

The case for reframing 'independent living'

'No man is an island, Entire of itself..'

No man is an island - John Donne

Two definitions of independence tend to dominate our thinking. One concerns autonomy and self-determination. The other centres on self-sufficiency and self-reliance. It is generally held that the two go hand in hand. This is why it has always been deeply challenging conceptually and practically for many people, including policy makers, to reconcile the idea of drawing on State assistance while 'living independently.'

The independent living movement has long sought to challenge this equation, arguing that what matters is self-governance, not self-sufficiency. Independent living is 'not about doing everything for yourself' but about enjoying the same freedom and choices as everyone else through having control over sufficient support.

Yet it seems an impossibly hard nut to crack. Take for example the opening sentence in the Ministerial foreword to the government's response to the No Voice Unheard, No Right Ignored consultation: 'Our vision of a civilised society is one in which we take more responsibility for ourselves and our neighbours as part of thriving communities working together, and with less dependence on remote bureaucracies.'

Here the concept of independence provides justification for a shrinking state, not a case for an enabling state that lies behind the struggle for independent living. Hence we see progress on 'choice and control' in the Care Act 2014, yet fewer and fewer people can access any support. We see Disability Living Allowance replaced with the Personal Independence Payment, with an explicit policy objective

of decreasing the number of claimants by 600,000 by 2018. Engaged, active and inclusive communities are important and much needed. But they are weakened, not strengthened, by a disengaging, increasingly inactive and excluding government.

Professor Gerard Quinn – one of the authors of the United Nations Convention on the Rights of Persons with Disabilities - has argued that disability rights merely provides proof of a universal truth: that individual freedom relies to a considerable extent on social solidarity. No man or woman is an island.

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Such social solidarity need not be expressed solely via the State. But the task of extending and expanding human freedom does demand a society that prizes values such as universal rights and human welfare and which is serious about tackling social and economic disadvantage.

Yet we seem to live in a society which often prizes individualism over any notion of common goods, which regards social and economic disadvantage to be the result of individual choices rather than structural barriers, and which is less and less willing to commit public resources to social welfare, save to care for 'the most vulnerable.'

Faced with such public attitudes, anti-austerity campaigners are increasingly pleading the vulnerability and intrinsic lack of capabilities of disabled people to shield them from cuts and punitive sanctions regimes. This plays to society's prejudices regarding disabled people as objects of charity and care rather than as equal citizens. It risks undermining efforts to put more power in the hands of disabled

people and to secure recognition of and action on discrimination.

Yet those who have pursued reforms such as direct payments and individual budgets have also risked giving credence to social values which may ultimately prove destructive to independent living. Emphasis has been placed on individual autonomy at the expense of social solidarity, on the idea of the 'rational actor' rather than acknowledging how social and economic structures determine opportunities and on opportunity for 'efficiencies'. Doing so makes sense both to gain traction for the agenda overall and as a vehicle for levering power away from professionals and public bodies into the hands of those requiring support. But it draws on the same values of individualism and the notion that we alone are responsible for our lot in life that underpins declining public support for spending on social security and public services.

What I say here should not be misconstrued as an argument against the promotion of choice and control, direct payments, personal budgets and the like. Loss of self-governance must not be the cost of receiving support. But self-governance cannot be divorced from questions of how much support is available.

The case for society to invest public resources in disabled people needs to be at least as strong as the case made to give disabled people control over those resources that presently exist. For the reason's I have outlined I believe it may presently be weakened by placing so much emphasis on independence.

We can't alone turn society's values around, but we can learn how to harness that which is valuable and to avoid re-enforcing that which is harmful. What I believe is required is a reframing that captures the notion of community, belonging, of interdependence, of relationships and reciprocity, of investment and return. We require a compelling narrative that persuasively conveys why an investment in disabled people's right to choice, control and participation is an investment not just in individual rights but in the common good.



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