration. People First's user-run committee found that once people had got used to the small, hectic office, they were more likely to talk to each other and discuss their problems while they were immersed in other activities like textile painting or even bingo.

For Gale, a participant in the group, being 'noticed and recognised' liberated her to talk about her concerns. Talking about them with other service users who were more confident and clear about their rights helped her to think differently about what she might do with her life. Often, this leads to service users becoming volunteers themselves. At Equalities, a national advocacy service for BME communities, their success is derived from the continuous flow of empowered users becoming advocates.

Many organisations actively try to spread the message that 'it's not just you' beyond the participants of peer support groups. NEST, an organisation supporting people with mental health needs, produces a newsletter following their peer support 'forums' for just this reason. The newsletter details the proceedings of meetings and contact details for anyone who might want to become directly involved. June Harper, the organisation's chief executive, has strong networks with local service providers who publish the newsletter on their websites. It is also distributed in GP surgeries, voluntary organisations and churches.

I can do anything

Realising that a right to independent living is there to be seized can sometimes be about proving to oneself that it is possible as well as coming to an intellectual revelation. Doing one thing well can be as important as realising that anything is possible. For example Ruth was a service user at NEST before taking on a job as an administrative assistant. Within months, she had gained in confidence and 'believed she could do things'. It completely overturned the perception she had when she first realised she had mental health problems that she would not be able to return to the workplace.

The existence of user-led organisations can often be a vital catalyst in the revelation that independent living is a right. They model the very values that they seek to perpetuate – that disabled people are equal citizens. For many organisations whose support and understanding were the things effecting most change in people's day-to-day lives, the bigger picture remained vitally important – People First valued highly their link with Essex People's Parliament, which feeds their views into the local council. It is symbolic of a type of political contribution that non-disabled people are regularly afforded. It communicates their value as individuals as well as their practical concerns.

It is clear that there is a huge variety of different 'entry points' for people to start thinking about independent living. Some of them are aimed explicitly at encouraging the revelation that every person has a right to independent living. Many are not. So independent living has to be the answer to every question, from any person, regardless of personality, impairment or background, even if it is not the question being asked.

The next section looks at the ‘what’. It is not sufficient to believe something better is possible. To be a reality, it needs shape and purpose. This is the next challenge for both service users and providers.

4. The *What* of independent living

Identifying what people want

Thinking about life in its entirety is something that non-disabled people rarely have to do in one go. The fact that decisions about how they choose to get somewhere, or what they might do with their leisure time, can be immediately translated into actions means that interlocking decisions are not so significant – they are flexible and adaptable. The whole picture of a non-disabled person's life is built up over time as a result of relationships that grow, mistakes they can often safely make and unexpected opportunities that arise.

Russell and Miles, part 2

Talking to Miles, Russell realised that what he was particularly fed up with was his lack of privacy. Russell's first instinct was to move back to his old house. Miles explored the option, but discovered that the expense of adaptation made it impossible, so outlined other possibilities. They were quickly able to isolate the option of a newly adapted flat as second best.

This was the key to unlocking the bigger picture of 'what'. The thought of living by himself helped Russell to realise that living alone would allow him to eat what he wanted when he wanted as well as affording him the privacy that he craved and was his right. It also opened up other possibilities like going to the cinema not 'in bulk' from the residential care centre, but with mates, and anonymously, like anyone else.

For people like Russell, for whom most decisions in life have been made on his behalf, suddenly arriving at the right to independent living presents a major challenge, that no individual is really equipped to deal with alone – what do I want to do with my life? At this point, support for independent living is about co-producing an initial blueprint.

Right to living, not just right to life

For many disabled people, living in a residential home, or even within a family whose attitude to support is oppressively ‘caring’, not only is their activity limited, but their identity is suppressed. Articulating the ‘what’ of a life is often about supporting the person to recognise the interests and skills that have always lain dormant. It is about realising there is more to independent living than ‘coping with life’ – ‘living’ is also about interacting with and contributing to family, friends, community and personal development.

Maria, a volunteer at IVS Essex, was clear that the success of Jenny (one of their users) in the Women’s Institute was about building confidence, not skills. ‘She is a very talented woman’ and just needed the support to recognise that what she could already do was of value, and the best starting point for what to do next.

For Carlo, the GAD advocate mentioned earlier, it often means simply pushing people to share the things they like doing. The trigger might be putting suggestions to people – ‘have you ever thought about sky-diving?’ – and picking up on and encouraging any sparks of interest. A blank slate is far harder to populate than building on seeds of ideas. But for that to be meaningful, those have to feel like realistic options. At Scope Options in Birmingham, when a user first comes to the service, this means starting a discussion about the ‘what’ of independent living from the basis of a list of suggestions. It is acknowledged that this is not exhaustive, but it includes things that other service users have undertaken – it provides a jumping-off point that has already been proved to be possible.

For care home residents moving into the community it can be crucial for peer supporters to go with them on visits to different parts of the country. For people who have only ever lived in residential care it is often impossible for them to know where they want to live.

Peer support

Peer supporters help to liberate individuals to articulate their own interests and concerns. For a peer supporter living in a different community, or just with a different worldview, this might mean setting aside their orientation on the world. As Miles told us, you might not like your person, or their choices, but that is part of the job. On the other hand, the peer supporter can help the person reconcile their individual dreams with the realities of the world in which they live. Russell's vision of independent living was to move back into his terraced house. Miles's responsibility was to explore this option but also to lay out other ways in which Russell might realise his independence given the difficulties of adapting the property.

In some cases, it is essential for a disabled person to do this. Miles believed that in his role as a peer supporter dealing largely, if not exclusively, with people moving into independent living from a residential home, his own experience was integral to success. For a life-changing decision, like the move to independent living, it is not enough for a peer supporter and the person being supported to discuss possibilities logically. What Miles does is make them demonstrably possible – he and others like him are the embodiment of their success.

At IVS, on the other hand, where the focus is on supporting and encouraging people's community participation, that kind of demonstrability is not so important for those who self-refer. Disabled volunteers act as positive role models for those who need their expectations raised. IVS also uses video and photographic images to deal with the issue. However, people self-referring to IVS tend to have participation as an existing aim. Finding the right manifestation for that is more about information and finding the confidence to do it. It is primarily about practical and moral support. It is not such a step-change in self-perception and the stakes are not so high; demonstrating that options are realistic is not always necessary – that belief already exists to a large extent.

The changing person

What every person wants from their life changes over time. Support for recognising the 'what' of independent living has to be similarly dynamic. Kate spent the first 41 years of her life living with her parents. On their death she moved to Colchester to live with her brother. She did not know the area but knew that she wanted to be independent and her aim was to live by herself in a flat. Kate worked with a volunteer at IVS to achieve this initial goal. As she did so, her self-esteem, confidence, friendship networks and understanding of the social model all grew. Her goals grew at the same rate; she has learnt to cook, is training as a disability equality trainer, studying for a qualification in sign language, was voted in as treasurer of the social club at the sheltered accommodation she lives in and has flown to Australia by herself.

As Jenny, another user at IVS, said, 'I used to have a diary with a week per page, now I've got one with two pages per week . . . I'm thinking of getting one with a page for a day now!' So a truly personalised system will be dynamic and respond to an individual's needs as they change and develop over time. This helps to explain what co-production can mean at its most effective. Usually, we think about co-production as working together to understand and articulate the service user's needs and to tailor a programme both to their interests and their aptitude. What this reveals is that it can also be highly generative, helping the person to develop and grow new interests at the same time as catering to those that already exist.

Finally, 'self-evaluation' recognises that definitions of success are as personal as the goals a person aims for and the ways they achieve them. Sometimes, this may be about acknowledging that exploring options and choosing to stick with the status quo is a successful outcome. As Kate said, 'sometimes independence is about feeling you can just say no.' Equally, it acknowledges that only the individual knows when they have the confidence to go it alone.

The next chapter takes the crucial step from ‘what’ to ‘how’ – identifying and obtaining the resources that make independent living a reality.

5. The *How* of independent living

Making it happen

Accessing independent living requires a wide range of tools and skills. This is true for everyone, whether or not they have an impairment. We all need to be able to budget our expenditure, to cook balanced meals and complete our tax returns – or to access the support to do so whether that is in the shape of a financial adviser or a personal assistant. In the next chapter, we explore the impact of government policy in areas from housing and transport, to education, on the 'twelve pillars' that disabled people automatically have access to. This chapter looks at the ways in which user-led organisations provide the 'emancipatory services' that support disabled people to navigate and sometimes overcome mainstream policies to gain access to those 'hard' services that government often fails to provide. This chapter cannot be a comprehensive blueprint of the ways in which user-led organisations support people to access independent living, but it can act as a showcase for the ways in which it is already working.

Information, advice and guidance

Access to information is a large and necessary component of how to make things happen for independent living. People need information about what resources are available, where they are and how they can be used. As Nick Danagher, CEO of NCIL, says, 'Information is the power that disabled people need.' And as Julie Charles of Equalities says, making information accessible to all involves 'more than interpreting a few written documents into community languages!’ It has to be flexible enough to respond to the ‘what’ of every member of the community.

If a request is clearly defined, it can be enough to deploy knowledge of an area and its systems to provide the person with the relevant information, for example providing an overview of accessible transport in the area. For some big, multi-impairment organisations, such as Greenwich Association of Disabled People (GAD), Glasgow Centre for Inclusive Living (GCIL) and Equalities, this means answering most requests directly. For other, smaller, impairment-specific organisations, this can simply mean pointing people in the right direction.

Information is rarely pure ‘fact’. It is intertwined with advisers’ personal experience of the system and their methods for navigating it. Although information is at the heart of the empowerment process of independent living, guidance on how to mobilise the information and use it effectively is an essential part of realising it fully. This is one of the reasons why it is so important that organisations are user-led. Advice and guidance has to be both well informed and credible.

Stevie Peel, from People First in Essex, stressed the importance of being able to recommend resources based on her own experience. She feels confident recommending Springboard, a housing association that she herself was referred to by People First, and which supports her and others with learning difficulties to live independently. They perform a variety of services from filling in forms to helping users secure a grant to decorate their flat.

But this relies on a person coming to the organisation in the first place. Answers have to be available from a variety of starting points which will depend on a person’s identity and characteristics.

Russell and Miles, part 3

Having discussed and agreed the fact that Russell’s best first step would be to try and find a flat in a supported living arrangement, it was up to Miles to use his expertise and networks to make it happen. His connections to the local authority and other information sources meant that he knew instantly when supported housing became available and was able to suggest that Russell put his name on the list. He is due to move out of the home in a few months' time.

As Miles said, being an effective peer supporter in this case was listening closely to Russell to be clear about what he wanted and 'having it all (information about local systems) in your head'.

Russell's story illustrates clearly how the 'why', 'what' and 'how' fit together. It also illustrates how keeping his personal aims, characteristics and background at the heart of the change process were absolutely central to its success.

People will often come to an organisation supporting independent living part way through the process so every step is not always necessary. But it is necessary for it to be a possibility in every locality.

People First found that women were initially underrepresented at Problem Places. It turned out that they found the busy environment particularly intimidating and felt shy in a large group, so were unable to voice their problems let alone access the information to tackle them. They have now set up one-to-one or small group conversations to address this. This has included coordinating with the local residential home to make appointments with residents individually. Stevie has found that they find it easier to 'have their say' this way.

Similarly, GCIL hopes to employ a member of the BME community as an information adviser, to do outreach work with sections of the community who they found were not coming forward for information and advice.

Getting down to the details

Personalisation of information, advice and guidance goes deeper than this. Many advisers that we spoke to talked of the necessity of building up a relationship with a person over time. That way, when the first major barrier has been overcome, an individual can approach the adviser with other more day-to-day issues that might arise. This liberates the individual to articulate and identify all their own real needs. It is not just about catering to those that are obvious 'on the surface'. As Janet Green, welfare officer at GAD, put it, 'it's about seeing people through to the end.'

Inclusive Living Solutions at GCIL recognises that hurdles to independent living occur all the time, not just at obvious transition points like moving onto a direct payment where an individual is likely to seek information and advice. Sometimes these can seem trivial but by building up a trusting relationship service users are able to approach their adviser at any time, on any issue. This can be particularly important with sensitive issues like personal relationships that are integral to independent living but which people are understandably uncomfortable talking about with a stranger.

Maureen McPeak, an inclusive living adviser at GCIL, related the instance of an older man who had spent much of his life in residential care and was re-housed in sheltered accommodation by the social services when the care home closed. The accommodation was within an isolated community. He spent all his time in a work centre and had contact only with disabled people. His liberty and activity were just as restricted as in the residential home and he knew he wanted – and had the right to – more.

The independent living adviser helped him to access a direct payment and facilitated the transition from a manual to an electric wheelchair. This person has learning difficulties and cannot read or write but nonetheless manages three members of staff. Among other things, he and his adviser co-designed a system of different coloured chequebooks that allow him to keep his personal business separate from his direct payment.

Over time, he and his adviser have built up a strong and trusting relationship. This meant that he felt comfortable talking to her about a specific health issue that he had not been able to broach for the past 50 years. It was as important to realising his vision for independent living as accessing a direct payment, but it took time for him to be able to broach the issue. His adviser was able to work with him in the same way as she did in resolving the cheque book dilemma and they were quickly able to find a solution.

Training and peer support

Many disabled people have come from the tradition of dependence that is the inevitable and disempowering consequence of a disablist society. This dependency may have been manifest in a residential home or within a family where decision-making was consistently exercised on their behalf – believing it to be part of the 'caring' responsibility. Many disabled people have also had a poor education either in a segregated institution with low expectations of pupil ability, or in mainstream education with little or no additional support.

So disabled people have a double challenge. They have to access and harness a wide range of support, from personal assistants to adapted vehicles. This requires learning a whole set of skills, including recruitment and management capability, which would require training regardless of whether one was disabled or not. But before they can do so many disabled people have to pick up life skills – from doing the washing up to basic literacy and numeracy – from scratch, or learn how to take responsibility for organising the completion of such tasks.

In some cases, this can be relatively straightforward to identify and deliver. In the short term, it can be personalised enough to identify a person as part of a group who need a certain set of skills to access independent living. The most obvious examples of this include training in recruiting a PA, or dealing with the financial management of direct payments. This is relatively simple as people's start and end points are often similar; few people have extensive recruitment and management skills and, in the short term at least, most have the same aim – effectively and competently to recruit and manage their PA(s) and direct payment monitoring procedures.

At GCIL, follow-up work from direct payment management training includes the offer to join a peer 'employer support group' where PA employers can resolve the day-to-day issues that basic training does not cover. Alan, a service user, was clear that the group was very useful as ‘people can speak about their experiences and learn from each other’. Participants feel confident both in sharing problems and in the advice they receive. So further training can initially be targeted at a group to ‘transmit’ relevant skills and information if personalised follow-up is available.

Work-based training can also be an important function of CILs and other user-led organisations themselves, alongside formal work placements in other companies. Many disabled people feel confident in user-led organisations that there is an expectation of ability to work, but also an understanding of what reasonable adjustments really are. Where self-esteem as well as practical work skills are low, as a result of a lifetime of under-expectation and discrimination, work in user-led organisations is often an important stepping-stone to employment elsewhere.

Where organisations are responsive to user need, informal training opportunities often arise to equip people to overcome particular disabling barriers. This is a good example of the ‘self-organising’ personalisation mentioned earlier.

Service users at IVS Essex identified a need for practice in ordering in a café. Users and volunteers now run a weekly coffee morning for all their peers. It gives them the opportunity to socialise in a ‘safe’ environment. A group of users and volunteers in one area have also now set up a lunch time meeting in a local café to extend the idea.

Often it is personal, moral support that helps people to overcome barriers. IVS supports disabled people to identify the ways in which they are interested in participating and helps them to access the tools to do so. Those ‘tools’ are often psychological as well as practical; for Jenny, having the confidence to pick up the phone was just as important as finding the right telephone number. ‘It was helpful to have her [Maria, her peer supporter] there just while I dialled the number . . . I wouldn’t have done it otherwise.’ She continued, ‘I just needed some egging on . . . once I’d done it once, it was easier to do it again.’ Outcomes are co-produced. As Jenny said, ‘they’re just there to support, you’re doing it.’

It is not enough for just anyone to provide this sort of support to someone whose confidence has been constantly suppressed by a disablist society throughout their life. 'Getting the right person for the job is key,' says Becky Reid, who runs IVS Essex. Matching personalities is crucial to getting this right. Once a client is on the scheme, a volunteer is 'matched' to the disabled person by one of two area co-ordinators who have an overview of users' and volunteers' skills and characteristics. The service user always has the final say over whether they are happy working with a particular volunteer.

Training the system

Training doesn't only have a role in equipping disabled people to overcome the barriers to independent living. It has a role in bringing them down. Accessing independent living requires non-disabled people to have a certain set of skills and understanding. Having work-based skills is irrelevant if employers are unable to comprehend their applicability or to navigate Access to Work and make the necessary workplace adjustments. As a result, many CILs and other user-led organisations see training for local organisations in combating disablism as a vital part of the support they offer for independent living. Disability Equality Training and the understanding of the social model are always at the core of this.

For non-disabled people, the social model is key in helping to understand the prejudice against disabled people that is inherent in society – not only within individual attitudes and behaviour of its citizens, but within its organisational structures and behaviours. From this comes an appreciation of the crucial role that every member of the community has to play in ensuring that every person's right to independent living and participation is upheld.

GAD works with a number of organisations to highlight and overcome some of the barriers and prejudice within society: the local police force, local colleges, neighbourhood services and the local council among others. The exact content of their training depends on the organisation. Techniques used to embed attitudinal change include agreeing an action plan for both the physical environment and organisational procedure to make it more inclusive.

The role of advocacy

Scope defines advocacy as: 'taking action to support people to say what they want or communicate their views, secure their human rights, represent their interests and obtain services they need'.[27] Ideally, every person would be able to self-advocate – to speak up for themselves and represent their own interests. But someone with a very profound learning difficulty may not be in a situation to self-advocate in a care review. The stress of the situation and the complexity of the issues the person is facing (or a combination of all three) might also make effective self-advocacy impossible. This is not just true for disabled people. As Wendy Lewington, Scope's head of advocacy pointed out, most people going through divorce will turn to someone to advocate for them, because of the stress of the situation.

As a result of a lifetime of low expectation and poor education and training, many disabled people do not feel confident self-advocating. So an intermediary sometimes has a role to play to redress the power imbalance between a disabled person and the statutory services they interact with. Advocates are people with particular expertise in a local area as well as relationships built up over time with authorities.

Independent Living Advocacy (ILA) is a professional advocacy service based in Essex, which focuses on particular issues on a casework basis. It grew out of the Essex Coalition for Disabled People when they realised its necessity. Last year, a middle-aged woman who was living in a sheltered housing scheme contacted ILA for support. She had no obvious physical impairment, but experienced epilepsy and severe fatigue following brain surgery. Her washing facilities and those of the other tenants were limited to a low bath only 30cm off the ground. It was utterly unsuitable for her. She applied through her occupational therapist to get an adaptation and it was declared that a walk-in shower was needed as a matter of urgency. The bath was unsafe and was restricting her in other ways; she had done voluntary work in the local hospital, but no longer felt clean enough to go out in public as she could only have strip washes. There was also the indignity of having to discuss in detail something as private as bathing with people she didn't know.

An 18-month battle with the local council had ensued. The council's view was that if you were living in sheltered accommodation then you were 'independent'. By their definition of this, if there was a need that could not be met within the accommodation then the tenant should move into residential care. This was clearly unnecessary and the woman resisted. If she had appropriate equipment she could carry on living by herself.

Martin, an ILA advocate, was called in to help represent her interests. His knowledge and expertise allowed him to find a legal loop-hole in the council's case; they would have been prepared to make an exception only in the case of terminal care. The stringency of this rule 'fettered their discretion', a legal term which means the local authority is legally obliged to take individual circumstances into consideration. These were grounds for taking the council to court but Martin laid out another option for the woman, as a protracted and expensive legal battle would be 'a failure for both sides'. Instead, he suggested that the chief executive visited her to see the bath for himself. This was a turning point in the process; the chief executive was deeply shocked by the reality of the bath and took personal responsibility for its removal. Following the adaptation, the woman continued to live by herself as she wanted, and went back to volunteering at the local hospital.

In this case, Martin was acting on the woman's behalf but the outcome remained co-produced. She directed the advocate throughout, even though she did not carry out the detail of each stage.

Changing the balance

The advocates that we spoke to were very clear that, while the individual always defines the goal, the level of participation varies significantly. Each person defines the ends, and sanctions the means, but their involvement might then take many different forms. An advocate's involvement may simply be about 'levelling the playing field' as Martin put it. 'It's just about having someone visibly and tangibly on their side', sitting next to them in a hospital review for example, and changing the balance of power. The presence of someone else means that they feel confident enough to represent themselves.

For Anna, the involvement of an advocate before her hearing was sufficient to make a difference. In 1991 she was in a mental health acute ward. The consultant recommended an unwanted treatment and refused to listen when she protested. Rather than talking through the alternatives, Anna was made to feel guilty and was told she was just wasting a bed. At this point, she went to the Advocacy Service in the hospital to see if they could help. They talked through her options and helped her to feel that refusing the treatment was a legitimate choice.

The doctor refused to let the advocate into the review but Anna felt stronger and stuck to her decision – she felt empowered to self-advocate. The advocate played a key role – although they were unable to intervene directly.

Carlo, the advocate at GAD mentioned earlier, was clear that an advocate needs to have a questioning and open mind; they do not need to know all the answers, they just need to ask the right questions. Forming the right relationship from the outset is also vital: 'The key . . . is the ability to separate the personal from the professional' (Martin Hampshire, ILA, Essex) while 'including people as partners' from the outset. Most importantly, absolute loyalty to the client is imperative. 'It must be clear that the advocate is only working for the client, and not the client's family or doctor' (June Harper, NEST). Once the person has determined a path, the advocate must support their choice.

Once again though, this process works only if an individual is able to access the service in the first place. One of the main difficulties faced by BME communities is that they are less likely to use formal advocates, because there are so few organisations providing a culturally sensitive and holistic advocacy service. So disabled people from BME communities are often more likely to receive support from well-meaning but often poorly informed friends or relatives. Equalities currently runs a very active campaign to raise awareness about the organisation and its services by visiting mosques, temples and leafleting in local housing estates in an effort to tackle this.

Why, What and How

So user-led organisations like these are expert at empowering disabled people to identify their right to living and in supporting them to exercise it. They embody a successful approach to holistic, supported self-assessment by combining meaningful engagement with service users, with long-standing experience of the support that 'works'. But as it stands they are compensating for a system which largely works by principles that are antithetical to independent living. They are key players in the fight for equality rather than supporting actors in a system which assumes that equal citizenship for disabled people should be the norm.

The next chapter looks at what a whole system of support might look like from top to bottom, if it were oriented by the philosophy of independent living. In this system, user-led organisations like the ones described here would still play a crucial role – in supporting the self-assessment that should be at its heart – but they would not spend their time making up for its other faulty components.

6. System failure

The perils of segmentation

Throughout the twentieth century, the basic structure of government was one of national departments built around *functions* and then lower levels designed around *geographical* boundaries. Although there have been many attempts at reform and plenty of new types of structures at every level throughout recent history, this basic principle has held true. But as Perri 6 writes, 'The result has been a culture of thinking and working inside departmental cages and a defensiveness about functional turf.'[28]

From the top of government, this segmentation of activity by functional division can look like a perfectly logical system, but, from the point of view of an individual person trying to live the life they want to live, it can often look hostile and even absurd. For the disabled people interviewed for this report, the problems of segmentation were manifested in a huge variety of ways.

Take the current definition of 'nursing care', which is based on the medical model and is provided free at the point of use by the state. It is divided from community or social care which remains chargeable. In a system which sees 'survival' and not 'living' requirements as the responsibility of the state, people could, as Nick Danagher suggested, be faced with the remarkable and ridiculous situation in which a personal assistant is funded to put the cereal in someone's mouth – but not to pour it into the bowl.

Segmentation is similarly borne out in the way user-led organisations are funded – for discrete areas, rather than the whole person. At GCIL, independent funding for housing work meant that, in one case, advisers were able to support a girl to find appropriate accommodation and arranged a package to fund it through social services. But they did not have the capacity to offer her ongoing support. This meant that when her father visited his daughter and found her sitting in darkness – the service provider used by social services was not insured to change light bulbs – he had to return to another arm of the organisation for information in obtaining appropriate community support.

The problems of segmentation are particularly evident in policies supporting disabled people back into the workplace. In our interviews we found a constant tension between policies encouraging people back to work, and those making it too risky or difficult to do so. Programmes like Pathways to Work and the New Deal for Disabled People are constructed with the aim of supporting disabled people, including those who are currently on Incapacity Benefit, back to work. But holding Incapacity Benefit relies on demonstrating an absolute inability to work, so as a recent ippr report has pointed out, 'this paradox asks Incapacity Benefit claimants to simultaneously demonstrate their incapacity to work and discuss their capacity to work with a view to taking steps towards moving into work.'[29] This is particularly risky, as many participants in our research pointed out, because it is so difficult to get back onto benefits quickly if a work placement is not suitable. As Carlo at GAD said, 'you can go months between moving out of the workplace, and getting your funding back.'

This is compounded by the fact that the necessary adjustments to the workplace that are likely to support disabled people to be successful in a new job are so difficult to come by. Access to Work is the government-funded programme that is supposed to provide resources for 'reasonable adjustments' to the workplace. But two of our interviewees had to wait for more than a year to receive the equipment they required and were able to stay in their new positions only because they were employed by user-led organisations that understood their predicament. So disabled people are encouraged to work on one hand, and excluded from doing so on the other.

Even where Access to Work does provide adequate funding for workplace adjustments and equipment, its assessment and provision are unconnected to the support disabled people require in other areas of their life – areas which are inextricably linked to disabled people's ability to hold down a job. John told us that according to the terms of funding for his work-based wheelchair, he was insured to use it in the building, but not outside it. Despite the fact that without it he had inadequate mobility funding to get him to work in the first place.

Moreover, very few actors within this segmented system work to a philosophy of independent living. This has fundamental and destructive implications. The most obvious exemplar of this is in the current provision of community care. As Mark Priestley has said, 'it contributes to the view of disabled people as dependent and different, thus reinforcing their social exclusion and marginalisation.'[30] It is based on a welfarist definition of need and one that essentially detaches those needs from the person themselves. As Linda Leone at GAD told us, 'this means that while a disabled person might be assessed for and provided with personal support to get out of bed in the morning, when this happens will be determined entirely by the service itself – when it fits into the schedule.' Similarly, support for going to the toilet will be allocated a certain number of times a day, but the timings will again be service-determined. So the current system has embedded a sense and tradition in professionals that disabled people are 'done to' – the very antithesis of the co-production exemplified in the successful work of user-led organisations. Clearly, this is not just undignified, but inhumane.

The Scottish system (by Jim Elder-Woodward)

Direct payments were granted as a mandatory provision by the Scottish Parliament in 2002 within the Community Care and Health Act.

Unlike England and Wales, though, in Scotland the legislation covered non-disabled community care groups, including older people, refugees, recovering addicts, people who are homeless, and those fleeing domestic violence. In terms of the social model and the principles of independent living, this universal legislation fitted neatly and was quite acceptable.

However, by and large the implementation of direct payments in Scotland has been much slower and more difficult to achieve than appears to be the case south of the border.[31] The reasons for this are open to a variety of interpretations, which are discussed below.

The schism between process and purpose

Direct payments constitute a process, along with accessible transport, and a myriad of other processes, which enable people to achieve the purpose of independent living: full and equal citizenship.

Unfortunately, there is now a danger that concentration on the bureaucratisation of the *process* of direct payments by professionals and administrators may overlook this *purpose* of independent living.

The effectiveness of the Scottish legislation for example is being measured by the growth in the number of direct payment recipients, not by quality of life outcomes of those who receive them.

No additional funding for direct payments

Direct payments were seen by the legislature as a redirection of existing resources; therefore no additional funding was necessary. This is also the case in the English green paper on the future of adult care, which announced individualised budgets without additional funding. The danger is that local authorities will take a similar stance in saying the lack of additional funding will deny them the opportunity to implement the legislation. This is the case for direct payments both north and south of the border.

The dominance of local authorities' duty of care

In Scotland direct payments legislation also came at a time of a raft of new social work legislation, as well as a change in priority funding at the Scottish Executive from community care to acute health care. In response, a trench mentality developed within local authorities to protect traditional services at the expense of developing new initiatives. This was reinforced by the fear of local authority workers, as expressed by their unions, who see direct payments as creating cheap labour in the private sector, with a diminution of terms and conditions, thereby creating a threat to public sector jobs.

These barriers to implementation have maintained the status quo of 'welfarism', rather than promoting the liberating outcomes of the independent living paradigm.

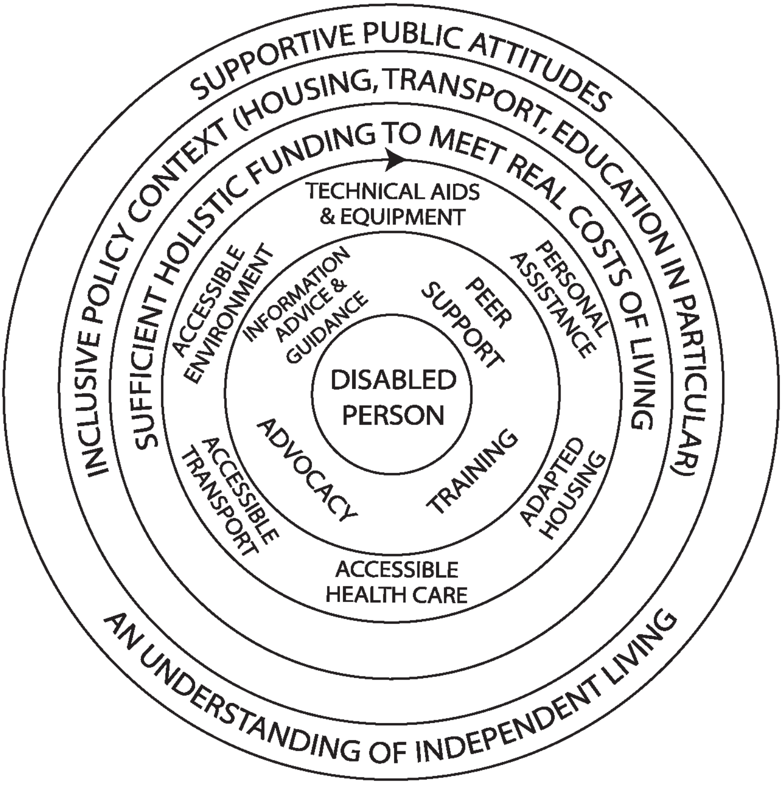
Putting the person at the centre

These false divides and segmentation of policy areas as well as the non-existent priority of independent living are what make user-led organisations such important pioneers in the current system. But what would the whole system look like if it were oriented by independent living, and user-led organisations were not soldiers in the battle for independent living, but co-workers in supporting disabled people to exercise it every day? Tony Manwaring has suggested that such a system could be characterised by a series of concentric circles with disabled people firmly at its centre.

He argues that:

1. Disabled people have to be empowered to:
    - ○ realise they have a right to independent living
    - ○ articulate what they want from their life
    - ○ identify what support they require to make this happen
    - ○ obtain that support
    - ○ manage and modify that support on an ongoing basis.

Figure 1 A model illustrating a system that aligns different levels of support around the disabled person



2. This requires suitably high quality and diverse provision of support including PAs, technical equipment etc, from a range of providers including private companies, local government and other agencies.
3. Disabled people require suitable funding to purchase this support.

4. A broader, supportive policy structure has to be in place at a national level, particularly in education, housing and transport.
5. Society more widely is rid of the disablist attitudes that are themselves a barrier to independent living.

In figure 1, the outer two circles of policies and public attitudes provide the framework within which the individual organises the support they need while social and political action is taken to challenge those attitudes. They frame all the decisions that the individual makes about the support they require. The three inner rings of 'emancipatory services', provision and funding for independent living move around the person to fit their personality, impairment, aims and requirements. They are the elements over which the disabled person has choice and control.

The funding of the individual and the payments they receive should provide the means to align each of the rings so that a person can achieve their full potential. At the moment, as described earlier, the way that Incapacity Benefit and Access to Work are structured reinforces the lack of alignment of these key elements so that the individual is trapped in dependency. Correcting it would enable disabled people to participate as empowered consumers of services.

One of the vital things about the diagram in figure 1, as Andy Rickell of Scope has pointed out, is that it meaningfully separates the empowerment, provision and funding components of the system. This type of separation is very different from the segmentation described in the current system. This separation avoids the conflict of interest which means that, at present, many parts of the system are working 'against' each other. The most common example of this is the fact that social services are often simultaneously assessors, providers and funders of support packages. As a result even if assessors are independently encouraged to work to a model of independent living, the provider would naturally be working against its assessor 'partner' to approach provision on the basis of lowest cost, rather than maximum effectiveness for independent living. Separating these three elements of the system allows them to work in true partnership – to the same end.

Underpinning this system would be equal and meaningful political rights for disabled people. The central aim of a system of independent living is full and equal citizenship for all. But it is also a key part of the means to attaining it. As Nelson Mandela's quote illustrated in the first chapter, reform of any or all parts of a system is meaningless unless the people whose lives it affects and shapes can feed into its design on an ongoing basis – as citizens, from the inside, rather than as complainants or lobbyists external to it.

Investing in independent living

Recent policy debate about Incapacity Benefit has focused on the existing cost to taxpayers and how this cost can be reduced by taking people off benefits and getting them into work. This focus on the numbers is understandable:

- The cost to the Treasury in 2002/03 was £6.8 billion.
- The employment rate of disabled people is roughly half that of the non-disabled population.
- Much of the British press works on an assumption that anybody on benefit (and particularly Incapacity Benefit) is 'scrounging' from the state. It does not recognise the argument of this report that independent living is a right for all.

So the question any policy-maker will be asking about the proposals in this report is what would moving to a new system cost?

The underlying assumption is that independent living costs more but existing evidence points in the opposite direction. Research on ageing and disability for example suggests that people who have been living independently for longer periods in their youth and middle age may be less inclined to seek assistance from directly provided social services when they are older.[32] Other potential savings may come from a reduction in demand for acute and/or long-term health care on the basis that full independence may well be associated with higher levels of quality of life and the associated benefits in terms of general well-being. Where living independently also contributes to increased economic activity then obviously people will also be in a better position to build up their own financial resources for older age. This is in fact becoming increasingly important given that the proportion of pensioners' incomes coming from savings and occupational pensions has been rising markedly over the last two decades.[33]

This also fits clearly with government policy on independence for people as they grow older, which saw Stephen Ladyman announce a £60 million increase in funding for councils to develop innovative ways to help older people avoid emergency hospital visits and to live independently longer. The Department of Health sees clear benefits in doing so: 'The Government wants older people to live as independently as possible and have great quality of life. That means keeping older people fit and healthy and out of hospital.'[34]

Similarly, preliminary evidence of projects supporting the self-management of health care for people of all ages has highlighted a comparable trend of decreased dependence and therefore spending, on statutory services:

> *For example, Arthritis Care is organising and delivering arthritis self-management programmes in a variety of settings. This programme of work is being evaluated and is indicating positive results in terms of reduced pain, improved psychological well-being and a reduction in visits to general practitioners (GPs).*[35]

The Disability Rights Commission (DRC) also cites specific examples such as the Audit Commission's estimate that £130 million per year is spent as a result of falls by people with visual impairments that could be avoided through supplying suitable aids or adaptations.

Evidence from pilots supporting independent living, such as In

Control, also suggests that user involvement in assessment for and procurement of support can decrease the cost to the state. 'We are finding they spend lower, and the odds are that they spend it more efficiently,' says chief executive of Wigan Council, Steve Jones.[36]

Although short- to medium-term costs may go up, the main gains of independent living will be on the benefits side of the equation. As Gerry Zarb has argued, we should 'shift the existing focus on costs towards seeing expenditure on independent living options as a form of social and economic investment'.[37] Government needs to shift the begrudging language and mentality of benefits into investment in the ability of disabled people to live independent lives. Questions should be not so much about spending on benefits and the arrangement of the systems of support as about how we maximise social and economic return on investment.

The DRC is currently working with SCIE and NCIL on research to examine and develop evidence relating to the cost–benefit of independent living for disabled people on a national scale. This work will be based on expert economic analysis and will include an illustrative analysis of the potential cost–benefit of investing in independent living, including estimates of the costs and benefits of alternatives to institutional care. It aims to provide a definitive answer to the cost of system change.

Making the change from the current fragmented system to one that can support independent living can be encapsulated, as Nick Danagher at NCIL told us, by a change in the duty of all players in it from a 'duty of care' to a 'duty of equality'. Making that move in the current timescale for reform – by 2010, for the end of the present government's five-year plan – is the challenge for policy-makers. The final chapter looks at the opportunities for change that should make this possible.

7. System success

The challenge of transformation

Moving from a system of segmentation to one compatible with independent living is a major challenge. But it only seems unrealistic or insurmountable given current approaches to policy-making. In this view, each element of the system is seen as separate, both vertically (through the many different layers of the system) and laterally (across departments). So in this model each component needs its own blueprint for reform.

System transformation is not just about mechanical change to the current infrastructure of support. It is about a radical realignment of the position of disabled people in society and the framework within which that support is constructed. By taking a systems approach to change, in which government recognises that every part of the system is interlocking and interdependent, reform in one area becomes a motor for and driver of change in all the others. It takes reform to another level, perpetuating and sustaining change for disabled people in a more profound way for the future.

More specifically, we would argue that now is the time to take advantage of this approach. We face a moment of opportunity created by the consultation on reform of Incapacity Benefit and the need to implement both the Strategy Unit report and the green paper on adult social care. The profile of these initiatives and debates provides a unique platform for changing the relationship between assessment, funding, choice and procurement of support in the UK without a massive increase in cost to the state. The energy created by the synergy of change in these interdependent components would accelerate and embed the change that disabled people want to and should see.

Systems thinking for policy-makers

In *System Failure*,[38] Jake Chapman writes about the possible ingredients for a national policy statement that would be consistent with a systems thinking approach. Some of the features of the policy would be:

- a clearly established direction and philosophy for change
- a clear remit for support organisations, which explicitly promotes and allows innovation
- ‘floor standards’ that cannot be crossed in implementation.

At the heart of these is the need for ‘the top’ or national policy-makers to outline a clear direction for policy that permeates to all levels and orients the actions of every player in the system. This replaces the need for the intricate structural design of the public service ‘machine’ of the past. With a combination of clear direction and operational flexibility, local organisations are free to innovate and adapt their practices and structures to achieve a mandated goal.

But that direction cannot be picked arbitrarily, or simply imposed from above according to a set of government priorities. It has to reflect and respond to the demands of system users. National policy-makers must arrive at a direction for policy in the same way that local organisations work to provide quality services and enshrine users’ roles and power as citizens – it must be co-produced.

For disabled people, this direction has existed since those 12 students at Berkeley recognised and began to realise their right to lead a self-determined life. A right to independent living must orient the system of support for disabled people. To some extent the outcome and process of putting together the recent Strategy Unit report and green paper on adult social care reflect and respect this. Both involved extensive consultation of disabled service users. Both reports also have at their heart the principle that disabled people should have choice and control over their own lives, but this direction has by no means permeated or been mobilised throughout the system at all levels. Organisations at a local level are still effectively co-designing resources with disabled people to support independent living despite the system, working to overcome it, rather than being endorsed by it.

So currently there is a major gap between the top and the bottom. The independent living philosophy 'message' seems to exist to some degree at senior and ministerial levels and the philosophy is obviously embedded in the user-led organisations in which it was born. But the mechanisms and layers that sit between the two mean that many CILs (the bottom), for example, are often in conflict with local authorities (the middle). This takes the analysis of the green paper on adult social care one step further; *Independence, Well-being and Choice* highlights the problem of segmented services not working together.[39] Our research highlighted services that could not work together because they were not working to the same end.

On one hand this is simply because the message about independent living is a young and often poorly understood one; both the Strategy Unit report and the green paper only came out in early 2005. It takes time for a deep understanding to filter from the bottom, via the top, to all other parts of the system. It is also because the gap exists laterally at the top – as the previous chapter showed, the segmented nature of disability policy means that various strands of support sit in a bewildering array of departments including the Department for Work and Pensions and the departments of Health and Education and Skills. The message is inconsistent and patchily understood across government departments as well as throughout the system more widely.

So if independent living is the message, then independent living has to be the message across departments and throughout the system with appropriate measures taken to challenge institutional disablism and bring down the barriers to independent living.

Action 1: Understanding of independent living should be improved throughout the system – from ministers and senior civil servants through to front-line staff. This might be achieved through a combination of user-led training, conferences and publications.

The debate around the reform of Incapacity Benefit potentially provides the ideal platform for establishing that direction and mandate for change throughout the system. Many of the principles behind it are sound – the assumption that those who want to work should receive suitable support to do so along with a more nuanced understanding of capacity that does not simply class people as 'capable' or not.[40] The four key pillars of reform are described as fairness, security, inclusion and 'results for all'.[41] But what these really describe are boundaries that should not be crossed in reform that aims for incremental change within the current system. These are important aims in themselves – primarily supporting the 'missing million'[42] disabled people on Incapacity Benefit who want to work, to re-enter the labour market. But if reform were to start with the aims of disabled people themselves – independent living and the full and equal citizenship that is its natural partner – then describing those boundaries would become unnecessary: they are implicit in the philosophy itself, and it could achieve much more.

First steps for reform

Reform of Incapacity Benefit should start from exactly the same place as user-led organisations begin – with the whole person – and with the same aim – self-actualisation. This would mean seeing work as part of life, integrated with the choices we make about who we live with and where we live and what we choose to do with our leisure time for example. 'It's not so much that we need to *balance* work and life; more, we need to find ways of *integrating* them.'[43]

Assessment for Incapacity Benefit would sit within a holistic self-assessment supported by local user-led organisations who are expert at supporting the Why, What and How of independent living. It would not begin with the GP-centred assessment that currently provides the gateway to funding and which remains at the heart of government plans for reform.[44] The current plan is that, 'initially people will be put on a holding benefit paid at JSA rates, accessing the new reformed benefits only once they have been through a proper medical assessment.'

This assessment would take a nuanced approach to the nature of work as many critiques of Incapacity Benefit have suggested.[45] Instead of seeing full-time work in an office environment as the barometer by which 'capacity' is judged, it would, as we argued in *Disablism*,[46] 'value and accord status to contributions of all kinds'. This is something that the independent living movement has been arguing for many years.[47]

Holistic, supported, self-assessment would look at the full range of integrated support needs of the individual in the here and now, at the support disabled people require to fulfil their current aspirations for work and how they want to lead their lives. It would also, like the user-led organisations described earlier, take account of the impact of the institutional disablism that contributes to disabled people's perceptions of what they believe they can do. It would look forward, working towards self-actualisation and putting in place the peer support and training that might be necessary to support disabled people into work.

The current Pathways to Work scheme does this in a limited way, providing regular meetings with employment advisers. It has had some success with disabled people, often with minor impairments, who are not so distanced from the labour market.[48] But this is a uniform approach to a diverse problem. Many disabled people are so distanced from and disillusioned by the discrimination of the workplace that regular interviews are simply not sufficient to penetrate their low self-esteem and self-belief.

Employment solutions

GCIL's employment project, Employment Solutions, illustrates the intensity of support and training that is necessary to build up skills and confidence in many people whose self-belief has been so undermined by a lifetime of being 'done to' or 'cared for'. This is the first Intermediate Labour Market project specifically aimed at disabled people in the UK. The project 'focuses on a temporary contract with a comprehensive "re-engagement package" ranging from the direct work experience through to basic skills and vocational training, personal development and confidence building for all participants'.[49] Seventy-nine per cent of participants leaving the project have moved into employment or further/higher education (compared with the national average of 53 per cent).

Finally, the funding that would flow from this assessment would reflect the real cost of participating in society as a full and equal citizen. As part of this, adjustments and adaptations to the workplace would be fully funded, as well as the equipment required by the individual to make participation possible. It would not assume that disabled people should contribute to the cost of this, just as no employee would expect to be charged for a new keyboard as a result of being diagnosed with repetitive strain injury.

Again, it is important to stress that evidence suggests that this is not only morally right, but that it would be economically advantageous. Over the two years of its existence, the GCIL employment project estimated a net economic benefit to the City of Glasgow of £433,681 for its 15 participants. This comprised a reduction in benefit payments, lost rent revenues and adaptations wastage, as well as positive contributions of income and council tax.[50]

This reflects and fits with the growing focus of employers on managing difference and flexibility in order to reflect and understand the needs of the communities they operate in better and to attract and retain employees in tight labour markets. Being able to employ individuals with a range of conditions and impairments who may want to work part-time or flexibly will increasingly be a priority for major employers.

Power brokering

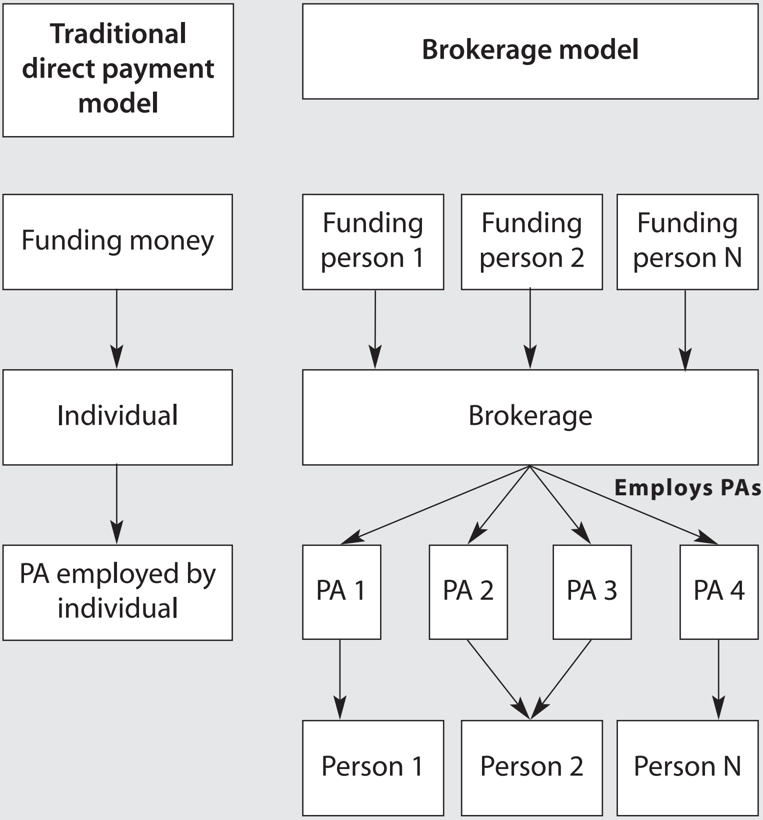
Empowering disabled people to obtain the resources they require to fulfil their self-assessment reveals two vital issues about the transition from one system to another, on both the demand and supply sides.

The first is a question of user power. The earlier diagram of concentric circles (figure 1) puts the empowered individual in direct contact with the market for services that will fulfil their requirements. This reflects and extends the model of direct payments that currently exists. It assumes that the only way to exercise choice and control is to put purchasing power directly in the hands of service users.

But, as Tony Manwaring has pointed out, this is in many ways tantamount to a sort of 'reverse disablism'. It puts more control – and responsibility – in the hands of disabled people than any non-disabled person would ever expect to shoulder. In the case of employing a personal assistant, for example, it includes responsibilities for health and safety, and tax returns on payment. These would be a challenge for anyone. For disabled people who have been denied the opportunity to develop skills and confidence because of a lifetime's experience of disablism, being saddled with this responsibility immediately may ultimately make that choice no better than the support they received as a result of a social worker's assessment. As in other sectors, the role of brokers and intermediaries will be vital.

Andy Rickell has suggested that user-led organisations would be the appropriate brokers in this system – they have the deep understanding of the individual and their needs that would allow them to be legitimate navigators of the market and to obtain resources on their behalf as long as they remained fully accountable to users themselves. As shown in figure 2, they would act as a buffer between the individual and the market. This has already been developed by organisations in some areas. GAD for example has a

Figure 2 Traditional direct payment model compared with brokerage model of funding personal care



PA = Personal assistant

user-run agency for employing personal assistants. This arose from the demand of many local disabled people for a system which kept them in full control of resources, but allowed them to delegate responsibility for the bureaucracy it entailed. Scope Options in

Birmingham is another similar scheme which supports around 30 disabled people, living as individuals or with their partners, in their own homes. Staff coordinate tailored support from local provision, ranging from a few hours up to 90 hours a week so that users have the support that they need to live independently. Currently, the scheme just lacks the user-led management that would make it a fully accountable broker.

Rickell's brokerage model (which draws on a great deal of experience and thinking from around the world) could have a whole range of governance options, including:

- an entirely user-led cooperative of the individuals using personalised budgets
- an organisation led by representative users but in which the individual client is just a customer
- a voluntary organisation offering services to disabled people as customers
- a private organisation offering services to disabled people as customers.

While this model is imperative in the transition from one system to the other, where the most disempowered individuals are at risk of losing out, it may also be an important part of a new system. Independent living does not necessarily mean keeping direct control of every detail of life. Some people may want to relinquish that direct control for more freedom to enjoy other parts of their life. But, as Nick Danagher told us, this is their choice and has to be balanced by the knowledge that many people who have been reluctant to take on the responsibility of a direct payment have ultimately been unwilling to give it up. Martin, the advocate from ILA, Essex, stressed that many direct payment users valued the direct monitoring and reward of an excellent PA that is manifest in paying them a cheque every month. Choice about how much control you exercise is as important and legitimate a choice as how you exercise it.

Shaping the market

The second issue raised by the transition from one system to another highlights the need for another enhanced role for user-led organisations in shaping the market as well as navigating it. In the new system, a liberalised market for provision of resources to support independent living will be necessary. That market would consist of a variety of players, including the local authorities and agencies (like Scope) that have been part of perpetuating a welfarist approach in the past. Disabled people themselves – whether collectively, via a brokering organisation, or as individual consumers – would determine who is successful.

But even if all disabled people were instantly empowered, well-informed and determined consumers, a market for resources, from personal assistance to wheelchairs, would take some time to develop in response to demand. Given the central importance of this to people's lives, these kinds of cost to transition would be unacceptable.

So, there is a role for user-led organisations to work in partnership with providers of all types at a local level to help them better orient their services to the user as well as navigating what is on offer to best suit the person. How this happens is crucial. In *Disablism* we argued that there is a need for 'trading zones' to be created between policy-makers and disabled people to feed user voice into the system meaningfully.

> *Trading zones often exist between cultures and institutions, representing zones whereby people from different backgrounds can come together to participate on an equal footing . . . difference needs to be understood and appropriate support provided, so that everyone can participate equally.*[51]

On the one hand there is a real opportunity and imperative for existing agencies to work in partnership with user-led organisations to provide the capacity and resources to achieve urgent change in the framework required for independent living. On the other there is a huge challenge for those agencies to model equality in practice, which will require significant organisational culture change. They will need to employ many more disabled people in leadership positions and move away from providing services that institutionalise and segregate disabled people.

Further embedding of this should include changing the statutory duty of all bodies involved from their current 'duty of care' to a 'duty of equality'. Without this kind of space for co-production in the new system, putting the user at the centre is not sufficient – they may have clarity about the life they want to live and the resources they require, but provision will remain unsuited to the task.

Action 2: The statutory duty of all bodies involved in the provision of services for disabled people should change from their current 'duty of care' to a 'duty of equality'.

Again, even though this model is initially crucial in transition, it should also accelerate change in the long run. Developing increasingly suitable resources to support independent living, in tandem with the empowerment of disabled people, contributes to the process of self-actualisation as well as fulfilling its outcomes.

This is where the In Control pilots that are currently being run in six local authorities are such a powerful model. First, the advice, guidance and information they provide supports users' holistic self-assessment. Where they take a step beyond many other organisations is in their relationship with other services. In Control represents a partnership of local service provider organisations. Its board is user-led and it is not just a partnership for the sake of the 'seamless' referrals promoted in the green paper. These can and often are achieved with well-connected and well-informed local organisations. It is a partnership where all organisations are working to the same end. By reconstructing the relationships between providers, it changes the nature of what they provide as well as how effectively they provide it.

Embedding change

Setting Incapacity Benefit reform in the context of holistic, supported self-assessment for an individual budget that supports the needs of the whole person highlights the central importance of the role of user-led organisations in a new system. It is their role that will make a specific blueprint for reform of other separate components largely unnecessary. Understanding the interlocking nature of the system means that government can support those who hold a deep understanding of the message to spread it, rather than attempting to do so itself.

Embedding and accelerating change will come if user-led organisations are supported and allowed to flourish and grow. High-profile Incapacity Benefit reform focused on independent living as an aim may establish a direction for change, but an understanding of and commitment to the philosophy alone is not sufficient for user-led independent living partnerships to flourish. Two key elements are required in that gap between top and bottom to empower local organisations to innovate in response to user need as part of the system, not despite it. The first of these is having the space to innovate. The second is being inspired and incentivised to do so.

Creating space for innovation is both passive and active. The passive part is about setting up an environment in which people are comfortable taking risks and experimenting with what works, without risk of losing funding or support. This is about a change in culture – from one of defensiveness and hidden innovation to one of excitement and shared innovation – and in governance – the rules by which people work and how they are accountable. The national message that we started talking about is the necessary first step and mandate for this. But it is not national policy-makers to whom local organisations are accountable each day. This brings us full circle to a question we raised in chapter 1: how do we navigate the point where bottom-up enthusiasm, authenticity and effectiveness meets requirements for top-down control and accountability?

For the top, this is about relinquishing control of minimum standards to the people who have to bear their consequences – service users. In this model, flexibility is not about getting rid of rules altogether. It is about adopting rules that are fit for purpose. If rules reflect and compound the aims of an organisation, reviewing working practice is not additional bureaucracy; it is self-evaluation that should be occurring regularly anyway. This should be achieved by local communities of users – the local organisations described earlier who are the authentic holders of user voice – feeding into a national framework of standards for organisations supporting independent living. This is not just about listening to the opinions of users. It is about developing a continually evolving and fully appropriate framework in real time, by using the knowledge generated from the encounter of supported self-assessment to keep it updated. A transparent arrangement for feeding into and developing such a framework would in itself contribute to innovation, by maintaining pressure on all actors in the system through user expectations.

It also matters who has responsibility for compiling that framework and to whom organisations are accountable – who monitors that ongoing self-evaluation. Many of the characteristics of services and the ways in which they engage users that are included in that 'checklist' would not necessarily be discernible to someone who had not been part of a similar organisation themselves. That national body should therefore also be user-led. This is, of course, important for the integrity and accuracy of the system. It is also crucial for maximising the freedom to innovate – the credentials of ex service users or workers and the language they use help providers to perceive and believe that auditors understand what it is they are trying to do as well as knowing it intellectually.

Action 3: A national, user-led organisation should be appointed to develop the framework for measuring progress towards independent living in collaboration with local organisations.

Finally, this framework would not only be crucial in monitoring the activity of user-led organisations in supporting independent living, it would form the backbone of measuring the success of Incapacity Benefit reform. If Incapacity Benefit reform is founded on its contribution to the aim of independent living, then this is how it should be measured. So establishing a period within which review of its success would be monitored would do two things. First, it would support the work of user-led organisations in independent living partnerships by helping to cut through traditional power relations to support their orientation of local resources to user need. Second, it would maintain public awareness of the issue, compounding change by transforming the public attitudes that frame the system as a whole.

Action 4: Government should commit to an evaluation of Incapacity Benefit reform within a period of three years, according to the user-developed benchmark established in action 3.

A blossoming system – creating exponential change

The active part of support for innovation is about making the most of the resources in the system. In a free, competitive market with perfect information, that means placing them squarely with the consumer. As we have already established, in this case that is not enough. Disabled people require the sufficient and flexible resources that would flow from holistic, supported, self-assessment to stimulate a newly liberalised market of support from personal assistants to technical aids. But amplifying the effect of the funds given to individuals requires placing sufficient resources with user-led organisations that are helping to shape that market as it grows: as user-led organisations support disabled people to identify what they need and how they would best receive it, they would also support key players in that market to meet those needs more effectively. But, as we have already identified, meeting needs is not a static achievement. Self-actualisation is dynamic, so better supply stimulates more ambitious and more accurate demand. The potential of a flexible and growing system is for disabled people's perception of their self-worth and ambition to grow apace with society's expectations and the provision of the market.

So a system oriented by independent living would be wholly compatible with the recommendation of the Strategy Unit's final report, *Improving the Life Chances of Disabled People*.[52] Disabled people should receive an individual budget, but these would be based on requirements identified through self-assessment supported by local user-led organisations, according to transparent national criteria for independent living and reflecting the needs of the whole person. As identified earlier, these national criteria would evolve over time as the capacity, expertise and innovation of local user-led organisations grows and develops. This budget would be fully under the control of the individual and accountable only to the terms of their current self-assessment.

Action 5: Disabled people should receive individual budgets that are fully under their control and are funded according to a holistic self-assessment supported by local user-led organisations. The national framework discussed in action 3 would provide the criteria by which this would be monitored.

But, as we have established, the funds that follow individuals are only part of the story. Without the empowerment to know *why* they are a right, *what* to do with them and *how* to use them, and suitable services on which to spend that money, system change is merely structural tinkering. User-led organisations leading and shaping local partnerships of support for independent living need sufficient funding as a priority for transformation to take off.

It is not sufficient to place funding for these organisations with individual users. It is accessing and experiencing these services through a variety of routes, at any number of different points on the 'why', 'what', 'how' spectrum that stimulates demand for them. Often people will not know they need them until they are using them. This is not always true, but it is certainly true for the most disempowered disabled people – those who have been so oppressed that they are not even ready to aspire to independent living. It would be those people that a market for support organisations would hit first and hardest.

So public funding for organisations offering personalised support to individuals, as well as to other service providers, is morally and logically the right step. Crucially, it is also the key piece in the puzzle that creates the synergy between supply and demand with the potential to create exponential change – for no more money.

Action 6: There should be publicly funded, user-led independent living partnerships in every area. User-led organisations would work to empower individual disabled people as well as with local services to empower the individual and shape the market for resources. The exact configuration of these would depend and build on existing services available in the locality.

But there is a vital final step in the argument. These organisations have to be user-led and work according to the philosophy of independent living for system change to be possible. If current tender procedures are used to achieve this, these organisations will be undercut and their function will be undermined – along with the right to independent living.

Equally, as previously discussed (see chapter 2), while employing disabled people should certainly be a necessary requirement of a tender, it is not sufficient. Tender specifications should be based on the user-designed framework of support for independent living discussed in action 3, or an agreed time-specific plan to develop a user-led group towards them.

Action 7: The national user-led organisation (see action 3) should draw up tender specifications for the running of independent living partnerships based on their guidance framework.

A learning system

Alongside the space to innovate, many independent living partnerships will need both inspiration and ideas to get started. As has been clear throughout, the exact configuration of services in each of these areas will vary, but the principles by which they work will be the same. Some basic concepts will be transferable and many working practices of other organisations will provide the seeds of ideas that can be developed into context-specific services. This is important not just for nascent organisations; it will be central to developing the momentum of system change discussed earlier.

It is for this reason that the In Control model described earlier talks about its framework for planning support as a 'draft' that is constantly being modified to best fit its guiding principle of 'self-directed support'. When the project was imported from North Lanarkshire to Wigan, version 1 became version 2. It's now version 2.1.[53]

Rules and auditors that reflect the working principles of an organisation help to persuade it to innovate along those lines. But seeing successful innovations demonstrated in other organisations, without being censured, is even more persuasive. This mirrors some of the importance of peer support for individuals.

Currently, organisations supporting independent living are clear that they do not generally talk to each other to share their work, although the British Council of Disabled People (BCODP) used to set up conferences to facilitate these sorts of discussions. This is partly a direct result of the fact that the work they are doing occurs despite the system; all the incentives are to keep it quiet. This is mainly in case it threatens their precarious funding, which is usually judged on other people's criteria and priorities. It is also because an awareness of the 'postcode lottery' of support leads logically to the assumption that they are a 'lone rider' organisation. Finally, organisations motivated by enabling the right to independent living have often been initiated by an exceptional individual or group of disabled people who were confident and dogged enough to challenge their oppression. It is natural to assume that the same is not generally true elsewhere.

Sharing between organisations tends to happen on an ad hoc basis where individuals or groups meet 'kindred spirits'. At ILA, Essex, they are working with a similar organisation in Bristol to share and develop their online referral system to be suitable for their needs. These relationships do more than enable existing practice to travel. The solidarity and support that practice sharing both requires and engenders helps to build organisational confidence. Often, it also gives rise to what Michael Fielding calls 'joint practice development'.[54] Sharing and reflecting on 'what works' often lead to improvement for both 'originator' and 'recipient'. So if this mutual development happened consistently, system-wide, the improvement in the support on offer would be exponential.

Action 8: Funding should be established to foster networking and collaboration between existing and nascent user-led organisations supporting independent living.

Practice sharing does not mean simply transplanting ideas from one location to another. Sharing ideas should be a trigger through which other organisations can develop community, impairment and person specific implementation. This process can be made easier by attaching as much information about context to ideas in the first place.

Action 9: A common information resource should be built on NCIL's fact sheets and organisational contact details to contain examples of good practice that could be accessed by both users and providers.

Whipping up demand

One of the most powerful features of a system that entitles every disabled person to support for independent living is that their demand can begin to drive excellence and change. Once the system is set up to enshrine the right to independent living, wherever you are, whoever you are (in contrast to the current postcode lottery which inhibits movement as well as demand), practice starts to travel with individual users. If organisations are co-producing and co-designing resources with those individuals, this becomes an important driver of change. Learning and innovation will happen because they have to.

In the current system users have a diversity of expectation as to what support should be available but receive provision based on service priorities and criteria. Over time, the system should encourage uniformity of expectation and diverse, personalised provision that reflects and respects the diversity of people and of their independent lives.

The system does not have to wait until disabled people start to take up the freedom to move round the country for users to drive change in the system. A checklist for users to check whether local resources meet independent living standards could start to ‘whip up demand’, as Simon Duffy from In Control put it.

Action 10: The national user-led organisation (action 3) should develop an evaluation checklist for users to assess the effectiveness of services in their area. A suggestion for what this might contain is included as appendix E.

If used in conjunction with the common information resource of ‘good practice’, described previously, this approach could be particularly powerful. Not only would users be able to identify and articulate what is wrong, but what might be better.

Going back to the centre of the circle

The empowerment of individuals is linked closely to the fact that systems do not exist in a vacuum. This is true for any system, but particularly important in this case. Disabled people are part of an inherently disablist society. Enabling disabled people to seize a right to independent living is partly about resolving the tensions of a complicated system of interlinking organisations, institutions and structures to work according to one principle. Using Incapacity Benefit reform to develop a system based on the aims of independent living and starting with holistic, supported self-assessment should make this possible.

But more fundamentally support for independent living is needed because of society's crushing lack of expectation of disabled people and because of the physical and structural barriers it creates. Public, attitudinal change about disabled people's right to independent living is vital because it affects disabled people's own attitudes to that right. And this takes us back to the centre of the circle. Disabled people are part of that society so transforming disablist attitudes contributes as much to their empowerment as to the way in which society responds to their impairment.

As earlier chapters have shown, for many disabled people, this is a key step in making independent living a reality – it cannot be assumed to be a given. So attitudinal change should be seen as a priority in creating a system oriented by independent living and one of the key reasons for using the high profile debate around Incapacity Benefit reform as an opportunity to raise awareness and contribute to changing public attitudes. Changing the nature of the debate to be about enabling disabled people to lead equal, self-determined lives would make the next stages of reform both politically and practically easier. It would embed public support for newly prioritised funding for resources to support disabled people. It would also start to shape the response of employers and other key players who will be part of making independent living a reality.

Action 11: Government should explicitly and publicly highlight independent living as the aim of Incapacity Benefit reform.

The media should also recognise the role that it has to play in this. It is not just a reporter of debates about social issues. In shaping attitudes, it is part of the system and an independent player in realising the right to independent living.

Action 12: Media organisations should take their position as upholders of rights as seriously in this debate as they do for other human rights violations.

If changing the nature of this public debate is the vital short-term trigger, longer-term strategies for entrenching attitude change will also be key. In the long term, the most important and often mentioned is embedding understanding about independent living in education for all young people to shape the expectations of disabled children as well as the responses of their non-disabled peers. This is not just about explicit learning about the civil rights of disabled people. It is also about inclusive education that genuinely provides the support that disabled children require to participate, so that all children lead independent lives alongside each other from the earliest possible age.

To summarise, the actions we believe need to be taken are:

Action 1: Understanding of independent living should be improved throughout the system – from ministers and senior civil servants through to front-line staff. This might be achieved through a combination of user-led training, conferences and publications.

Action 2: The statutory duty of all bodies involved in the provision of services for disabled people should change from their current 'duty of care' to a 'duty of equality'.

Action 3: A national, user-led organisation should be appointed to develop the framework for measuring progress towards independent living in collaboration with local organisations.

Action 4: Government should commit to an evaluation of Incapacity Benefit reform within a period of three years, according to the user-developed benchmark established in action 3.

Action 5: Disabled people should receive individual budgets that are fully under their control and are funded according to a holistic self-assessment supported by local user-led organisations. The national framework discussed in action 3 would provide the criteria by which this would be monitored.

Action 6: There should be publicly funded, user-led independent living partnerships in every area. User-led organisations would work to empower individual disabled people as well as with local services to empower the individual and shape the market for resources. The exact configuration of these would depend and build on existing services available in the locality.

Action 7: The national user-led organisation (see action 3) should draw up tender specifications for the running of independent living partnerships based on their guidance framework.

Action 8: Funding should be established to foster networking and collaboration between existing and nascent user-led organisations supporting independent living.

Action 9: A common information resource should be built on NCIL's fact sheets and organisational contact details to contain examples of good practice that could be accessed by both users and providers.

Action 10: The national user-led organisation (action 3) should develop an evaluation checklist for users to assess the effectiveness of services in their area. A suggestion for what this might contain is included as appendix E.

Action 11: Government should explicitly and publicly highlight independent living as the aim of Incapacity Benefit reform.

Action 12: Media organisations should take their position as upholders of rights as seriously in this debate as they do for other human rights violations.

Living systems

These are suggestions for establishing a meaningful interface between top and bottom devised with independent living as a guiding philosophy. They arise from interviews with people who experience the system as it exists currently. But systems are living things. As top, bottom and middle change and develop, so will the configuration of services that best supports disabled users.

Discussion in this final section has so far been concerned with embedding the individual empowerment of disabled people in a new system. But the need for a continuous feedback loop from user to providers also illustrates the need to embed the collective empowerment that was discussed in chapter 2 – the political right of citizens to shape the services they receive. If that voice resides authentically in the user-led organisations at the heart of a new system, then it makes sense to use these as a starting point going through local partnerships and up to the top, allowing the interface to be continually redesigned and adaptable.

Any organisation transmitting user voice at a national level has to be legitimate to the top and accountable to the bottom. In the emergent structures involved in implementing the Strategy Unit report, this might be the user-led steering group for the newly formed Office of Disability Issues. Putting user voice at the heart of reform should also help to speed it up, supporting government to implement its obligations under the Disability Discrimination Act and Human Rights Act. This would further contribute to the system and public attitude change already under way as a result of the individual empowerment afforded by Incapacity Benefit reform and other change it necessitates.

A golden opportunity

Incapacity Benefit reform, properly situated within the aims of independent living for all, could be the starting point for fundamental transformation of the system. Putting resources in the right place through fully funded individual budgets, based on holistic self-assessment supported by user-led organisations, would be one part of the catalyst. The other part would be funding for user-led organisations to work with other local providers to shape the market for provision. Set together in the context of a system aligned by the principles of independent living and liberated to innovate, a radical overhaul of the system becomes possible in a relatively short space of time.

The challenge for government is to recognise that taking a systemic approach to change can set in train a series of positive feedback loops that accelerate and deepen the process. Incapacity Benefit reform, along with the implementation of the Strategy Unit report and green paper, is the ideal platform for this, to change public attitudes as well as working practices. It provides a unique opportunity to establish an equal right to independent living for disabled people at the heart of society. It is an opportunity that should not be missed.

Appendix A

List of project interviews and case studies

Interviews

19 January	Bruce Calderwood, Department for Work and Pensions (DWP)
20 January	Julie Charles, Equalities UK
7 February	John Evans, European Network of Independent Living
8 February	Rachel Hurst, Disability Awareness in Action
10 February	Phil Miller, Essex Coalition of Disabled People
16 February	Nick Danagher, National Centre for Independent Living (NCIL)
17 February	Clare Evans, Marianne Scobie and Anne MacKay, Disabled People's Forum, Leonard Cheshire
16 March	Angie Farrell, Disabled People's Forum
18 March	Tracy Bird, Scope Options, Birmingham
21 March	Caroline Waters, BT
19 April	Simon Duffy, In Control

Case studies

28 February	Independent Living Advocacy (ILA), Essex Independent Visitors Scheme (IVS), Essex
1 March	People First, Colchester North Essex Stronger Together (NEST), Colchester
2 March	Greenwich Association of Disabled People (GAD)
3 March	Glasgow Centre for Inclusive Living (GCIL)
4 March	Glasgow Centre for Inclusive Living

Appendix B

List of attendees at the project workshop

Seminar participants – 24 March 2005

Sue Bott, Chief Officer, Shropshire Disability Consortium
Julie Charles, CEO, Equalities
Nick Danagher, CEO, NCIL
Rachel Duke, DRC
Jim Elder-Woodward, independent consultant
Sarah Gillinson, researcher, Demos
Hannah Green, researcher, Demos
Wilma Jackson, DWP
Tanya Joseph, consultant, Grayling UK
Alex O'Neil, Principal Research Mgr, JRF Independent Living Committee
Rachel Pillai, ippr
Roy Webb, Head of Policy, NCIL
James Wilsdon, Head of Science and Innovation, Demos

Participants from Scope

John Adams, ED, Community Development
Mide Akerewusi, Head of High Value Appeals
David Alcock, Head of Business Development
Jane Aldous, Head of Corporate Partnership
Paul Appleyard, Head of Diversity Works
Claire Ardley, EA to Pauline Simpson
Jean Dolphin, ED, Operational Services

Alan Farquar, Project Manager – Daily Living
Richard Hall, ED, Finance & Management Services
Louis High, Head of Communications & Campaigns
Tony Manwaring, CEO
Richard Parnell, Head of Research & Public Policy
Munira Pirmohamed, EA to CEO
Andy Rickell, ED, Diversity & Corporate Planning
Pauline Simpson, ED, Marketing
Jon Sparkes, ED, Human Resources
Petra Wöstefeld, Business Support Manager

Appendix C

The human and civil rights of disabled people: a statement of collaboration

Sharing a common anger at this situation, and acknowledging that we are all working within our own spheres to effect social change, we believe that it is important to grasp an opportunity to work together to:

- find collaborative solutions to ensure that disability rights are pushed further up the political and social agendas, and mainstreamed within national and local policy
- challenge the barriers faced by disabled Britons
- explore the potential for new partnerships.

We are united in wishing an end to institutional disablism and the enforced segregation of disabled people.

We are all committed to the full and equal participation of disabled people as citizens of the UK.

We acknowledge that we are coming to this unity and commitment from different perspectives and agree to observe the dignity and expertise of each of us equally. We recognise that our diversity offers a source of real strength.

However, we acknowledge that the voice of disabled people themselves has, traditionally, been left out of planning policies and programmes that directly affect them.

Therefore we believe that this voice must be positively supported and should provide a leading role in our collaboration.

We also acknowledge that, historically, there has been an unfair distribution of resources – and the resulting power structures – between the disability rights movement and the large charitable disability organisations.

Therefore we will take that imbalance into consideration.

We are therefore committed to collaborating, because we believe that working together we must achieve more to advance our common goal – that disabled people achieve the full human and civil rights that should be enjoyed by all Britons, irrespective of difference.

Appendix D

About the ILzone

Meetings on implementing independent living terms of reference for ILzone (independent living trading zone)

Purpose

To bring together disabled people leading the independent living movement and allies to explore independent living policy and good practice and consider their implications.

To discuss and promote independent living in terms of policy and practice – locally, nationally and internationally.

In so doing, to guide, challenge and advise Scope in its programme of service reform.

Activities

To commission research and, where possible, to evidence outcomes using appropriate and independent research and practice organisations.

To review current thinking and practice, relevant to the above purpose (which may therefore explore associated concepts and thinking as relevant).

To enter into dialogue with relevant stakeholders, at local, national and international level, within the independent living movement and elsewhere.

Key issues to tackle

To ensure that the needs and rights of disabled people with high support requirements are fully identified and understood, and are met according to the principles of independent living.

Recognising the age, socialisation and institutionalisation of disabled people within Scope and beyond, to challenge and explore issues of choice and control, with the appropriate and effective exercise of commensurate responsibilities.

To develop sustainable models of provision, which recognise and help practical solutions to practical challenges such as the need to escape from the vicious circle of full occupancy of services to secure funding.

To recognise and affirm the autonomy of the independent living movement, and the broader disability rights movement, as new initiatives are developed and taken forward; and to underpin their lead role in the future provision of services to disabled people within the community at large.

Rules of engagement

To work as a ‘trading zone’ – so that people of different experiences and with different resources and capacities can contribute on an equal basis, by making proactive and ‘reasonable adjustments’ through providing the tailored support required.

Membership

Will be by consensus, bringing together people of different skills and capacities who will make progress in achieving the purpose identified.

Frequency and length of meetings

Will be at least quarterly, each lasting for at least two to three hours.

Administrative support

Will be provided by Scope.

Appendix E

Support for independent living: an evaluation tool

A suggested evaluation checklist for users to assess the effectiveness of support services for independent living in their area:

- ○ Am I comfortable talking to someone in my locality about what I want to do with my life?
- ○ Have I actively made choices about social and family activities, leisure and sports, all areas of education, including evening classes, school, college and university, plus life-time learning opportunities, preparation for and training for seeking and finding work, support in maintaining education and work?
- ○ Do I feel that providers are listening and helping me to think through the implications of those choices?
- ○ Are they laying out a range of relevant options that I might like to consider?
- ○ Am I excited by the outcome?
- ○ Is someone helping me to think through what support I will need every day to make that life a reality and not on the basis of what I cannot do by myself around the house?
- ○ Do I receive funding for that support on the basis of that self-assessment described above?
- ○ Can I go to one place or person to obtain the support I need?

○ Have I received enough advice and training to feel confident managing that support?
○ Is there somewhere I can go with any queries about my support package?
○ Can I adjust my support as my requirements and life change over time?
○ Do I understand and feel comfortable with the arrangements for feeding back comments on the performance of organisations I come into contact with?

Notes

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