Independent Living in Europe and Beyond

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Special Issue Editorial

Independent Living in Europe and Beyond: Past, Present, and Future

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ABSTRACT

This article introduces this special issue of the *International Journal of Disability and Social Justice* focusing on Independent Living, understood both as a social movement and an analytic paradigm. The aim of the special issue is to mark the 50th anniversary of the first Centre for Independent Living, as well as the tenth occurrence of the Freedom Drive, a biennial advocacy event organised by the European Network on Independent Living (ENIL). We first explain the significance of these two initiatives, tracing their history and rationale in terms of disabled people's struggle for self-determination. We then discuss the meaning of Independent Living and associated definitional struggles. In the main part of the article, we explore the relations between Independent Living and the state, the market, and the family. This helps us to understand Independent Living as critique of professional power, self-sufficiency, and parental authority. The practical implications of these critiques are explored by looking at current struggles for deinstitutionalisation and personal assistance. We conclude by presenting the pillars of Independent Living and their consideration in the contributions to this special issue.

KEYWORDS

disability studies; European social policy; independent living; self-determination; social movements; professionals; neoliberalism; parents; familialism; UN CRPD

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The year 2022 marked five decades since the formal establishment of the first Centre for Independent Living (CIL) in Berkeley, California. Independent Living ideas and practices emerged earlier, in the late 1960s, from the activism of Ed Roberts and other disabled students at the University of California, Berkeley, who were seeking alternatives to their institutional, restrictive, and medicalised living arrangements on the university campus. Eventually, this activism resulted in the founding of the first CIL in 1972. The pioneers of Independent Living:

> *became aware of the degree to which control over their lives had been taken over by medical and rehabilitation professionals. They thus came to realize that the concerns about self-determination raised by the black and student movements had considerable relevance to their own lives as disabled people. (Zukas, 1975: n.p.)*

For many who fight for empowerment, equality, and inclusion of disabled people, the founding of the first CIL in Berkeley marks the symbolic birth of the disability rights movement. The latter was influenced by the struggle of Black Americans for civil rights, as well as by other liberation movements that defined the 1960s (Charlton, 1998: ch. 8). Five decades later, the desire for freedom on the part of the pioneers, as well as their courage to challenge professional power and socially created disablement, continue to be a source of inspiration and insight for disability activists all over the world.

2022 was also the year of the 10th Freedom Drive, a biennial Independent Living advocacy event organised by the European Network on Independent Living (ENIL). The Freedom Drive currently brings together several hundred disabled activists and allies from all over Europe. They gather in Brussels, the symbolic capital of the European Union (EU), for three days of discussions, lobbying, celebration, and protest. The recent Freedom Drives have included workshops, an international conference, and a hearing in the European Parliament. There is also a party. The culmination of the event, however, is a march past the EU institutions in the city in protest against the continuing violence and denial of freedom experienced by disabled people throughout Europe. The Freedom Drive is a powerful reminder that the Independent Living movement is very much alive and as needed today as it was 50 years ago.

ENIL, the Freedom Drive's organiser, is a membership organisation which, since its inception in 1989, has been led and controlled by disabled people. It is the pan-European heir of CIL – Berkeley and was founded by a group of disabled activists soon after the first CILs emerged in Europe. The 1980s were a time of fervent activity and international exchange. John Evans (2002: 10), one of the pioneers of the movement, recounts how in 1983 British activists attended the first Conference on Independent Living in Sweden:

> *This was reciprocated in the UK with its first Conference on Independent Living and attended by Adolf Ratzka and Judy Heumann, who was then the Director of the CIL from Berkeley, California. After these two Conferences there was a very close liaison and relationship between the UK and Swedish Independent Living developments, which would form the basis for the beginnings of an European movement. (Evans, 2002: 10; see also Ratzka, 1996)*

In Britain, the movement received a decisive boost in 1979 from a group of disabled people confined to a residential institution in Hampshire, England – the Le Court Cheshire Home (Evans, 2002). The Le Court residents sought ways to live independently in the community, similar to their CIL – Berkeley peers. This led to the establishment in 1984 of one of the first CILs in the UK, the Hampshire CIL (for a detailed history of the Independent Living movement in the UK, see Hunt, 2019: ch. 8). In Sweden, the Stockholm Cooperative for Independent Living (abbreviated in Swedish as STIL) was conceived in 1984 but started activity later, first as a pilot project in 1987 and then permanently in 1989, after overcoming 'massive resistance from some political parties, the labor unions, traditional service providers and the established disability organizations' (Ratzka, 1996: n.p.).

Both John Evans, a founding member of the Hampshire CIL, and Adolf Ratzka, founder of STIL, were involved in the establishment of ENIL, described by Evans (2002: 13–14) as:

> *one of the most significant events in Europe for the Independent Living Movement. … It started when over 80 disabled people, most of whom were personal assistance users, from 14 different European countries, congregated at the European Parliament in Strasbourg to discuss issues of concern on Independent Living.This ended up being an historic event because the main outcome of this meeting of minds was the establishment of ENIL and hence for the first time there was a co-ordinated approach for Independent Living at a European level.*

Currently, ENIL has 81 full and 30 associated organisational members from 44 countries, most of them in Europe. ENIL's mission is 'to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible' (ENIL, n.d.-a: n.p.). At present, the organisation is financially supported by the European Union and its Nordic allies in Norway and Sweden.

This special issue is created and edited by people working in ENIL or associated with the organisation, to mark the twin anniversaries of the CIL – Berkeley and ENIL's Freedom Drive. It includes articles by the members of ENIL's Independent Living Research Network, as well as interviews with activists who celebrate the achievements of the Independent Living movement, reflect on the difficulties and successes along the way, analyse current issues, and consider possibilities for future developments.

We begin our editorial introduction with a discussion of definitional struggles. We then consider Independent Living advocacy in historical and political perspective by exploring its relationships with the state, the market, and the family. This helps outline key elements of Independent Living theory, as it developed organically over five decades of campaigning for self-determination. We then explore more recent issues of practical import by discussing advocacy for deinstitutionalisation and personal assistance (PA) in Europe. This overview of Independent Living practice is completed by considering the pillars of Independent Living and their presence

in the interviews and the articles included in our special issue. We finish with a brief reflection on the future of Independent Living in Europe and beyond.

Independent Living and Definitional Struggles

Definitional struggles have always been at the heart of disabled people's fight for self-determination. They have entailed challenges to pathologising, undermining, and restrictive definitions created and maintained by 'caring' professionals and societies. Along the way, disabled people have shifted the meaning of disability from individual deficiency to restrictions imposed on people with impairments by the way societies are organised (UPIAS & the Disability Alliance, 1976: 14). We adopt this definition and the language of the social model of disability (Oliver, 2009) by using the expression 'disabled people' instead of 'people with disabilities'. Accordingly, we follow the social model in distinguishing between individual 'impairment' and socially imposed 'disability', although we also recognise the interrelations between the two, in conformity with paragraph 5 of the Preamble and Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

With regard to Independent Living, we capitalise the term to distinguish our use from a more general understanding. An example of the latter is when social workers and other 'caring' professionals talk about 'independent living' in the sense of living on one's own and/or having skills for 'coping' without support with everyday tasks, such as cooking or cleaning the house. We consider this use of the term to be misleading. Independent Living is not about living on one's own and/or without support, but about having the necessary supports to make choices and be in control of one's life (ENIL, n.d.-b). Accordingly, only skills of expressing preferences, making choices, and managing support can be regarded as properly Independent Living skills, and such skills may also be exercised with support rather than in isolation (as in supported decision-making).

We follow DeJong (1979) in regarding Independent Living as both a social movement and an analytic paradigm created by disabled people in their fight for self-determination. It embodies the 'nothing about us without us' principle (Charlton, 1998). On the practical level, Independent Living:

> *is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives.This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs. (ENIL, n.d.-b: n.p.)*

Independent Living has been codified as a human right in Article 19 of the CRPD, whose provisions have been explained in detail in General Comment No. 5, drafted by the Committee on the Rights of Persons with Disabilities (2017). As such,

Independent Living is part of a more general paradigmatic shift in disability policy, reflected in the CRPD – the shift:

> *from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. (United Nations, n.d.: n.p.)*

Other definitional struggles of the Independent Living activists have focused on the meaning of key Independent Living policies such as deinstitutionalisation, or key supports such as personal assistance (PA) (both discussed in detail below). The advance of the Independent Living movement in Europe has resulted in the mainstreaming of such policies and supports through their incorporation in national legislation, strategies, guidelines, and professional practices. The CRPD has greatly contributed to this process, particularly after its ratification by the EU in 2010. However, the mainstreaming of Independent Living has also meant increasing misinterpretation and misuse of key Independent Living policies and supports (Angelova-Mladenova, 2017: 11). Currently, such appropriations of Independent Living ideas and terms constitute a major strategy for maintaining the status quo of keeping disabled people confined to residential institutions or at home – controlled and patronised by their 'carers', pathologised, undermined, neglected, or abused as in the early days of the struggle.

Independent Living and the State

The recollections of Hale Zukas (1975), one of the founders of CIL – Berkeley, make it clear that the Independent Living movement has focused from its very inception on challenging the power of 'caring' professionals – physicians, rehabilitators, nurses, psychologists, social workers, special teachers, therapists – to control and define the lives of disabled people. Independent Living has been about critique of professional dominance, a concerted fight against the maltreatment of disabled people at the hands of welfare 'experts', whose power significantly grew during the 'golden age' of the welfare state in Europe. This period was between the end of the World War II and the end of the 1970s, when the 'increase in state-sponsored welfare and the increased professionalisation of the services meant that the newly trained medical professionals and social workers, the so-called "experts", were increasingly making decisions about what a disabled person's needs were and what support was best for them' (Roulstone & Prideaux, 2012: 32).

When thinking about the history of the Independent Living movement, it is important to remember that the post-war welfare state had disabled people assessed, labelled, treated, and disciplined by medical professionals, in medical settings, through medical-administrative categories. Some were left at home with little formal support, while others were confined in residential institutions where they were subjected to segregation, paternalism, block treatment, rigid routines, deprivation of privacy, physical and medical restraint, neglect, and abuse. For many disabled

people, professionalised 'care' has amounted to restrictions, control, or outright violence (Oliver, 2009; Oliver & Barnes, 2012).

Looking at the Swedish welfare state of the 1970s, Ratzka (1996: n.p.) recounts the 'apparent paradox' that, on the one hand, disabled Swedes at the time had a relatively good standard of living due to being cared for by publicly funded structures and functions, but on the other, they lacked opportunities to make choices and be in control of their lives, and their social standing was poor. The 'paradox' disappears when realising that widespread publicly sponsored measures such as clustered housing have been institutional in character – they may have kept people fed and warm, but they have also prevented the residents' self-determination:

> *Among the shortcomings specific to the [clustered housing] solution, as cited by residents, is that services are based on the 'house arrest principle', i.e. they are not available outside the apartment, at work, about town or when travelling. … With time many residents have learned to assess the probabilities of receiving assistance for various tasks at a given time of the day and week and to adjust their needs to the staff's schedule. (Ratzka, 1996: n.p.)*

The state socialist societies in Central and Eastern Europe (CEE), although billed as alternatives to Western and Sothern European capitalisms, did not differ substantially in their treatment of disabled people (Rasell & Iarskaia-Smirnova, 2014). They also provided 'care', and this 'care' was comparably medicalised and institutionalised, although generally of poorer quality and more decisively oriented towards re/insertion of disabled people into employment – the state socialist social policy was 'summoned to enhance production by making and keeping people work-ready' (Mladenov, 2018: 7). As in the West, the cultures and practices in state socialist residential care facilities corresponded to Goffman's (1974) 'total institutions' by subjecting residents to surveillance, control, depersonalisation, block treatment, and rigid routines (Tobis, 2000: 11). However, due to widespread repression of civil society organising, the Independent Living movement emerged in CEE later than in the West, in the 1990s, after the fall of state socialism (Mladenov, 2018).

The entrenchment of state-sponsored, medicalised, paternalist 'care' has made the fight for self-determination of the people at its receiving end bitter and protracted. 'Caring' creates a situation where restrictions of freedom or outright violence could easily be framed as exercised 'in the best interests' or 'for the good' of the cared for. It is more difficult to oppose violence when it is presented as benevolent – the Scottish Independent Living pioneer Jim Elder-Woodward (2001: 3, citing Oliver, 1994) highlights the branding of disabled people as 'ungrateful bastards' due to their criticisms of ostensibly well-meaning professional interventions and limitations. In response, Independent Living activists have regarded the term 'care' itself as reflecting the traditional approach to disability, in which disabled people have been expected to passively submit to the will of their 'carers' – parents/relatives, physicians, service providers, charities (see Oliver & Barnes, 2012: 66).

The structures, discourses, and practices of the 'caring' state are by no means confined to the past. European welfare systems continue to deliver 'social care' of a

type rejected by the European Independent Living movement. As we will argue in our discussions of deinstitutionalisation and PA below, traditional forms of paternalist 'caring' for disabled people keep finding ways of maintaining and reproducing themselves – in more recent years, by appropriating and misusing Independent Living terms and ideas. This is a stark reminder of the immensity of the task that Independent Living activists began 50 years ago.

Independent Living and the Market

The critique of 'caring' professionals and welfare-state structures, voiced by the Independent Living activists, has converged with the market-promoting, neoliberal critique of the state (Harvey, 2005). The latter intensified in the 1980s with the ascendance of Thatcherism in Britain and was further bolstered in the 1990s by the disintegration of state socialism in CEE and its widespread 'shock-therapeutic' substitution by neoliberal capitalism (Dale, 2011).

In an early critique of the Independent Living movement, the British medical sociologist Gareth Williams (1983: 1004) disapprovingly characterised it as incorporating 'a basic commitment to the American capitalist system with its free-market pluralist ideology'. Indeed, pioneering Independent Living legislation in Europe like the Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments (abbreviated in Swedish as LSS) of 1993 and the British Community Care (Direct Payments) Act 1996 were adopted under right-wing governments that sought to restructure and/or retrench the welfare state. Accordingly, trade unions have traditionally been suspicious of the demands of Independent Living activists for direct payments instead of service in kind, perceiving them as a form of 'creeping privatisation' (Priestley et al., 2010: 311).

However, the convergence between Independent Living and neoliberalism has always been *partial*. The agreement between the two paradigms has rarely extended beyond critique of traditional authority and promotion of individual choice. Indeed, some European Independent Living activists have embraced the consumerist ideas of their American counterparts (DeJong, 1979) and have sought to mobilise the market in the fight against the authority of the 'caring' state. For example, Ratzka (2012: 3) has criticised 'state monopolies' in service provision and has argued for their substitution with 'demand-driven markets' where disabled people receive direct payments to choose and purchase support from a variety of competing providers. And yet, such arguments have sought *redirection rather than retrenchment of public support*, accompanied by a shift in the role of authorities from 'providers' to 'purchasers' of services:

> *as statutory authorities switch to become purchasers rather than sole providers of services, so users become more vociferous in their demands for a voice in shaping these services, whoever they are purchased or provided by (Oliver & Zarb, 1992: 7).*

At a deeper level, whereas neoliberals have framed choice in terms of *self-sufficiency*, as 'individual entrepreneurial freedoms' (Harvey, 2005: 2), the promoters of

Independent Living have framed choice in terms of *self-determination*. The advocacy of Independent Living activists for self-determination has illuminated the context of interdependence that the discourse of self-sufficiency has obscured. Accordingly, whereas neoliberals have insisted on cutting public support to promote self-sufficiency (or individual enterprise), Independent Living activists have argued for rechannelling of public resources towards support that enhances self-determination – such as PA funded through direct payments.

In a nutshell, Independent Living campaigners have combined their critique of welfare-state paternalism with a resolute defence of public support. For example, the British Independent Living activist and scholar Jenny Morris (2011: 16) has called on disability rights campaigners to 'start from an explicit and vigorous promotion of the welfare state and of the concept of social security in its broadest sense'. Another example: whilst consistently criticising state-sanctioned institutionalisation of disabled people, ENIL has also been active in campaigning against austerity since cuts to public supports intensified in the aftermath of the financial crisis of 2007/2008 (e.g. ENIL, 2014: 7; 2020a: 8). The recognition of the need to simultaneously criticise and promote the welfare state has been a core feature of the Independent Living movement, and both tasks continue to be imperative.

Market-based individualism has also been at odds with another prominent feature of Independent Living advocacy and policy – its foundational collectivism. From its very inception, the Independent Living movement has been characterised by a strong reliance on peer support and mutual empowerment (DeJong, 1979). In his otherwise scathing critique of the Independent Living paradigm, Williams (1983: 1004) has recognised that what he identified as the individualist, free-market ideology underpinning the movement has been counterbalanced by 'mutual aid, community action and support, a focus on environmental pathology as opposed to victim-blaming and the development of coalitions with other vulnerable groups'. For Independent Living activists, peer support has been a cornerstone of their resistance to professional and paternal power. We should remember that CIL – Berkely became possible because its founders:

> *were in close, continuing contact with other people having similar problems and concerns. A sense of unity and self-confidence gradually developed, largely as a result of the free flow of communication and sharing of experience. The residents' political consciousness grew as they became aware of the degree to which control over their lives had been taken over by medical and rehabilitation professionals. (Zukas, 1975: n.p.)*

The reduction of Independent Living to a neoliberal assault on the welfare state grossly misrepresents the movement. This misrepresentation has been enabled by other misconceptions, such as the rendering of Independent Living in terms of self-sufficiency that has sometimes been used to legitimise cuts to social support amidst creeping austerity (Elder-Woodward, 2016; Manji, 2018). However, as already argued, Independent Living activists have actively campaigned against austerity measures. Independent Living is about interdependence, although unqualified

praise of interdependence can also be counterproductive and end up bolstering professional power, institutionalisation, paternalism, and familialism. Independent Living is about *a particular form of interdependence*, one that enhances self-determination. On the level of practice, such interdependence is guaranteed by the pillars of Independent Living that we will explore in more detail below.

Elder-Woodward (2016: 254) has argued that the movement and paradigm of Independent Living have incorporated several political philosophies – the classical liberal one, associated with individual choice and control; the communitarian one, associated with peer-support and peer-advocacy; and the civic-pluralist one, associated with the ideas of co-production or the 'nothing about us without us' principle. According to Mladenov (2015: 445), in the age of austerity and radical marketisation, disability activists need 'to defend self-determination while criticising market-based individualism, and to defend the welfare state while criticising expert-based paternalism'. In terms of strategy, it is likely that Independent Living advocacy in Europe will continue to revolve around shifting the balance of power from professional 'care' to support for self-determination, where a key challenge in recent decades has been fake or reinstitutionalising deinstitutionalisation.

Independent Living and the Family

The family is the third major organising principle of social support, together with the state and the market. Feminist scholars have insisted that familial support should be considered as a political rather than personal matter due to, among other issues, the gendered division of labour (Orloff, 2009). Indeed, classifications of welfare state regimes are incomprehensible or partial without considering the role of the family. In particular, Southern European welfare states have been characterised by high reliance on family members (mostly women due to the gendered division of labour) to provide 'care' to disabled people, in addition to caring for children and older people. For example, in Türkiye, 'the image of the mother as the carer of her impaired adult "child" is almost a cultural norm' (Bezmez & Porter, 2022: 57). In recent decades, such 'familialisation' of disability support has increased in the post-socialist societies of CEE as well, largely due to their well-researched retraditionalisation during the neoliberal transformations that followed 1989.

Independent Living advocacy has been in agreement with feminist scholarship that family support is a political issue that shapes and is shaped by social policy mechanisms and political agendas. Disabled people in familialist cultures are often positioned as 'eternal children' and experience lifelong paternalism within their families, in addition to professional and societal paternalism in the public domain. In such contexts, Independent Living activists have fought with parental power as much as they have fought with professional power. As the disability studies scholars Sara Ryan and Katherine Runswick-Cole (2008: 201–202) have argued, the parents of disabled people – overwhelmingly the mothers, who tend to remain 'caregivers' during disabled people's adult life – may be regarded as both 'oppressors' and 'allies'. As 'oppressors', parents restrict self-determination and transmit disablement

(often in the name of 'protection'); as 'allies', they experience and fight disablement when they are subjected 'directly and by proxy' to the discrimination faced by their young or adult children.

Indeed, the over-reliance on family members to provide PA in familialist contexts has contributed to the 'institutionalisation at home' of disabled people, discussed in the section on PA below. 'Institutionalisation at home' has also been fuelled by the persistent lack of adequate formal supports in the community. Dependence on family 'care' tends to limit self-determination and produce feelings of entrapment on both sides that become increasingly acute with the ageing of the parents. Such a dependence cements the gendered division of labour. At the same time, familial support has some benefits, including 'not being exposed to the financial costs of care or the stigmatised status of resorting to professional care [in a familialist culture], and intimacy and trust common to positive filial relationships' (Bezmez & Porter, 2022: 61).

As 'allies', parents have also been strong advocates for disability rights. This is evidenced by parental mobilisations in recent years in the post-socialist countries of CEE (e.g. Dimitrova, 2020). These mobilisations have included protests, lobbying, and peer support that have criticised professional power, opposed neoliberal cuts, and demanded reformed public support for disabled people, including increase in disability benefits, funding for PA, and changes to legal capacity legislation. Still, the outcomes of these initiatives have often amounted to the bolstering of familialism and institutional care, instead of their undermining (see e,g, Mladenov & Petri, 2019).

The Independent Living movement continues to challenge parental power on a par with professional power, while recognising the significance of familial support. Crucially, Independent Living is not about living on one's own or destroying the family but about living in families of self-determining equals. This goal overlaps with the goal of those feminists who seek to increase the independence of women both within and outside families (Orloff, 2009). As Ratzka (2019: 4) explains:

> *My wife was familiar with my system of personal assistance. We both wanted to live together but also needed to feel free in a relationship where we, independently from each other, could develop and grow as human beings. We knew this was possible with personal assistance. With the help of my assistants I would continue to take care of myself, with the help of my assistants, I would do my part of the household chores.*

Independent Living and Deinstitutionalisation in Europe

In 2007, a major European report estimated that 1.2 million people, including children and adults with psychosocial impairments, were living in residential institutions in 25 European countries (Mansell et al., 2007: 25). Ten of the 15 top-ranked countries from this sample, as arranged according to the rate of institutionalisation in large institutions (with over 30 places), were former socialist states. Since then,

the situation has remained relatively unchanged. Despite widespread deinstitutionalisation reforms supported by the EU through its Structural Funds, in 2020, 1.4 million people still lived in residential institutions in the 27 EU member states (Šiška & Beadle-Brown, 2020). How is this possible, considering the decades of Independent Living advocacy in Europe, EU's ratification of the CRPD in 2010, and EU's explicit commitment to deinstitutionalisation (European Commission, 2021, 2010)?

ENIL's extensive experience in campaigning for deinstitutionalisation at the EU level suggests that a major reason for this lack of progress has been the entrenchment of the power of 'caring' professions across Europe. Financially and organisationally, the European Independent Living movement has always been small and weak when compared with the service provider industry, its academic lobby, and their satellite provider-led civil society organisations. It is these stakeholders who are continuing to reproduce the (still) dominant discourse of 'social care'. In most European countries, small groups of local Independent Living activists have opposed large national and international networks of much better resourced welfare 'experts' and disability charities, with much stronger representation in academia, on government panels, and within the EU institutions. In effect, deinstitutionalisation reforms in Europe have been sluggish, half-hearted, and have often resulted in reinstitutionalising solutions:

> *We have received numerous reports of plans to replace large residential institutions with small group homes and similar residential facilities, as well as with foster care for disabled adults. While these services may be located in the community, they perpetuate the segregation and social exclusion of disabled people by failing to provide disabled people with the opportunity 'to choose their place of residence and where and with whom they live on an equal basis with others' [as stipulated in Article 19(b) of the CRPD]. ENIL is also concerned that Member States are not using ESI [European Structural and Investment] Funds to invest in mainstream services, such as housing, employment or inclusive education. (Bulic Cojocariu & Kokic, 2018: 7)*

The continuous misframing of deinstitutionalisation as renovation of the old institutions or as relocation of residents to newly created smaller institutions such as 'group homes' has been particularly prominent in the post-socialist countries of CEE due to their weaker Independent Living traditions and heavier legacies in institutional care (Mladenov & Petri, 2019). Examples include Croatia, the Czech Republic, Bulgaria, Hungary, Romania, Latvia, Lithuania, Slovakia, and Slovenia, where EU funds have consistently been used to maintain institutional care (Bulic Cojocariu & Kokic, 2018: 9–10; Parker & Bulic Cojocariu, 2016). However, it is certainly not a CEE-specific issue – investment in group homes and clustered housing has also been regularly made across Europe, in Western and Southern European countries such as Austria, Denmark, and Malta, to name a few (ENIL, 2022).

Research on group homes has shown that, even if small-scale, better resourced, and/or placed within communities, such settings nevertheless tend to reproduce key features of institutional life (e.g. Deneva & Petrov, 2016; Fylkesnes, 2021). However, the language of Independent Living has increasingly been misused to

justify the creation of these settings as part of 'deinstitutionalisation' programmes. To counteract such misuse, the Committee on the Rights of Persons with Disabilities (2017: 4) has stated in its General Comment No. 5 that neither large-scale institutions nor smaller group homes can be called 'independent living arrangements' if they deprive their residents of choice and control in their everyday lives through rigid routines, block treatment, surveillance, and other practices characteristic of institutional care. Moreover:

> *No new institutions may be built by States parties, nor may old institutions be renovated beyond the most urgent measures necessary to safeguard residents' physical safety. Institutions should not be extended, new residents should not enter when others leave and 'satellite' living arrangements that branch out from institutions, i.e., those that have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established. (Committee on the Rights of Persons with Disabilities, 2017: 10)*

To avoid fake or reinstitutionalising deinstitutionalisation, it has been imperative (although far from straightforward) to include smaller and critical disabled people's organisations in the monitoring of deinstitutionalisation programmes (Parker et al., 2017). Independent Living activists have also insisted that the European Structural and Investment Funds should only be used to promote Independent Living and inclusion in the community (Bulic Cojocariu & Kokic, 2018), and that this requires establishing appropriate community-based supports such as PA. And yet, the advocacy for PA in Europe has encountered similar misuse and misappropriations as the advocacy for deinstitutionalisation.

Independent Living and Personal Assistance in Europe

The provision of support for hiring and managing of personal assistants was among the priorities of CIL – Berkeley (Zukas, 1975) and has become a defining feature of its European heirs (Hunt, 2019: ch. 8; Ratzka, 2004). Article 19(b) of the CRPD explicitly includes PA among the community services that the states parties should develop to enable disabled people to live independently and be included in the community, and PA is discussed extensively in the General Comment No. 5 of the Committee on the Rights of Persons with Disabilities (2017).

However, as with deinstitutionalisation, with PA the devil is in the details. Whereas properly resourced, user-led, and user-controlled PA is key for Independent Living, provider-controlled and/or restrictive one-on-one support billed as 'PA' may actually hinder self-determination and lead to 'institutionalisation at home'. Ratzka (2019: 10–11) makes the point clear:

> *The transition from institutional to community living is not automatically accompanied by higher degrees of independence and self-determination for the person who requires assistance. Depending on the number of assistance hours, the organizational structure of the service provider and the resulting division of power over services between staff and client, the individual user – although living by him- or herself in an ordinary apartment – might in effect not have more self-determination than*

> *someone who lives in an institution of brick and mortar. Not being in charge of important functions, such as recruitment, training, scheduling, supervision of your assistants can turn your home into an institution.*

Independent Living activists have created and promoted detailed definitions of PA to prevent such mis-provision of PA or misuse of the term. A prominent example is the model of PA developed in 2004 by a coalition of nine Independent Living organisations from nine European countries (Austria, Finland, Germany, Greece, Ireland, Italy, Norway, Sweden, and Switzerland) and described by Ratzka (2004). Drawing on this work, ENIL (n.d.-c) has defined PA as 'a tool which allows for independent living', characterised by funding through cash allocations, provision on the basis of individual needs and circumstances, rates of pay that ensure adequate salaries for the assistants and cover additional expenses (e.g. employer contributions, administration, and peer support), and, perhaps most importantly, the ability of the PA users to recruit, train, and manage their assistants. This definition is also in line with the detailed definition of PA provided by the Committee on the Rights of Persons with Disabilities (2017: 5) in its General Comment No. 5.

Notwithstanding such definitional efforts, ENIL's monitoring of PA programmes in Europe has consistently highlighted the significant variability of supports identified (sometimes misleadingly) as 'PA' in different countries (ENIL, 2013, 2015, 2020b; Mladenov et al., 2019). For example, a comprehensive 'PA Checklist' was co-produced with the members of ENIL and applied in 2019 by Independent Living experts in eight European countries (Mladenov et al., 2018). The results showed that some of the PA schemes assessed – such as the one in Sweden – have enhanced Independent Living, whereas others – such as a programme in Bulgaria or in Ireland – have created barriers to Independent Living. Instead of enabling disabled people's choice and control, the latter have been restrictive. Similar to reinstitutionalising deinstitutionalisation, restrictive and/or provider-controlled PA deprives the people who use the support of their independence.

PA has also been subjected to critique by those suspicious of the Independent Living movement and philosophy due to its aforementioned (partial) convergence with neoliberal marketisation. Such criticisms have been voiced by trade union representatives, feminist advocates of the 'ethics of care', and disability scholars embracing interdependence:

> *The discourse of direct payments and PAs, which has evolved from the social model, has, to date, been managerial … and devoid of a language of mutuality, partnership and interdependence. (Watson et al., 2004: 338)*

A related concern has been the possibility of PA users of exploiting their assistants, who have usually been non-unionised and have included large numbers of migrants and/or women (Shakespeare et al., 2017: 11; Watson et al., 2004: 339). Feminist scholars have been most vocal in highlighting the intersectional vulnerabilities of personal assistants that have allegedly exposed them to potential abuse in contemporary PA schemes (Christensen, 2009; Kittay, 2018).

In response to these criticisms, it is important to emphasise that the interests of the PA users and personal assistants largely coincide. Research has shown that PA users consider the good working conditions of their assistants as a major enabler of Independent Living (Mladenov, 2019: 11). The European model of PA described by Ratzka (2004: 6–7) has similarly called for payment of 'competitive wages' and the necessity to cover indirect labour costs such as compensation for unsocial hours and overtime, social insurance and leave, as well as to maintain a 'safe and healthy working environment'. On their behalf, the assistants have indicated higher levels of job satisfaction than traditional care workers, even in cases of weaker formal employment protections (Leece, 2006; Woolham et al., 2019). PA enables continuity of support and the development of personal relationships, which are difficult if not impossible for traditional care work due to regimentation of tasks, demands of travelling, and lack of personalisation. It is hardly surprising that friendships between the PA users and their assistants are a prominent feature of PA (Shakespeare et al., 2017).

The Pillars of Independent Living and the Contributions to the Special Issue

PA is key but not enough – it is but one of the pillars of Independent Living. The practical realisation of Independent Living requires a system of interrelated supports and accommodations controlled or overseen by disabled people. The pioneers at CIL – Berkeley promoted 'a holistic, integrated approach by providing a comprehensive array of services' designed and monitored by the people who use them (Zukas, 1975: n.p.). Originally, these user-led and user-controlled services included support with finding and managing personal assistants, advocacy and advice concerning benefits and services, and help with maintaining assistive devices such as wheelchairs (Zukas, 1975). Hunt (2019: n.p.) describes the first CILs as:

> *facilitators, trying to provide support, information and advice, so that people could make better use of existing resources for themselves. At times, this might mean becoming negotiators with other service-providers to highlight the absence of services, such as tackling a local housing department to provide accessible housing where none existed or engaging with local transport providers where no accessible transport existed. At other times, it could be about providing support to individuals to achieve more for themselves.*

The supports considered key for Independent Living, sometimes conceptualised as the '12 Basic Rights' (Spectrum CIL, n.d.) or the '12 Pillars of Independent Living' (Disability Rights UK, n.d.), include accessible environment, accessible transport, accessible and affordable housing, accessible information, appropriate assistive technology, PA, inclusive education and training, adequate income, access to employment, independent advocacy, peer support/counselling, and accessible and appropriate healthcare. We may add to this list support with decision-making that is needed to make Independent Living possible for some people with intellectual and psychosocial impairments (Gooding, 2018).

The pillars of Independent Living are summarised in Article 19 of the CRPD and detailed in General Comment No. 5 of the Committee on the Rights of Persons with Disabilities (2017), while supported decision-making is addressed in Article 12 and General Comment No. 1 (Committee on the Rights of Persons with Disabilities, 2014). It is the simultaneous and coordinated presence of all these supports and accommodations, as well as their use-led and user-controlled management and development, that constitutes the holistic and integrated approach envisioned by the Independent Living pioneers.

Taken together, the 12 interviews with Independent Living activists, the five research articles, and the three current issues papers in our special issue constitute a comprehensive assessment of Independent Living supports and accommodations in present-day Europe. We interviewed Adolf Ratzka from Sweden, Antonia Trikalioti from Greece, César Giménez from Spain, Diogo Martins from Portugal, Elena Pečarič and Klaudija Poropat from Slovenia, James Cawley from Ireland, John Evans from the UK, Milica Mima Ružičić-Novković from Serbia, Nicolas Joncour from France, Suvad Zahirović from Bosnia and Herzegovina, Vanya Pandieva from Bulgaria, and Vibeke Marøy Melstrøm from Norway. In the interviews, the activists reflect on the impact of Independent Living on their lives. They highlight their advocacy achievements and challenges, and identify their allies and enemies along the way. They also explore current barriers to Independent Living in their countries, making links to the war in Ukraine, the COVID-19 pandemic, Euroscepticism, and the cost-of-living crisis. Thinking about the future, the activists discuss Independent Living strategies at local, national, and international levels.

The research articles mobilise the conceptual and methodological tools of social sciences to provide evidence and develop Independent Living theory further. Thus, Miro Griffiths expands our understanding of European disability advocacy by exploring activist discourses and approaches prominent among young disabled activists from different European countries. Drawing on Beckett and Campbell's (2015; Beckett et al., 2017) work, Griffiths conceptualises Independent Living as an 'oppositional device' capable of mobilising collective resistances to oppressive cultures and identities, thus creating liberatory 'heterotopias'.

Without the pillars of Independent Living, communities can be as restrictive as residential institutions. This is evidenced in the research of Gabor Petri, Agnes Turnpenny, and Aniko Bernat on disabled Hungarians living in both institutions and the community. The authors explore contemporary barriers and some facilitators to Independent Living in Hungary, covering most of the pillars of Independent Living mentioned above. In another contribution from Hungary, Anikó Sándor, Csilla Cserti-Szauer, and Vanda Katona focus on inclusive education and the 'nothing about us without us' principle. They argue that an approach of participatory teaching is capable of challenging traditional academic hierarchies and ableism by involving disabled people as 'co-instructors' in training future professionals.

Shifting the attention to housing, Áine Sperrin explores the situation in Ireland to argue for making accessible and adequate housing in the community a constitutional right. Sperrin highlights defective construction materials, inaccessibility, the invisibility of disabled people's homelessness, lack of PA, and ongoing institutionalisation as key barriers to the Independent Living of disabled people in Ireland. Darja Zaviršek and Svenja Fischbach discuss the state socialist and post-socialist challenges to Independent Living in the countries of former Yugoslavia, focusing on Slovenia and Serbia. Considering the distinctive trajectories of the post-socialist development in these two countries, Zaviršek and Fischbach explore the negative impact on Independent Living of delayed deinstitutionalisation, reinstitutionalisation, familialism, retraditionalisation, and persisting paternalist attitudes towards disabled people.

Three shorter current issues articles complement the five research papers with details about emergent issues. Jim Elder-Woodward mobilises postcolonial theory to criticise the current attempts of the Scottish Government to professionalise PA in Scotland on the model of mainstream 'care work'. Drawing on their experience of promoting Independent Living in Türkiye, Melike Ergün, Lilia Angelova-Mladenova, and Bahar Yavuz discuss the challenges faced by Independent Living campaigners in a context of entrenched charity attitudes, familialism, depoliticisation of disability issues, and sustained attacks on human rights defenders. Violeta Gevorgianiene and Egle Sumskiene discuss deinstitutionalisation in present-day Lithuania, highlighting the resistance of local communities to accepting disabled people as neighbours when deinstitutionalisation is reduced to relocation of disabled people from big institutions to group homes.

The reflections and analyses included in our special issue indicate the issues likely to shape the Independent Living agenda in Europe in the future. These issues include ongoing and intensifying definitional struggles due to increasing appropriation of Independent Living ideas and policies by professionals and service providers; fake deinstitutionalisation; lack of PA or provision of fake PA; chronic deficiency of accessible and affordable housing in the community; increasing poverty and inequality, linked to continuing retrenchment of the welfare state; transnational migration; and rising European authoritarianisms that threaten to undermine the human rights paradigm and, by extension, the fragile achievements of the CRPD and other international human rights instruments.

More generally, Independent Living campaigning and analysis are likely to become increasingly intersectional and transnational. Although we have not specifically addressed policy responses to COVID-19 and the war in Ukraine in this introduction, we are acutely aware that they have intensified many of the existing barriers and challenges to Independent Living on the continent. Europe is currently at a crossroads. To direct the outcome of the crises befalling the European communities towards human wellbeing, we need to remember the key lesson of 50 years of Independent Living advocacy – that all lives matter, and that all lives are entitled to self-determination.

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