

The Independent Living Movement and Capitalism: Challenges and Contributions

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Abstract

This article critically discusses how the Independent Living Movement (ILM) both reflects and challenges capitalism, especially its contemporary neoliberal variant. We first take a brief historical look at disability. Since time immemorial, physical and intellectual impairments have been viewed negatively, and these views - together with structural barriers – have served to disable people with impairments. The Enlightenment heralded social reform, yet the emerging scientific tradition medicalised and marginalised disabled persons who came to be seen as tragic and dependent. This was true of capitalist and state socialist societies, as both saw disabled persons as less productive and often in need of institutional care. Excluding disabled persons is not, therefore, solely a function of capitalism. Indeed, it was in capitalist societies that the Disabled People's Movement freely and successfully mobilised after the 2nd World War. This Movement developed the social model which, unlike the medical model, explains disability in terms of societal barriers which need to be removed. The spread of neoliberal philosophy from the late 20th century has had a paradoxical impact. On the one hand, its notions of choice, control and autonomy have provided a further impetus to independent living aspirations; on the other hand, austerity, welfare conditionality and a narrative of self-reliance have undermined effective independent living services. We argue in favour of a relational, interdependent view of autonomy, and for the political choices necessary to stamp out discrimination, ensure labour market integration and support the independent living aspirations of disabled persons.

Keywords: disability, independent living, capitalism, socialism, relational autonomy.

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This article critically discusses the ways in which the Independent Living Movement (ILM) both reflects and challenges capitalism, especially its contemporary neoliberal variant (Mladenov, 2015). The ILM developed in the late twentieth century to assert the rights of disabled people to self-determination and equal opportunities. Three broad influences have shaped the development of the ILM. First, the social model of disability challenged the earlier medical model's view of disability as a condition to be fixed, and disabled people as being only in need of professional intervention and advice (Oliver, 2009). The social model proposed, instead, that the difficulties faced by disabled people do not arise solely from their impairments but from discriminatory social and economic structures. As Oliver (2009) argues, these structures present difficulties that cannot be dealt with only through medical and therapeutic interventions and welfare benefits.

Second, the ILM was also driven by a growing awareness of human rights. One of the landmarks to follow the devastation of the Second World War was the United Nations' Universal Declaration of Human Rights which, as stated in its Preamble, is based on the concept of a shared humanity with no exception and a focus on each person as a rights-bearing individual (United Nations 1948). This Declaration was followed by many international legislative instruments, the most recent and important of which is the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) adopted in 2006. The UNCRPD followed decades of lobbying by disabled people for their rights and for recognition of the social model of disability. Indeed, the UNCRPD notes in its Preamble that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 1).

Third, and possibly most significantly, the ILM knows its origins to the disabled people's movement which has focused its struggle on the removal of attitudinal and environmental barriers. This work has meant campaigning for legislative change, for the removal of structural barriers, and for increased awareness about the rights and dignity of disabled people. It has also entailed campaigning for services that enable disabled

people to be included, and to participate, in the life of their communities. These services are often referred to as independent living services (European Network on Independent Living, 2013).

The ILM grew at a time when many of its core tenets such as independence, choice and the personalisation of services were gaining political currency in the late 20th century. However, while the ILM shares some of the values of capitalism, the exclusionary effects of the latter have been criticised in the disability literature (Rosenthal, 2019; Ryan, 2019). In this article, we explore and critique the relationship between capitalism and the ILM, looking briefly at disability through history and within capitalism and communism, before turning to consider the ways in which the ILM not only draws upon, but also challenges and corrects the neoliberal outlook that is widely taken for granted today.

Impairment and Disability Over Time

Impairment and disability have been conflated since time immemorial, yet the distinction is important. It allows for critical analysis of societies' response to impairments (Metzler, 2011) which are, in themselves, not necessarily disabling but are made so by socially constructed barriers. As Gardou (2015) puts it, disability "draws upon geological layers" (p. 14, authors' translation) of negative associations which over time became entrenched in the culture of different societies, regardless of historical period or socioeconomic arrangements.

The different - and negative - treatment of those with a physical or mental impairment can be dated back to at least Ancient Greece and Rome (Hughes, 2020). According to Garland (as cited in Draycott, 2015), such treatment was due to three factors: "first, that it was a means of bolstering group cohesion at the expense of the outsider; secondly, that it was a means of expiating fear and embarrassment; and thirdly, that it was an outlet for sublimated aggression" (Draycott, 2015, p. 202). Indeed, disability hate crime – though only recently coined as such – is certainly not new; while a rise in such crime has been registered in the past few years, there is evidence of it having occurred from antiquity (Ralph et al., 2016).

Kudlick (2003) highlights the significance of

the perfect body for classical Greek thinkers like Aristotle, and how any deviations from such perfection were described in the most demeaning ways that endure until today as terms of insult. This has contributed to “one of the most challenging aspects of disability...to convince non-disabled people that even when it involves pain and hardship, disability is not always a tragedy, hardship or lack, but in fact often provides much of value” (Kudlick, 2003, p. 769).

In the Middle Ages, speculation was rife about the origins of impairment. Wheatley (2010) and Metzler (2006) both refer to two such views: first, that impairment was a result of sin (one's own or one's parents'); and second, that it offered the opportunity for miraculous healing. Impairment was sometimes inflicted as a punishment for crime, a practice which Wheatley (2010) claims went on well into Renaissance Europe. The Middle Ages also saw the widespread giving of alms, encouraged among the faithful as a means of salvation (Wheatley, 2010). Even so, Metzler (2006) contends that there is very little evidence of persons with impairments being particularly reliant on aid, and they lived in a more or less integrated manner within their communities.

With the advent of the Renaissance from the late 15th century and its rediscovery of the classical world, reason began to displace religion as the foundation of social and political thought. This brought a new challenge to those with physical and mental impairments. “This re-emergence of the rational individual required the definition and particularization of ... reason's ‘Other’: the idiot, the blind and the disabled” (Stainton, 2004, p. 226). Reflecting on Bruegel's art, Stainton argued that representations of disabilities in the Renaissance became “metaphors for human misery, isolation and moral decrepitude” (p. 238).

By the early 18th century, scientific and intellectual progress had made the improvement of human and social conditions seem both possible and desirable. Superstition was challenged and authority criticised. The revolutions of the 17th and 18th centuries introduced principles of freedom, equality and democracy, and of government based on the consent of the governed. Influential Enlightenment scholars contributed to a growing body of liberal

philosophy, and were to leave an enduring influence on ethical, political and economic thought (Ferrone, 2017). In the German Enlightenment, Immanuel Kant called for respect for human dignity, for treating people as ends not means, and for the courage of critical intellect. For Kant, being autonomous meant being free to deliberate and choose, and that as moral agents, people had both rights and duties (Kant, 2009). In England, John Locke argued that humans had inalienable rights independent of any laws and that indeed, the scope of government should be limited to protecting these rights (Rosenblatt, 2018). In the Scottish Enlightenment, Adam Smith called for greater economic freedom and less government regulation of trade that had benefited only the few. Smith argued that leaving people alone to pursue their self-interests in a competitive market would result in a self-regulating and benign prosperity (Smith, 2012).

However, Enlightenment ideas have been criticised and are sometimes linked to the violence of the French Revolution and even to the genocide of the Holocaust (Peters, 2019; Baumann, 1989). While these links are controversial (Rasmussen, 2011; Healy, 1997) it seems fair to say that the universal humanity at the heart of Enlightenment thought was understood quite narrowly in male, European and ableist terms. Women's physiology was thought to diminish their capacity for reason (Bostic, 2012) while pejorative ‘scientific’ classifications of different races were used to justify slavery (Foutz, 2008). For persons with disability, the Enlightenment was a mixed blessing. Scientific knowledge expanded rapidly, impairments were no longer attributed to moral failure, and medical assistance became more sophisticated. At the same time, people with impairments became objects of diagnosis and treatment, and the line between those with and without a disability was firmly drawn (Russell & Malhotra, 2002). Many disabled persons who, under feudalism, had at least participated in life on the estates, were dispossessed in newly industrialised societies. According to Russell and Malhotra (2002), industrial capitalism created “a new class” (p. 213) of disabled persons whose body did not conform to that of the standard worker. As a result, they were excluded from paid work, were seen as a social problem and gradually marginalised in

institutions that “became the instruments for the facilitation of social death. Through a presumed scientific status, care for people with disability became depoliticised, technicalised and professionalised, predicated on notions of tragedy, burden and helpless dependency” (Clapton & Fitzgerald, n.d., para 12). This tragic notion of disability has been robustly challenged by disabled persons, who call for an affirmation model of disability that validates the positive identity and experiences of persons who live with impairments (Swain & French, 2000).

The Emergence of Modern Capitalism

The exclusion of persons with impairments was further strengthened by modern capitalism. While merchants have bought and sold for profit since the earliest times (Fulcher, 2015), the onset of industrialisation allowed for the investment of private capital in new productive technologies that had a far wider effect on social and economic life than had the merchant trading that preceded it (Fulcher, 2015). The nineteenth century saw productivity rise in leaps and bounds, as industrial capitalism was enabled by the rise of political liberalism and free markets (McCloskey, 2019). Waged workers were essential to capitalism, as both producers and as consumers. However, working conditions were often very poor, giving rise to early social reform and the organisation of labour (Fraser, 2009). Early capitalism was blamed for causing much human misery, though not by all. Carver (1924), for instance, lamented that when referring to capitalism, too many pulled a “wry face [when] the masses of the people are better off under it than they have ever been under any other system” (p. 442).

The historical materialist view of capitalism, developed by Karl Marx in the nineteenth century, was less benign (Singer, 2018; George, 2012). His work articulated the forces of production and the relations between them, and how a legal and political superstructure comes to overlie, and prop up, the economic base on which it sits (Marx, 1992). For Marx, humans become free and fulfilled through their labour, as work allows them to master nature and meet their needs. It was the conditions of material life that shape consciousness, not vice versa. Under a capitalist system with its division of labour and appropriation of surplus value by owners, people

are estranged from what they produce and become alienated. The state was part of the problem, captured by the interests of the propertied class. And yet, capitalism was thought necessary to generate the class struggle necessary for its eventual overthrow. Marx’ slogan “from each according to ability, to each according to need” became central to left-wing thought (Bovens & Lutz, 2019).

The economic turmoil of the early 20th century slowed down capitalist growth, and the Great Depression of the 1930s saw increased sympathy for socialism, which bifurcated into communism and social democracy (Sassoon, 2003). This “turn to the social” (Sassoon, 2003, p. 8) persisted after the Second World War, as capitalism was regulated and most political groupings supported universal suffrage, labour regulation and welfare provision. For three decades after WWII, it was a left-of-centre vision that characterised the *trentes glorieuses* of economic growth and the rapid development of welfare benefits and services (Pierson, 2006).

However, rising inflation and unemployment in the 1970s saw this vision of egalitarian capitalism give way to a neoliberal variant inspired, at least initially, by the classical liberal ideals of small government, free trade and private enterprise (Fulcher, 2015). The ascendance of neoliberalism coincided with, and was in part driven by, discontent with the welfare state on both the left and right of the spectrum (Offe, 1982). Critics on the left pointed out that welfare provisions did not adequately respond to need, and that they were usually delivered in a bureaucratic and paternalistic manner which failed to respect and empower service users (Beresford & Carr, 2018). On the right, the welfare state was accused of fostering a dependency culture, of reducing the efficiency of markets and of over-extending the role and scale of the state to the detriment of initiative and personal responsibility (Fitzpatrick, 2011).

For Steger and Roy (2010), neoliberalism is something of an opaque catchphrase with three main manifestations. The first is an ideology of the primacy of individual choice, and the equation of rationality with the pursuit of wealth, which “puts the production and exchange of material goods at the heart of the human experience” (p. 12). The

second is a mode of governance based on enterprise, the self-regulating free market and the adoption of business practices from the commercial sector, also known as new public management. The third is a policy package of deregulation, liberalisation and privatisation, as well as tighter control of public expenditure and a move from 'welfare to workfare'. These authors assert that for many, neoliberalism is now a pejorative umbrella term, associated with unbridled selfishness, selective austerity and (mostly) American economic and cultural imperialism.

By the 1990s, neoliberal capitalism became global, aided by technology and by the financial liberalisation undertaken across the political spectrum (Stiglitz, 2019; Steger & Roy, 2010). Capitalism is now the predominant economic system around the globe. For some, this is good. McCloskey (2019), for instance, spoke of the "Great Enrichment" (p. 10) that has occurred since 1800, claiming that capitalism has brought about an increase of 3000 per cent in the real income of the poorest that would not otherwise have happened. Innovation, imitation and commercialisation have made an increasing number of commodities affordable even to those on lower incomes, to an extent that would not have been thought possible only decades ago. Others are less sanguine. Milanovic (2019) stressed the hegemonic nature of contemporary capitalism as legal and political institutions are geared to protect and foster a profit-driven economy, where making more money is widely deemed the principal way to better one's standard of living. While inequality between nations has gone down, within countries it has risen. Milanovic (2019) points to a number of explanatory factors. Financial assets have become concentrated not only among the owners of capital but also among a minority of highly skilled, highly paid workers while wages at the lower end of the spectrum remain stagnant. Assortative marriage between rich, educated men and women also serves to concentrate wealth and drive up inequality between households. In turn, the children of richer parents are more likely to access high-quality education, increasing inequality down the generations. The trend towards increasing inequality would seem inexorable, leading activists across the world, but also supranational

organisations that have championed neoliberal reforms, to call for inclusive growth (IMF [n.d.]; OECD [n.d.]). The disability movement was one of the earliest to take on unequal treatment, as discussed in the next section.

Capitalism, Disability and the Disabled People's Movement

From the 1980s, prominent disability scholars adopted a materialist view to explain disability. Oliver (1999) and Russell and Malhotra (2002) argued that it was capitalism's 'productivist' exclusion of people with impairments that actually created disability, while at the same time creating a false consciousness among disabled people that their difficulties are due to their personal impairments. Efforts to normalise disabled people into an unequal society were not sufficient; only "[m]aterialist social theory [could] ... transform the society in which they live into one in which all roles are valued." (Oliver, 2009, p. 105).

Yet evidence from 20th century state socialist countries such as Russia and a number of Eastern European countries (Mladenov, 2015) suggests that the treatment of disabled people therein did not differ significantly from that of the West. Writing of Russia, Phillips (2009) noted how between the late 19th and early 20th centuries, care of the disabled by the Church and philanthropic élites gave way to a rise in medical treatment by experts. Institutional care was widespread, and it was in such settings that disability advocacy started in the USSR as early as the 1960s, though residents were often moved around to nip such advocacy in the bud (Phillips, 2009).

In the Soviet state, where work was glorified and citizens were, above all, to be useful (Dinu, 2019), persons with impairments were diagnosed and classified in terms of what they could not do. It was work, not need, upon which state socialism revolved. Under state socialism as under capitalism, those unable to work became poor and culturally devalued, and their disability was seen as a tragedy. While in the West, disability was tragic for the disabled person, under state socialism the tragedy lay in lost labour capacity (Mladenov, 2017).

It would thus seem that the commodification of persons with disability is not necessarily the

fruit of any one political economy. History has shown both capitalism and communism to embrace an ideology which, as Mladenov (2017) states, “reduces humans to resources utilizable for the enhancement of productive output” (p. 1110). Neoliberalism has entrenched this productivist philosophy, now evident also in welfare discourse and practice (Jordan, 2008). Particularly, there has been tighter conditionality applied to benefit systems, as “[p]eople are expected to practice personal responsibility by investing in their own human capital to make themselves less of a burden on society as a whole or face the consequences of a heightened disciplinary regime” (Schram, 2018, p. 308). In the case of disability, as with most other groups, the right to an adequate income has become increasingly conditional upon stringent work availability requirements, with tighter eligibility criteria intended to exclude those without a ‘genuine’ disability (Grover & Soldatic, 2013). This move to replace welfare with workfare for disabled people has been accompanied by an authoritarian and stigmatising discourse that is redolent of the distinction made in the 1834 English Poor Law Amendment Act between the deserving and undeserving poor (Grover & Soldatic, 2013).

Even if the productivist exclusion of disabled people is not peculiar to capitalism, we will now turn our focus to the relationship between the latter and the disabled people’s movement. This relationship is especially important to consider, since the mobilisation of disabled campaigners into an organised movement first occurred in capitalist countries, especially in the US and the UK (Campbell & Oliver, 1996; Zames & Zames, 2011). The most significant achievement of the disabled people’s movement has been its social model of disability, which distinguishes between biological impairment and socially created disability. This model has been a very powerful tool in campaigning for disabled people’s rights, as it brought about a realisation amongst disabled people themselves that many of the difficulties they faced were the direct result not of their impairments but of societies that did not cater for their impairment-related needs (e.g.: Barnes & Mercer, 2010; Camilleri, 1999; Shakespeare, 1993). Oliver (2009), while not denying “the influence (some positive, some negative) of medicine, charity and welfare in the

lives of disabled people” (p. 43), regarded the social model and its focus on removing economic, cultural and environmental barriers as the best foundation for understanding and addressing disability.

The social model has not been without its critics. Thomas (2004) writes of her regret that the original relational conception of disability by early disabled pioneers Vic Finkelstein and Paul Hunt, in which impairments and barriers interact to cause disability, was eschewed in favour of a position that equates disability solely with socially created barriers. The relational nature of disability is acknowledged in the Preamble to the UNCRPD (2006). Barclay (2010), too, pointed out that impairments cannot be left out of any understanding of disability. Moreover, she contended that it is not really “plausible to suggest that failure to design a society equally favourable to all people, irrespective of their physical and mental traits, constitutes discriminatory treatment” (p. 161). Social institutions cannot be made to ensure the equal access and success of everyone, not least because the needs of one group may contradict those of another. In fact, anti-discrimination disability legislation includes the principle of reasonable accommodation which ensures that adjustments required to cater for impairment-related needs do not impose an unjustifiable burden on the persons or organisations required to make these adjustments. One of the first such laws was the Americans with Disability Act, promulgated in 1990 and followed by the enactment of similar anti-discrimination legislation in many other countries in the decades that followed (Breslin & Yee 2002), and by the UNCRPD (United Nations 2006).

While significant positive change has been registered in the quality of life of disabled people and in respect for their rights, decades of progress have still not brought about the levels of equality and inclusion that disabled people have campaigned for since the 1950s. In fact, the Concluding Observations on the by the Committee on the Rights of Persons with Disabilities (2020) on the State Reports submitted by countries that have ratified the CRPD highlight numerous shortcomings in each country. The limitations in the scope and extent of the progress achieved can be at least partially attributed to the

persistence of the logic of the individual 'tragic' model of disability which requires medical intervention, welfare and charity provision, or even the abortion of disabled fetuses and euthanasia (Prusak, 2005).

Challenging this logic means moving away from an exclusive focus on the negativity of living with an impairment, thus flying in the face of the age-old conflation of impairment and disability. As seen above, the negative associations of disability are entrenched in the culture of different societies, regardless of historical period or socioeconomic arrangements. While there may be differences in how disabled people were and are viewed and treated in, for example, Ancient Greece and Soviet Russia, what binds these different views together is not only their negativity but also the fact that they are based on non-disabled people's views of what it means to live with a disability. Adopting the social or social relational model of disability has meant questioning ideas that have become so deep-rooted as to be mistaken for objective facts.

In aiming to dismantle socially created barriers, these campaigners set their sights on the obstacles created by the socioeconomic systems that they themselves lived in. It is therefore not surprising that it was capitalism in its various forms that has come under fire from many of these activists (see for example Marta Russell's criticism of American capitalism in Rosenthal (2019) and Ryan's (2019) analysis on the effects of austerity on the lives of British disabled people in the past decade). At face value, the market logic of capitalism, and the retrenching of the state in its neoliberal version, run counter to the demands made by disabled people for equal rights and equal opportunities. In fact, the arguments made by Russell and Ryan, among others, are based on theories from the left of the political spectrum, since they argue that the social and economic disadvantages experienced by disabled people are structural problems, and that it is society that needs to carry responsibility for them, rather than disabled individuals themselves. From this perspective, the costs of services and measures in this area should be borne by the state on behalf of society.

Legislation, policies and related measures aimed at dismantling, or at least reducing,

disabling barriers are based on a political philosophy that challenges those who recognise only negative (or liberty) rights. For example, libertarian reasoning that welfare states restrict people's freedom is refuted by the argument that without state intervention, the rights of disabled people, as enshrined for example in the UNCRPD (2006) and in various national anti-discrimination disability laws, would only be hollow words. The funding of support services and measures to increase community access is essential for disabled people to live their lives in dignity and on an equal basis with others. In fact, article 19 of the UNCRPD (Living independently and being included in the community) obliges governments to take 'effective and appropriate measures' for disabled people in this regard (United Nations 2006, p. 13). Even if, as is often contended, negative rights enjoy primacy over positive ones (Cranston, 1983), the positive (social and economic) rights of disabled people must first be met if they are to enjoy their negative rights. After all, freedom of expression means little to a person who cannot communicate without adaptive technology, nor does freedom of association make sense to persons who lack the mobility aids they depend upon to meet and socialise with others.

Independent Living and Individualised Services

Thus, for disabled people, liberty and autonomy mean having the necessary assistance to live life on their own terms in a society which has removed cultural and structural barriers (Morris, 1993). This means that disabled people need accessible environments in the mainstream of society, and varying degrees of assistance from others in their daily lives to cater for their impairment-related needs both at home and to participate in their community.

These are the foundational arguments of the independent living movement which, as Zames and Zames (2011) described, started with people with severe physical impairments working for deinstitutionalisation which in turn brought "a new population to the developing disability rights movement" (p. 33). The work of these activists involved not only campaigning for governments and other societal actors to dismantle barriers and to provide assistance for disabled people to lead

independent lives, but also disabled people getting organised and taking charge of these services, thus creating the changes they were calling for. Zames and Zames's (2011) account of the disability rights movement foregrounds the activism of Ed Roberts, one of the key figures in the US independent living movement in the 1960s and early 1970s. His work is testimony to what disabled people have managed to achieve through this approach. At age fourteen, Roberts became a tetraplegic in need of an iron lung after contracting polio. Against the odds, he graduated from Berkeley University with a Bachelor of Arts in 1964 and a Master of Arts in 1965 (Dawson, 2015). Roberts opened the way for other severely disabled people to enrol at Berkeley. Together, they formed the 'Rolling Quads' and "organized an agency in 1972 governed by and for people with disabilities, the Center for Independent Living (CIL) that eventually gained national and international prominence" (Zames & Zames 2011, p. 39, emphasis in the original).

What was strikingly different about the services provided in these CILs was that, first of all, it was disabled people themselves who were in control. They were no longer simply passive recipients of care, dependent on decisions made by professionals and family members, but were running the services themselves. Furthermore, the services they developed were not based on the provision of daily care in a way that perpetuates dependence. Instead, what the CILs began to offer was a range of services that enabled their members to be active in their community. Zames and Zames (2011) explained that in these centres, the disabled person was no longer "the 'patient' or 'client', connoting dependence on authority ... [but the] 'consumer', suggesting control by the user of the service" (p. 46). The North Carolina Statewide Independent Living Council (NCSILC) reported that to this day, CILs are run mostly by disabled people and their goal is "to promote and support opportunities for people with disabilities to fully participate in an integrated community and search for the possibilities to live as they choose" (NCSILC 2020, para 2).

The changes in service provision brought about through the pioneering work of the CILs and of disabled activists and their allies in the US, the UK and elsewhere, would eventually be adopted to some extent by governments and service-

providers in the disability sector. By the 1990s, the independent living movement and the wider disability rights movement had come to the policy forefront. Service personalisation, as one of its lead proponents put it, had the potential to "overcome the limitations of both paternalism and consumerism" (Leadbeater, 2004, p. 11), as it gave choice and control over how support is delivered (Department of Health, UK, 2008).

In the UK, this policy provided for a direct payments system, where disabled people had the choice of either receiving support from an agency (often entailing mixed models of funding and provision among state, non-profit and private organisations) or being given funds by the state to directly pay for services by personal assistants that they choose themselves, thus becoming their own assistants' employers (Department of Health 2020). For Beresford (2009), receiving support from an array of user-controlled service providers was a collective and liberatory approach. The granting of budgets to individuals, on the other hand, reflects a 'managerialist/consumerist' philosophy dependent upon the market, where the cash allocated, and services available, may be less than optimal.

This individualising of disability services has been criticised by prominent disabled activists. Oliver (2009) pointed out how, in its individualised approach, the ILM placed the social model and its radical potential for collective action on the backburner. Duffy (2014), the founder of In Control - the social care reform organisation that led the individual budgets system in England for years - wrote that personalisation has failed to empower vulnerable citizens in three main ways: some recipients find individual budgets hard to manage; the monitoring of individual budgets is administratively complex; and individual budgets have been restricted in the context of cost-cutting policy. These criticisms lead Duffy to claim that personalisation has become "an excuse for abandonment... [and] to cut costs" (para. 5). Land and Himmelweit (2010) agreed that personalisation makes it easier to cut costs, because it is easier to contain cash payments than it is to reduce service costs (Land & Himmelweit, 2010). And yet, only adequate funding can ensure the success of good quality standards (Slasberg et al., 2012).

Kendall and Cameron's (2013) small scale study with service users and professionals bore out many of these concerns. While their participants expressed positive views of self-directed support as offering them more choice and control, they also spoke of the complexity in navigating the system and a lack of transparency in resource allocation. Participants felt pressures to resort to the use of informal carers such as family members, which once again reduced them to gratitude rather than empower them through the ability to transact in the market. These data led Kendall and Cameron to identify "a retrenchment to paternalism [and] an acceleration of the neoliberal cost-cutting agenda" (p. 269). They further concluded that their contradictory findings reflected the ideological conflicts at the heart of personalisation:

If independence is conceptualised in terms of reduced dependence upon others, particularly the state, budgets will be generated to operate at the minimum possible level, reliance upon informal support will be entrenched, and direct payments will be promoted over managed services. By contrast, if independence is conceptualised as having access to the right level of support (Brisenden, 1989), there will be an emphasis upon service users' rights to access adequate and varied support, without the involvement of their family and friends if they so choose. (pp. 269-270)

How the ILM Challenges Capitalism

The ILM casts disabled persons as consumers of independent living services and as employers of their own personal assistants, except that disabled people are not consumers or employers in quite the usual sense. Consumption in this case refers to the procurement of the most fundamental services to a person's life, a far cry from the consumerism to which many are accustomed. The employment of personal assistants is also quite different from the typical employment relationship. No capital is invested, as funds are generally provided by the state, and no profit is derived. The problem, as Russell (as cited in Rosenthal, 2019) implied, is that many disabled people are too poor to access the marketplace. She criticised the ILM for its unquestioning acceptance of capitalism:

On the one hand, it seeks to promote

autonomy and self-determination for disabled people. On the other, it implicitly accepts the foundations of free market ideology by framing the debate in terms of the right of disabled people as consumers to receive equal treatment from the marketplace. (p. 8)

However, the ILM (and the disability rights movement more generally) are not so much a rejection of capitalism as an adaptation of it. It is the existence of a social market, where the welfare state coexists with the freedom to contract, which makes the support for individual autonomy possible. Indeed, the ILM aims to bring about a society in which structures that curbed the individual freedom of disabled persons in the past (and to a considerable extent still do) are transformed into ones that provide them with the support and adjustments that are crucial for them to make meaningful choices and maximise their agency (Morris, 1993). In so doing, the ILM addresses the contrasting definitions of independence - reduced dependence versus appropriate support - identified by Kendall and Cameron (2013).

The two positions can be explained in terms of whether the emphasis is placed on societal structures or on personal agency. A person can attribute their success or failure purely to their own merits (and hence to the exercise of their personal agency), or to the favourable circumstances that the person finds themselves in (and hence to the societal structure to which they belong). A sole focus on personal agency risks solipsism, while a sole focus on societal structures risks losing sight of the individual altogether. These two positions can be seen as the extreme ends of a continuum along which most debates on structure and agency can be placed:

Sociologists who define social forces as though they are real things independent of the reflection and actions of human beings concoct the sociological fallacy of determinism and reification. If individuals believe and act as though they are autonomous and sovereign, then those individuals obscure the effects of structure... Yet the power of social forces does not determine individuals. As long as humans are alive and in possession of their consciousness, agency exists. (Musolf, 2017, p. 5)

Seeing disability as being only socially

created emphasises structural barriers and is based on an expectation that societal structures bear the responsibility of removing these barriers for disabled people to enjoy their rights to a life on an equal basis with others. The issue with this view is that it can be difficult to establish at what point the disabled person's autonomy and independence come into effect. Even if autonomy and independence are seen to be mediated through the support of others, namely from personal assistants on an individual level to macro-structures that enforce accessibility requirements in the community, there must be a point at which disabled persons are responsible for their own actions and lives, with the consequences of the decisions they have made. After all, the focus on disabled people's right to live life on their own terms, rather than it being determined by those whose support they depend on, is predicated on a view of disabled persons as active agents in their own lives (Morris, 1993).

The strength of the ILM is that it is based on a relational view of the individual and is thus less a rejection of the Kantian autonomous and rational being than a re-conceptualisation of personhood. The individual remains more important than the societal structures they inhabit (Musolf, 2017), even as all energies are directed towards changing these structures. The need to change these structures for disabled people to be able to exercise their individual agency is undeniable. Equally important is the need to emphasise this agency. In fact, apart from the social model of disability, the other crucial tenet of the independent living movement is encapsulated in the slogan Nothing About Us Without Us (Charlton, 1998), a slogan that reacts to millennia of disabled people's lives being entirely determined by other people, who are often not disabled themselves.

Concluding Reflections

Ensuring the continuation of the positive changes ILM has achieved requires action on a number of fronts. The first is a matter of outlook. Appreciating our interdependence, and acknowledging how the progress of even - perhaps especially - the most successful, has depended upon the support and resources of others, may help to counter the view of care services as residual and pertaining only to the

vulnerable Other. It is also important to recognise that reducing the experience of disability - or of any diversity for that matter - to negative terms such as tragedy or dependence is simply not accurate. Disabled people share widely-held aspirations. Achieving them involves strength of character and ability - especially in the face of socially-created obstacles - as well as having the right support.

Attitudinal change is not enough. The ILM reminds us to challenge the subordination of values to economic growth, the profit motive and narrow cost-benefit analysis. Policies to strengthen the inclusion of disabled people, through choices such as accessible infrastructure and educational systems as well as good jobs are not simply "inefficiencies that impede the natural economy of self-interest" (Robinson, 2020, n.p.) but are fundamental to the exercise of disabled people's most basic rights. The choice to allocate sufficient resources that enable disabled people to exercise the rights and freedoms that most of us take for granted must be made and sustained. While containing public expenditure may be necessary, we must challenge a mindset of scarcity that would impose selective austerity upon those for whom such cuts have the most devastating effects.

To conclude, the ILM emerged from a long struggle to assert disabled people's rights to autonomy and social participation (Zames & Zames, 2011). As outlined, the movement has its own internal tensions but these do not arise from any problem inherent to the nature of the movement's claims, but from the complexity of the contexts that disability activists have had to grapple with. We contend that the ILM offers a good example of the way in which capitalism both creates, and defies, expectations of choice and self-determination, but also of how capitalism may be informed by the ILM and by the disabled people's movement more generally. The lessons that the ILM has brought into broader policy are invaluable. We grow up together and are interdependent. Our relations are, by their very nature, reciprocal and the social and economic contribution of everyone should be recognised and valued. The experience of CILs has shown us the value of cooperative enterprise and service-user involvement. More broadly, too, the ILM reminds us of the transformative force of collective

action; of the fact that rights and freedoms must be universal and resourced if they are to have any meaning at all; and the fact that economic progress should be slave, not master, of those higher values that make society a better place for us all.

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