

A brief history of independent living

**(taken from the DEMOS report
Independent Living: The right to be equal citizens)**

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*'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 twelve 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. Whilst 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 only in close contact 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 has put it², 'A sense of unity and self-confidence gradually developed, largely as a result of the free flow of communication and sharing of experience.'

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 similarly full and active lives 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 programs which 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 working 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 socio-political reactions, which discriminate against them on the grounds of their impairment. It is also vital of course to recognise the multiple discrimination experienced by those who are Black and are also disabled.

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'⁴, 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.'

On this basis, it has been suggested that there are four assumptions underpinning the philosophy of Independent Living⁵ 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.

On this basis, 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 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. Just to give two examples cited in the ‘Improving the Life Chances of Disabled People’ Analytical report published in June 2004:

- Around 55% 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% of disabled men and about 30% of

disabled women aged 16-44 have no qualifications, compared to about 10% 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 life 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 it⁹. 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, whilst 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 a passive service 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 lifestyle 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 realize 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 need. Fulfilment is described by survival – by meeting our basic needs as 'natural beings'; for food,

shelter and health for example.¹⁰ Needs themselves are defined by the individual's ability to fend for his 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 his or herself.

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 a recent JRF paper on 'Disabled people's costs of living'¹³ 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.'

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 report 'Improving the Life-Chances of Disabled People'¹⁴ 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.'

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 realize 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.'

This is true for all the interconnecting parts of the system of support. This system is basically comprised of 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 organizations 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, user-led organisations refer to all groups working within the Independent Living philosophy. These might be Centres for Independent Living, 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'¹⁷ and that certain roles can be equally well-filled by non-disabled people. This often applies particularly to 'back-room' roles like financial administration.

Generally, there is consensus that user-led organisations should 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 of 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 categorization developed by the National Centre for Independent Living: peer support; information, advice and guidance; training; and advocacy as defined in chapter 5. ¹⁸

The Living Options project in Derbyshire drew up the following checklist to assess an organisation's commitment to user involvement: ¹⁹

- 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?

For policy makers, user-led organisations demonstrate more than 'what works'. Firstly, recognising, harnessing and spreading the

success of local organisations that are working with people as mentors, 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?

Secondly, 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 this 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.

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- ¹ A Ratzka, based on principles set by Disabled Peoples' International Independent Living Committee in 1989
- ² H Zukas, CIL History; Report of the State of the Art Conference (Berkeley CIL, California, 1975)
- ³ J Elder-Woodward, 'Making sense of community care'; Community Care Providers Scotland Conference (2001)
- ⁴ J Rawls, *A Theory of Justice* (Harvard University Press, 1971)
- ⁵ J Morris, *Community Care or Independent Living*, (Joseph Rowntree Foundation, 1993)
- ⁶ P Miller, S Parker and S Gillinson, *Disablism* (London, Demos, 2003)
- ⁷ Internet publication URL: www.southamptoncil.co.uk/basic_needs.htm
Internet publication URL: www.dpScotland.org.uk/0304dps/canedit/factsheets/fsheet02.asp
- ⁸ Improving the Life Chances of Disabled People Analytical report, (June 2004)
Internet publication URL:
http://www.strategy.gov.uk/downloads/work_areas/disability/Disability%20interim.pdf
- ⁹ J Elder-Woodward 'Making sense of community care'; Community Care Providers Scotland Conference, (2001)
- ¹⁰ M Ignatieff, *The needs of strangers*, (Chatto & Windus, London 1984)
- ¹¹ Internet publication URL: <http://web.utk.edu/~gwynne/maslow.htm>
- ¹² J Elder-Woodward, 'Making sense of community care'; Community Care Providers Scotland Conference (2001)
- ¹³ N Smith, S Middleton, K Ashton-Brooks, L Cox and B Dobson, with L Reith, *Disabled people's costs of living: 'More than you would think'* (Joseph Rowntree Foundation 2004)
- ¹⁴ Strategy Unit Report, *Improving the Life Chances of Disabled People*, ch 4, Independent Living section, (January 2005)
- ¹⁵ Social Care Green Paper, *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England* (March 2005)
- ¹⁶ Department of Health White Paper, *Valuing People; A New Strategy for Learning Disability for the 21st Century; a really useful guide to the Government's ideas on how to get services right for all people with learning difficulties* (July 2001)
- ¹⁷ C Barnes, G Mercer and H Morgan, *Creating Independent Futures; An Evaluation of Services Led by Disabled People Stage One Report* (University of Leeds, Disability Press, 2000)
- ¹⁸ NCIL information leaflet, *The Support Scheme Infrastructure* (1998) available at http://www.ncil.org.uk/info_ss_infra.asp
- ¹⁹ D Gibbs and M Priestley 'The social model and user involvement', in *Disability rights: A symposium of the European Regions*, (ed) B Walker, Hampshire Coalition of Disabled People (1996)