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Prefiguration and the independent living movement

Teodor Mladenov^a and Miro Griffiths^b

^aSchool of Humanities, Social Sciences and Law, University of Dundee, Dundee, UK; ^bSchool of Sociology and Social Policy, University of Leeds, Leeds, UK

ABSTRACT

This article facilitates a productive encounter between social movement studies and the Independent Living Movement (ILM), a collective mobilisation that advances disabled people's self-determination. More specifically, we analyse the ILM from the perspective of prefiguration, understood as the activist practice of collectively realising a desired future in the present. This helps illuminate pivotal aspects of the ILM that remain hidden in more instrumental or policy-oriented accounts of the movement. Such aspects include, for example, ILM's bold experimentation and its important work on generating, exchanging, and preserving organic knowledge through self-education and norming. The first part of the article introduces the ILM and the concept of prefiguration. We then apply this framework to archival accounts detailing the activities of the first Centre for Independent Living (CIL) in the world – CIL Berkeley – in the 1970s. In the second part of the article, we shift our attention to the present by exploring attitudes to prefiguration displayed by young disabled activists in Europe in a recent research project. We conclude with some conceptual remarks about prefigurative research, complemented by a practice-oriented call to strengthen the prefigurative dimension of the ILM as a prerequisite for its more strategic, longer-term, and policy-oriented aspirations.

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Introduction

The first Centre for Independent Living (CIL) was incorporated in 1972 in Berkeley, California. This event signalled the emergence of a new social movement – the Independent Living Movement (ILM) – which advanced a radical change of disability discourses and practices, initially in the United States, then in Europe and globally. The ILM has had a significant impact on disability organising, knowledge production, and policy making around the world. The global footprint of the movement becomes clear when considering the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD was adopted by the United Nations in 2006 and entered into force in 2008, following years of intense consultations with disabled people's organisations from

CONTACT Teodor Mladenov  tmladenov001@dundee.ac.uk  Old Medical School, University of Dundee, Nethergate, Dundee DD14HN, UK

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different countries in the North and the South (Reina, 2008). Since then, the CRPD has been ratified by nearly all countries in the world, becoming a globally embraced disability policy and rights standard. Notably, the basic tenets of the ILM largely underpin the paradigm shift represented by the Convention. As clearly stated by the CRPD's monitoring body, the Committee on the Rights of Persons with Disabilities, this shift boils down to the promotion of disabled people's self-determination as an alternative to their objectification within systems of paternalist care:

The Convention ... takes to a new height the movement 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. (CRPD, n.d.: n.p.)

The CRPD also makes direct references to the ideas of the ILM in its Preamble and Article 19 on 'Living independently and being included in the community'. The fact that the CRPD has suffered from widespread misappropriations and failures of implementation only emphasises its radicality and paradigm-changing character (Mladenov, 2024, 2025). The ILM has been a major (although certainly not the only) contributor to the CRPD's potential to transform societies. But notwithstanding this impact and significance, the ILM has remained largely absent from Social Movement Studies (SMS). This is a disappointing – although not a surprising – omission, considering that disability is routinely disregarded by social sciences outside the relatively small 'disability studies' niche (Mladenov, 2024).

This article contributes to filling the gap by developing a study of the ILM that considers the movement from an SMS perspective informed by the idea of prefiguration – the practice of realising a desired future in the present (Boggs, 1977), whereby the organisation and activities of a movement embody the very social changes and emancipatory ends it seeks to achieve. Embracing this perspective is conceptually innovative since, to our knowledge, such an approach has not yet been used to understand the ILM. Existing accounts of the movement have focused on its policy relevance, strategic potential, pragmatic utility, or epistemic value (e.g., Evans, 2002; Hunt, 2019; Mladenov, 2024; Shapiro, 1993; Tarrant, 2022; Zukas, 1975). Indeed, recent scholarship has begun to explore utopian and prefigurative dimensions of disability rights activism – examples include Vogler's (2024) analysis of 'acting as if' in the US disability rights movement and Chis's (2024) examination of prefiguration in UK disability activism around precarious work. However, these contributions have focused on specific national contexts and thematic concerns. Our study advances the emerging conversation on prefiguration in disability activism by providing the first cross-generational and transnational analysis of prefiguration as a constitutive feature of the ILM.

We argue that the perspective of prefiguration helps overcome the limitations of prevailing policy-oriented accounts by showing that the ILM's political significance lies not only in its policy and legislative victories but also in its capacity to realise a desired future in the present. In other words, prefiguration allows us to uncover aspects of the ILM that complement its important instrumental features but remain hidden when considering the ILM in terms of its utility for longer-term, larger-scale societal change.

These hidden aspects concern enacting a utopian transformation of society here-and-now.

More specifically, a prefigurative lens helps illuminate several critical practices of the ILM: (1) the movement's systematic work of generating, exchanging, and preserving organic knowledge through peer-led self-education and archival practices; (2) the ILM's intervention in the micro-politics of intimate and private life, where disabled people enact self-determination in their daily relationships and personal support arrangements, creating lived alternatives to paternalist care that exist regardless of legislative recognition; and (3) the dialectical relationship between these prefigurative practices and the movement's strategic successes – rather than viewing expressive and instrumental politics as separate trajectories, a prefigurative analysis reveals how the ILM's capacity to materialise self-determination in the here-and-now has been an important complement to its longer-term policy achievements.

In this way, our analysis not only contributes to existing accounts of the ILM in disability studies but also advances theorisations of prefiguration in SMS. The latter is achieved by expanding Yates's (2015) seminal framework for analysing prefigurative action (discussed in detail below) in three distinct ways: (1) we highlight the role of intergenerational self-education and archives in sustaining the momentum through which prefigurative practices and political commitments are transmitted and renewed over time; (2) we broaden the understanding of 'consolidation' to include the micro-politics of intimate and private life; and (3) we challenge the dichotomy between expressive and instrumental politics by demonstrating that prefiguration serves as a dialectical prerequisite for successful long-term strategic and policy-oriented action.

Given that SMS has historically overlooked the ILM, we begin by recounting the movement's history to provide the necessary context for our subsequent analysis. We then define and discuss the concept of prefiguration and present our methodology. The ensuing framework allows us to understand the prefigurative aspects of some pioneering ILM efforts, as described in archival sources depicting the founding and consolidation of the first CIL in the 1970s. We then shift our attention to the ILM's present by discussing the attitudes of young disabled activists in contemporary Europe towards the prefigurative aspects of IL activism. To this end, we draw on qualitative data collected as part of a research project conducted in 2020–2024. On this basis, we outline several important features of the ILM that have so far remained under-theorised but whose understanding is crucial for the politics of IL.

Historical sketch of the ILM

The ILM emerged from the activism of Ed Roberts and other disabled students with extensive support needs pursuing degrees at the University of California, Berkeley, United States, in the 1960s (Mladenov, 2024, pp. 7–9). The accommodation and assistance they were receiving on the university campus were inadequate to let them participate on a par with their fellow students in the everyday life of the university, as well as in the burgeoning countercultural and protest initiatives characterising this centre of the 1960s youth radicalism (Shapiro, 1993: Ch. 2). The existing supports and arrangements

were unnecessarily restrictive, institutional, paternalist and medicalised. Eventually, discussions within the group helped its members to become:

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.)

The resultant self-help initiatives, support alternatives, and disability counter-discourses led to the establishment of the first CIL in Berkeley in 1972. As the quotation from Zukas (1975), one of the founders of the organisation, makes clear, the ILM was influenced by other emancipatory movements of the time, including Berkeley's Free Speech Movement, the civil rights movement of the Black Americans, the anti-war movement, and the women's movement (Charlton, 1998: Ch. 8). CIL Berkeley's work soon gave rise to a whole new paradigm for understanding disability (DeJong, 1979), which reflected disabled people's fight for self-determination and embodied the 'nothing about us without us' principle (Charlton, 1998). The latter asserts that no policy or decision regarding disabled people should be formulated without their participation and leadership, serving as a radical rejection of the paternalism imposed by care professionals. Thus, at the heart of the movement one finds the achievement of self-determination through collective mobilisation and self-help. As recent disability scholarship notes, mutual aid strategies are central to realising social change by communities routinely subjected to violence or neglect (McKane et al., 2024).

In the 1980s, the ILM spread to Europe, where it was spearheaded by disability activists such as John Evans (2002) in the UK and Adolf Ratzka (1996) in Sweden. In the UK, the ILM's history is associated with early deinstitutionalisation initiatives such as Project 81, when in the beginning of the 1980s a group of disabled people moved out of a residential institution and self-organised to live independently in the community. This led to the establishment in 1984 of one of the first CILs in the UK, the Hampshire CIL (Hunt, 2019: Ch. 8). In Sweden, the Stockholm Cooperative for Independent Living (STIL) was conceived in 1984, starting activity as a pilot project in 1987 and then permanently in 1989 (Ratzka, 1996).

In the 1990s, the ILM expanded eastwards and southwards. Organisations fighting for IL, including CILs, were established in the postsocialist countries of Central and Eastern Europe such as Bulgaria, Serbia, Slovenia, and Poland (Mladenov, 2024, p. 9). The movement was also growing in Southern Europe, making strides in Spain and Portugal. It received a pan-European representation with the establishment of the European Network on Independent Living (ENIL) in 1989, referred to by Evans (2002, pp. 13–14) as 'one of the most significant events in Europe for the Independent Living Movement' (see also ENIL, n.d.). In the 1990s, the ILM also spread beyond North America and Europe, with CILs emerging in Cambodia, Costa Rica, Japan, Korea, Mongolia, Nepal, Palestine, and the Philippines (Mladenov, 2024, p. 9).

Prefiguration

The idea of 'prefiguration' or 'prefigurative politics' has informed important and influential studies of new social movements, including seminal discussions of the alter-

globalisation and environmental movements, general anti-capitalist mobilisations, and other forms of contemporary anarchist and autonomist organising (e.g., Graeber, 2002; Maeckelbergh, 2011; Yates, 2015). As originally defined by Boggs (1977, p. 100), prefiguration means realising a desired future in the present. Although this usually happens at a smaller scale, the experience can be profound – in the words of Graeber (2002, n.p.), ‘It’s one thing to say, “Another world is possible”. It’s another to experience it, however momentarily.’

In prefiguration, the means become as important as the ends. Analyses of autonomist initiatives show how in the very act of decentralised, democratic organising, the movement realises what it seeks to achieve (Graeber, 2002). Prefiguration is thus about enacting alternative structures and building different communities here-and-now (Epstein, 1991). Drawing on Alberto Melucci’s (1989) seminal work, Neil Stammers (1999, p. 985) depicts social movements as having a ‘dual face’, since they usually combine ‘overt’, instrumental claims, with ‘covert’, expressive functions. Thus, every movement can be analytically described as bringing together ‘instrumental – political, economic, or social – demands with an expressive dimension oriented towards norms, values, identities, lifestyles, etc.’ (Stammers, 1999, p. 985). In prefigurative politics, the expressive dimension of a social movement becomes equal if not superior to the instrumental one. However, this emphasis on the expressive side does not mean that prefigurative action is less transformative than revolutionary action.

The distinction between ‘affirmative’ and ‘transformative’ approaches to social change was productively explored by Nancy Fraser (1995) while developing her influential theory of social justice in the 1990s. Fraser (1995) was interested in distinguishing redistributive and recognitive initiatives that generate deep changes in social structure from initiatives that amount to mere surface-level reallocation of material or symbolic resources. She argued that affirmative measures tend to strengthen the status quo of oppression while providing (some) alleviation in the form of (piecemeal but immediate) improvements in the living conditions and attitudes. According to Fraser (1995), only transformative initiatives lead to profound social change, but they usually take longer to yield results.

Prefiguration solves this problem by creating radical change here-and-now. With prefiguration, the focus is on internal articulation and enactment of norms and values (the expressive side of mobilisation) which, it is hoped, will eventually translate into external political and economic gains (the instrumental aspect of activism). The downside is that prefiguration’s smaller scale and expressive orientation may hinder wider and more sustainable shifts in policies, practices, and discourses. The intention, however, is to achieve social transformation through expressive means.

Following Yates (2015, p. 14), it would be useful to also distinguish several different features of prefigurative politics. *Experimentation* includes creating and enacting (in everyday and organisational life) new, alternative, utopian practices and relations – ‘another world’, in Graeber’s (2002, n.p.) words. Prefiguration also involves *self-education*, which means developing, discussing, and clarifying ideas, epistemic frameworks, or positions. Then, there is the activity of *norming* – creating new codes of conduct or ‘repertoires and routines’ (Yates, 2015, p. 14) that reflect experimentation and internally produced knowledge. Prefiguration also involves *consolidation*, which

entails changing actual entities, facilities, and spatial arrangements to embody the new norms, ideas, and practices. And finally, prefiguration is characterised by *dissemination* or informing the public about the new ideas, norms, and practices: ‘communicating messages of dissent, collective force and the existence of political alternatives’ (Yates, 2015, p. 14).

With these conceptual clarifications and distinctions in place, we are now ready to explore the ILM archive in view of the argument that the ILM has sought social transformation and has achieved it, at least partly, through prefigurative action. To this end, we will consider accounts of the movement’s early days in Berkeley, exploring the activities of CIL Berkeley in the 1970s. We focus on this organisation and this period as they represent the ILM not only in its genesis, but also at its best. These formative years are marked by extraordinary energy, creativity, informality, learning, and enthusiasm. The latter would eventually be tamed by the process of professionalisation that all successful social movements undergo – as argued by Stammers (1999, p. 998), ‘[t]he trajectory of institutionalization [of social movements] is always the same, from “change” to “order,” from challenging the status quo to sustaining it’.

Before explaining our methods, it is also important to emphasise that our analysis extends beyond applying an existing framework to a new case. Rather, we use the specificities of the ILM to advance theorisations of prefiguration in SMS. We do so by expanding Yates’s (2015) seminal framework to: (1) highlight the pivotal role of inter-generational self-education and archives in sustaining prefigurative momentum; (2) broaden the understanding of consolidation to encompass the micro-politics of intimate and private life; and (3) challenge the binary distinction between expressive and instrumental politics by demonstrating that prefiguration serves as a prerequisite for successful long-term strategic and policy-oriented action.

Methodology

This section outlines the methodological approaches informing the two linked strands of inquiry within the article – an archival study of IL activism during the 1970s and an analysis of survey and interview data focusing on how young disabled activists across Europe articulate, enact, and contest prefigurative political attitudes in the present. We situate the study of contemporary prefigurative attitudes against the historical backdrop of the 1970s activism to trace the movement’s prefigurative trajectory from its early articulation to its contemporary re-enactment. This juxtaposition is deliberate, as it enables us to examine how foundational norms, repertoires, and archival traces are carried across time and geography, and how they are subsequently reworked through intergenerational processes of self-education, translation, and strategic adaptation.

Archival research

The archival strand focused on the foundational years of the ILM by analysing documents detailing the activities of the first CIL in Berkeley, California, during the 1970s. The inclusion criteria targeted archival sources that explicitly depicted the founding, consolidation, and everyday operations of CIL Berkeley within this decade. This temporal and spatial boundary was established to capture the movement during its genesis

and prior to the process of professionalisation that typically tames successful social movements (Stammers, 1999). Accordingly, accounts lacking a focus on the Berkeley CIL's activities in the 1970s were excluded. Data collection drew from key academic and civil society repositories, including the Disability Rights and ILM Project of the University of California, Berkeley (<https://www.lib.berkeley.edu/visit/bancroft/oral-history-center/projects/disability-rights>; the project is discussed in depth and with fascinating detail by Farrel, 2025), the archive of the Independent Living Institute (<https://www.independentliving.org>), and the Disability Archive UK maintained by the University of Leeds (<https://disability-studies.leeds.ac.uk/library>). The final corpus comprised oral history interviews with prominent ILM pioneers, early organisational histories and foundational codes, and journalistic accounts of the CIL Berkeley.

The selected sources were subjected to a directed qualitative analysis informed by an expanded version of Yates's (2015) framework. Following Braun and Clarke's (2006) approach to thematic analysis, documents were systematically coded to understand the prefigurative aspects of these pioneering efforts and to identify how the early ILM embodied social transformation in the here-and-now. This approach facilitated the identification of key themes corresponding to five core features of prefiguration: (1) bold experimentation through the creation of decentralised, horizontal support structures; (2) self-education and bottom-up organic knowledge generation; (3) emergent norming through the articulation of new guiding principles for disability; (4) consolidation via interventions in material reality, such as accessibility modifications and deinstitutionalisation; and (5) dissemination of the movement's new ideas and practices. These themes are discussed in depth in the section 'Prefiguration in the early days of the ILM'.

Survey and interviews with young disabled people

Across the survey and interview phases, 228 participants were included (mean age = 27 years, standard deviation = 4.83). This comprised of 203 survey respondents and 25 interview respondents. Participants were required to be aged 18–35, self-identify as disabled, have an interest in or be actively involved in disability activism, and reside in a European state (classified using United Nations M49 European regions, with minor adjustments¹ for data collection). In total, 101 participants were from Northern Europe, 74 from Western Europe, 45 from Southern Europe, and 8 from Eastern Europe. Recruitment was conducted through disabled people's organisations across Europe (defined as organisations lead by and for disabled people that incorporate IL into their strategy and work), youth networks, online peer groups, and social media platforms (Facebook, Twitter, and Instagram).

The survey and the interview phases were intentionally sequenced and analytically linked but did not involve the same individuals (interview participants did not take part in the survey). The survey's purpose was to explore young people's experiences of disability activism and participation across Europe. Its findings were analysed prior to the interviews to establish an empirical map of participants' orientations and priorities, and to identify areas requiring deeper interpretive attention. Closed-response items were analysed using descriptive statistics (frequency distributions) to summarise patterns across the sample. Free-text responses were subjected to line-by-line coding,

with codes iteratively grouped into provisional themes. These descriptive and thematic findings were then used to refine and target the interview topic guide, enabling the interviews to probe the meanings, tensions, and ambivalences that sat behind the survey patterns and to test, complicate, and extend the emergent thematic frame. Interview transcripts were subsequently coded using an iterative thematic approach (Braun & Clarke, 2006), moving from initial coding to clustered themes through comparison within and across cases. The transcripts were read in dialogue with the survey-derived themes, which included importance of disability activism, restricting or increasing participation within activism, types of resistance practices, and the future of activism. This supported an integrated account of how prefigurative attitudes are articulated and enacted.

Aligned with the social model of disability (Oliver, 2009; UPIAS, 1976), the research did not record participants' specific impairments or diagnostic labels. Data collection prioritised the shared experiences of disability within a disabling political and social context, focusing on the restrictive barriers imposed on people with diverse health conditions, impairments, and diagnoses. While acknowledging the importance of addressing hierarchies of impairment within disability activism and social movements (Campbell & Oliver, 1996), this issue fell outside the scope of the data collection.

Ethics approval was granted by University of Leeds Research Ethics Committee. All participants provided consent before completing the survey and taking part in interviews. Responses were anonymised to preserve confidentiality.

The findings suggest that young disabled activists express a desire for prefigurative action manifested in three distinct ways: (1) participation in existing activities that constitute prefiguration; (2) pursuit of knowledge to enact experimental and creative social change in the present; and (3) recognition of the potential of IL activism to productively intervene in private and public spaces. We discuss these themes in the section 'Prefiguration and the ILM in the present', identifying how they resonate with early ILM prefiguration, to which we now turn.

Prefiguration in the early days of the ILM

When contrasted with mainstream disability organising, the ILM has clearly embraced a transformative approach to social change (Shapiro, 1993: Ch. 2). From its early days, the movement has endeavoured to change society by substituting professional and parental control over disabled people's lives with self-determination and mutual aid, which entailed expanding and democratising disability support (DeJong, 1979; Zukas, 1975). In other words, the transformation sought by the ILM has amounted to restructuring society so that disabled people are no longer treated as objects of care but are enabled to live as self-determining subjects (Mladenov, 2024). This, we argue, has included efforts to 'seriously challenge the existence of reigning institutions' (Graeber, 2002: n.p.).

The ILM has sought such a profound social transformation by setting up disabled-people-led services and advocating for policy and legislative changes (Heumann, 2004; Zukas, 1975). However, many of the activities of the movement can be characterised as prefigurative in the sense that they have realised some of the desired changes in the here-and-now and at the smaller scale of a local organisation and its host community. This

becomes clear when considering the early days of the first CIL, as it made it possible for many disabled people to directly experience ‘another world’ – a world free of disablement, paternalist care, and exclusion. In the 1970s, CIL Berkeley embodied all the features of prefiguration mentioned in the preceding section – experimentation, self-education, norming, consolidation, and dissemination.

Let us start with *experimentation* – or realising a utopian, alternative future in the present. In an oral history interview, Judy Heumann, a prominent ILM pioneer who led CIL Berkeley as Deputy Director in the second half of the 1970s, suggestively describes the organisation as ‘an incubator, a laboratory’ (Heumann, 2004, p. 393). A similar assessment is provided by a journalist who visited the organisation in 1979, encountering there a ‘revolution in microcosm’ (Kleinfeld, 1979: n.p.) – a term that would fit any prefigurative action worthy of the name. There were no historical precedents to what the early activists were doing (Heumann, 2004, p. 304) – hence, the exhilarating feeling of ‘making history’ rather than just enduring it (Heumann, 2004, p. 372). Notably, the bold experimentation of CIL Berkeley was – at least initially – decentralised and horizontal: ‘You know, in the beginning it wasn’t that formal. How did you become a client? You just came in and said you needed something. There was no federal money. There was no state money. There was no system.’ (Heumann, 2004, p. 300)

CIL Berkeley was also a hub for *self-education* that entailed the development of bottom-up, organic knowledge. Roberts (2007, p. 43) points out that before the ILM’s emergence, ‘other people had spoken for us. We were speaking for ourselves [now].’ Heumann (2004, p. 365) makes a very similar point by arguing that CIL – Berkeley ‘was enabling us to see that disabled people did need a voice that was controlled by disabled people . . . I think it was an opportunity for many disabled people to express themselves for the first time with the support of other people.’ Tellingly, to the question of ‘What would you do differently if you were starting IL today?’, Roberts (2007, pp. 44–45) answers by emphasising self-education: ‘I would do a lot more training, getting people in touch with the history and philosophy. Today we are not grounded in our own ideology.’

As far as *norming* is concerned, a ‘code’ was articulated by CIL Berkeley’s founders at an early stage, as reflected in Hale Zukas’s (1975) history of the organisation. This ‘code’ was already underpinning the design of CIL’s predecessor, the Physically Disabled Students’ Program (PDSP) at the University of California, Berkeley. As explained by Zukas (1975: n.p.), the guiding principles of the fledgling ILM included: self-determination (‘Those who know best the needs of disabled people and how to meet those needs are the disabled people themselves.’), holistic support (‘The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services.’), community inclusion (‘Disabled people should be integrated fully into their community.’), and cross-disability coverage (‘CIL would be an organization of and for all disability groups’). These principles would subsequently underpin the ‘pillars of IL’ (Disability Rights UK, n.d.) – another echo of the early ILM’s pioneering work of ‘norming’. The latter aligns with what Buchter (2022) describes as the prefigurative creation of new ‘social scripts’ that reorganise interactions between disabled and non-disabled people, moving from charity towards solidarity.

At CIL Berkeley, we also witness *consolidation* – the organisation intervened in material environments in a number of ways, most prominently by negating the

spatial and societal segregation of disabled people created by existing disability services and inaccessible environments. The Centre itself was architecturally and socially accessible: ‘you could not help but be totally blown away by the type of people who were there, coming in and out, and how accessible it was and how we were so much a part of the community of change’ (Heumann, 2004, p. 307). It also helped cut curbs and install ramps in the local community (Kleinfield, 1979: n.p.). In addition, CIL Berkeley sought to overcome the institutional confinement of disabled people: ‘We were getting people out of state institutions’ (Heumann, 2004, p. 305). Wheelchairs were redesigned by their users to enable more active lives, an adapted van helped disabled people travel in the community, and a separate programme urged homeowners to welcome disabled people by making appropriate housing adaptations (Kleinfield, 1979; Shapiro, 1993: Ch. 2). These are just a few examples of the first CIL’s decisive intervention in the material reality of disablement.

And finally, *dissemination*. The news that ‘another world’ was emerging in Berkeley quickly spread and towards the end of the 1970s:

Around 100 requests a month were streaming into the [CIL Berkeley’s housing] department, far too many to fill. ‘One of the problems we have is that Berkeley is being advertised as a Utopia for disabled people,’ Wolf said. ‘But not enough housing is available. People are literally flocking here from all over the country. They are landing at the airport and calling us up. About once a month someone pulls up outside in a taxi with all his belongings and says, “Here I am.” One person showed up with an assistant and we had to put him in a hotel. His assistant left and he started asking bellhops to empty his leg bag. The hotel kicked him out. We finally found him a place with another assistant. People commonly show up with no money. One guy hitchhiked here with his wheelchair.’ (Kleinfield, 1979: n.p.)

In this quotation, Kleinfield’s interviewee Jerry Wolf, who coordinated the housing department at CIL Berkeley at the time, describes the consequences of disseminating information about a ‘revolution in microcosm’ – in the context of a largely unchanged, disabling ‘macrocosm’, the revolutionised ‘microcosm’ may quickly get overwhelmed. This observation links to an earlier point about the downside of prefiguration – its smaller scale may make the experiment unsustainable. And indeed, towards the end of the 1970s, CIL Berkeley overexpanded to meet exponentially increasing demand and hope, which nearly ruined the organisation: ‘At the same time, there were a lot of pressures within the organization because of the funding problems and because, you know, as the organization got older, people were not as idealistic.’ (Heumann, 2004, p. 394)

To summarise, in the 1970s, CIL Berkeley exhibited all of the key features of prefiguration identified in the preceding section – bold experimentation, counter-cultural self-education, emergent norming, consolidation through changes in material reality, and dissemination of new ideas and practices. Has ILM’s prefiguration endured the test of time? How does the young generation of disability activists consider the prefigurative aspects of the movement? To answer these questions, we now turn to the findings of a recently completed research on present-day disability activism.

Prefiguration and the ILM in the present

In this section, we analyse data from a multi-phase research project (2020–2024) on disability youth activism across Europe. The analysis draws on data from Phase 1 (an online survey with 203 responses) and Phase 2 (25 online interviews), focusing on young disabled people's experiences with activism and the ILM.

Participation in existing activities that constitute prefiguration

The analysis of CIL Berkeley's activities in the 1970s showed that the organisation's prefiguration was never limited to the enclosed space of its office but extended to the local community and beyond – for example, through accessibility initiatives and action for deinstitutionalisation. Expanding interventions beyond the organisation to realise material changes in the wider community and everyday life is essential for the *consolidation* aspect of prefiguration. Indeed, ordinary actions and interactions hold significant prefigurative potential (Forno & Wahlen, 2022). By its very nature, the ILM challenges dominant norms and arrangements of everyday life, from promoting personal assistance (Ratzka, 2004) to acts of resistance that support disabled people to leave institutionalised settings (Hwang et al., 2024). Consider the kind of activism outlined in this remark from a respondent from Georgia (30 to 33-year-old woman):

I work with friends, some new and some long remaining in independent living movement, to tell people in the local area how to be personal assistants. We work with unemployed to understand independent living and then find the jobs so they work to assist disabled persons.

The respondent highlights the importance of using the IL philosophy to build consciousness amongst people attempting to access the local labour market. The emphasis is on the significance and employment opportunities associated with personal assistance – a key prerequisite of IL (Ratzka, 2004). When properly resourced and user-led, personal assistance has the potential to disrupt social configurations that promote traditional care services or institutionalised forms of service provision (Mladenov, 2024). The activism described by the respondent utilises existing political, economic, and social arrangements to make personal assistance possible here-and-now. As already discussed, prefiguration relies on the articulation of alternatives that destabilise entrenched material and discursive arrangements (see also Maeckelbergh, 2011). Promoting personal assistance among unemployed people is meant to extend the reach of IL philosophy in the community, situate the practice within local economies, and facilitate disabled people's liberation in the present. At the same time, to remain aligned with IL principles, the professional realisation and development of the assistants should emphasise user-led training, user-designed curricula, and contractual arrangements that embed user control at every stage (for a recent discussion, see Riobóo-Lois et al., 2023).

The desire to participate in existing ILM activities that prefigure disability emancipation is clearly expressed by this respondent, a 30 to 33-year-old transgender person from Poland:

I want to find independent living campaigns and activists who want to promote the ending of struggles on disabled people. This gives me hope that people like this already exist and we don't start from nothing.

This statement reveals several dimensions of prefigurative engagement. First, the respondent seeks to locate and join existing campaigns rather than initiate new ones, suggesting they view the ILM as a living tradition with established practices worth learning and adopting. The phrase 'we don't start from nothing' indicates a need for identifying already existing activism. This is precisely what *dissemination* accomplishes – making visible the 'another world' that others have already begun realising. Second, the activist derives hope not from abstract ideals but from the existence of activists already enacting change, which aligns with prefiguration's emphasis on experiencing alternative futures in the present (rather than merely imagining them). The desire to find these campaigns reflects an understanding that prefigurative transformation requires participation in communities where new relations are actively being practiced. In this sense, the respondent's statement demonstrates a prefigurative orientation – seeking spaces where liberation is being enacted now, not merely imagined or advocated for as a future goal.

As the preceding analysis of CIL Berkeley's bold *experimentation* in the 1970s suggested, prefigurative activism can serve as a testing ground for alternative social arrangements (see also Flaherty, 2023). By experimenting with new ways of organising their lives and personal support structures, disabled people can gain valuable insights into the feasibility and desirability of changes that seem utopian from a mainstream perspective, as highlighted by a research participant from Germany (26 to 29-year-old agender person):

I engage with Centres for Independent Living to understand possible mechanisms for proving independent living is more than dream. When people tell me it is not possible I can show them that we can have choice, we can have control, and we will have autonomy over our bodies.

The respondent's engagement with CILs is about demonstrating the present possibility of disabled people's self-determination. The expression 'more than a dream' echoes the original definition of prefigurative action as realising a desired future in the present (Boggs, 1977). Enacting dreams of choice, control, and autonomy has been a hallmark of CIL Berkeley in the 1970s and has remained a key motivation for engaging with IL activism. CILs create a tangible reality that helps resist representations of IL as unrealistic. They offer concrete examples of social transformation in action. Thus, CILs function as prefigurative spaces demonstrating the viability and desirability of disabled people's self-determination. They are evidence that alternative social arrangements are not only possible but already exist, albeit at a small, local scale.

Knowledge for enacting social change in the present

While Yates (2015) identifies *self-education*, *norming*, and *dissemination* as key features of prefiguration, our findings suggest that these categories must be expanded to include an intergenerational dimension. We already saw how during the first decade of its existence, CIL Berkeley became a veritable hub of epistemic innovation. The academic and civil society archives that emerged subsequently – such as those maintained by the

University of California, Berkeley, the Independent Living Institute, and the University of Leeds – have been important enablers of current efforts at IL prefiguration. Such developments align with Earl's (2018) argument that knowledge within social movements should go beyond consciousness raising towards informing and conceptualising activities that create change in the present. Consider, for example, the following remark by a disabled activist from France (34 to 36-year-old man):

I look to find ways to understand independent living terms, philosophies, actions. I spend my time reading, listening, and learning about what we can do to show independent living is real and possible for many people to access.

This statement reflects a commitment to understanding and enacting IL, which is very much in line with the intention of knowledge generation and exchange initiated by CIL Berkeley in the 1970s. The respondent engages with IL ideas in view of moving beyond detached contemplation and naïve idealism towards concrete action that realises utopian possibilities here-and-now. The pursuit of knowledge through 'reading, listening, and learning' becomes a crucial step towards making IL a tangible reality for broader populations. Efforts at *self-education* and *dissemination* blend here to create a foundation for prefigurative action oriented towards making IL a reality for the many.

Archives play a crucial role in enabling such learning (Rigney, 2024). They serve as active repositories of collective memory, offering valuable insights that can inform present-day actions and strategies. In other words, they function as 'prefigurative spaces' where marginalised communities can (re)construct their own histories to fuel current resistance (Lobo, 2019). Archival resources enable disabled activists to explore ILM's historical records and personal narratives, which facilitates understanding the past and building upon the legacies of previous movement configurations (Farrel, 2025; Sellie et al., 2015). This role of archives is clearly acknowledged by a Swedish activist (26 to 29-year-old woman):

My local organisation – and it is controlled by disabled people – keep records of activism from old activists [...] I enjoy learning because it gives me creativity in my attempts to do activism [...]. It helps me know why we do what we do now.

The point that peer-generated historical records help 'know why we do what we do now' reveals the contribution of archives not only to prefigurative *self-education* and *dissemination*, but also to prefigurative *norming*. The statement highlights the function of historical memory and intergenerational learning in guiding present action within the ILM. In other words, the respondent's engagement with their local organisation's archives underscores the importance of preserving and accessing the legacies of past activism. This act of learning connects activists with a history of struggle and resistance, motivating creative and experimental forms of activism here-and-now. Archives are also useful for activism because they illuminate the historical roots of contemporary social problems. By examining past struggles, activists gain a deeper understanding of the systemic injustices they are challenging (Robinson-Sweet & Caswell, 2025). This historical context becomes essential for developing effective strategies for enacting social change in the present.

The point that historical records stimulate creativity in the Swedish respondent's attempts to engage in activism is also significant from the perspective of prefigurative

experimentation. However, it may seem counterintuitive that engaging with the past helps realise creatively a utopian future in the present. Another respondent – a 30 to 33-year-old woman from Italy – untangles this temporal complexity by suggesting that engaging with the IL archive is not about replicating old strategies but about adapting them to innovate here-and-now. Learning from previous generations of IL activists is thus regarded as a foundation upon which to build new forms of activism, equally informed by contemporary challenges and opportunities. This *intergenerational self-education* fosters a dynamic and evolving approach to social change. By drawing on the past to realise creatively a desired future in the present, young disabled activists co-produce change with their older peers:

It is awesome to look through what organisations would do, let us say 20 and 30 years ago. Yes, I can understand what independent living means to them, but it inspires me in the very moment, like today. It makes me feel I need to do things – like campaign – now [...] and spend time with new campaigners.

This statement highlights a connection between historical inspiration and contemporary activism. The respondent engages with archival materials to produce knowledge, but it also serves as a catalyst for immediate action. The transformative potential of utilising historical records to coordinate peer networks and activities in the present means that young disabled activists participate within – and through – intergenerational collaborations. Their efforts to realise IL necessitate the coalescence of their own critiques with historical articulations by previous activists, going back to the original *experimentation* at CIL Berkeley in the 1970s. Thus, social movement archives are not neutral repositories but affective spaces (Assmann, 2006) with the potential to connect the past, present, and future in prefiguration.

The potential of IL activism to intervene in private and public spaces

We propose expanding the concept of *consolidation* beyond physical or organisational structures to include the micro-politics of the private sphere. This broader lens reveals how social change is enacted by way of subtle, localised interventions in both private and public spaces (Dussault, 2022). To be more precise, this approach to understanding social movements illuminates how the activism's impact on personal relationships is complementing its impact on community dynamics and broader social and political landscapes (Auyero, 2004). Examining the ways in which activists negotiate and reimagine both public and private spaces helps recognise how IL is realised in everyday acts of resistance. Consider, for example, this statement by a respondent from Greece (22 to 25-year-old man), in which he discusses resisting family expectations about life as a disabled person and emphasises the importance of IL peers in his personal life:

I take time with my friends talking about challenging my family expectations of me. Taking part in activism has given me confidence to speak against my parents and tell them I can decide for me. I feel safer with my friends, being together, knowing that life where I can choose what do I want to do is possible. I experience it with my friends who also are campaigning.

This account illuminates the potential of IL prefiguration to effect personal transformation. The respondent's experience of challenging familial expectations, enabled by

his involvement in IL activism, reveals how prefiguration can intervene in intimate relationships and everyday interactions. Challenging parental power is an act of rebellion but also a declaration of self-determination (Mladenov, 2024) – a core tenet of both the ILM and prefigurative practice. However, the self-determination thus enacted has an important collective dimension, as reflected in the support from fellow campaigners – a form of prefigurative *self-education*. By asserting his right to make his own choices, the respondent is prefiguring the autonomous *and* interdependent life he envisions. This captures the essence of prefigurative politics as *experimentation* that operates horizontally through a collective nurturing of ideas, goals, and activities to advance liberation (Swain, 2019). The respondent emphasises the importance of engaging collaboratively with his peers to sustain IL values at the level of the everyday. In turn, this allows for identifying fracture points, which can be manipulated to progress IL within private lives.

As already argued, prefiguration re-constitutes the nature of social change by incorporating properties of the alternative world within the present (Boggs, 1977; see also Asara & Kallis, 2023). This is strategically important, as it helps individuals and communities recognise that possible and desired futures can exist and – more importantly – do exist. Aspects of these futures can be experienced within the present, bringing into focus prefigurative *consolidation* that has already happened. In the ILM, transformative experiences like these are often reported by disabled people using personal assistance and consistently recognised in research (Riobóo-Lois et al., 2024). Personal assistance highlights the intimate connection in IL prefiguration between, on the one hand, the personal and the political, and on the other, the individual and the collective. A respondent from Turkey (18 to 21-year-old woman) captures the essence of such a multidimensional transformation:

It was a struggle to know how I use personal assistants. I did not know what to do. It upset me, having strangers in my parent's home, who interfere in my life. Then independent living campaigners would share their guide tools so I could be better [...] Now I feel I have independent living with good personal assistants.

The respondent's initial struggle with personal assistants reveals the tension between dependence and autonomy, a central theme within IL values (Griffiths, 2023). The turning point in the respondent's narrative comes with the intervention of ILM peers who provide guidance and resources. As discussed in the preceding section, acts of *self-education* through *dissemination* of internally generated knowledge are crucial for IL prefiguration (see also Schiller-Merkens, 2022). Since the early days of CIL Berkeley, IL campaigners have been producing the tools and resources necessary for disabled people to achieve self-determination in their private and public lives. Such knowledges include detailed descriptions of tried-and-tested personal assistance models that have become prominent parts of the IL archive (e.g., Ratzka, 2004).

In a nutshell, the prefigurative creation of alternative trajectories in the here-and-now requires the *consolidation* of social spaces that demonstrate the possibility of other ways of being (Yates, 2015). For disabled people, such spaces can be not only personally transformative but also lifesaving, which explains their repeated celebration by the respondents in the study:

You need to know that independent living movement in my life, in the Netherlands, saved my life. It got me to know that I do not need to be despair. People around me feel liberated and saved. Okay, struggles still around, yes. But there are solutions and people are fucking living them now. (26 to 29-year-old non-binary person from Netherlands)

To be ‘fucking living [the IL solutions] now’ is a powerful way to express the impact of IL prefiguration in disabled people’s everyday lives. The ILM in the Netherlands, as experienced by the respondent, has created a space where IL prefiguration can take place – where despair can be replaced by hope, where liberation can be experienced collectively, and where responses to injustice can be enacted. Such spaces, even when created within the private sphere of personal relationships and local networks, are essential for fostering liberatory practices (Griffiths, 2024). They serve as microcosms of a desired future and are crucial in supporting disabled people’s lives to survive and thrive.

Conclusion

This article developed a pioneering account of the ILM from the perspective of prefiguration – an SMS concept that has not yet been used to understand IL activism. Such an approach helped overcome a dual gap in existing research. On the one hand, the field of SMS has so far failed to consistently engage with the ILM, notwithstanding the latter’s importance for contemporary disability politics and policies, as reflected in the adoption of the CRPD and related trends. On the other hand, disability studies literature on the ILM has not yet considered the potential of the concept of prefiguration for understanding the movement. This potential boils down to prefiguration’s capacity for illuminating aspects of the ILM that complement its more prominent instrumental features but that may remain hidden in accounts focusing on the movement’s success or failure to produce longer-term and larger-scale societal change.

We started by presenting a brief history of the ILM. We then introduced the concept of prefiguration and its utility for exploring the ILM. To this end, we developed a reformulated version of Yates’s (2015) seminal framework by discussing five key features of prefigurative action. Loosely following Yates (2015), we termed these features *experimentation*, *self-education*, *norming*, *consolidation*, and *dissemination*. Our subsequent analysis of ILM prefiguration further reconfigured Yates’s framework by discussing the crucial role of archives and, therefore, intergenerational learning in *self-education* and *dissemination*, and by exploring the interrelationships between the individual and the collective and the personal and the political in prefigurative *consolidation*. In this way, we demonstrated that prefiguration operates across temporal and private-public boundaries, highlighting mechanisms that were previously under-theorised.

Our analysis of ILM prefiguration in the second part of the article used archival materials describing CIL Berkeley’s explosive development in the 1970s, and qualitative data collected during research on young disabled activists in Europe. We discussed the ways in which CIL Berkeley realised prefigurative social transformation through bold experimentation, countercultural self-education, emergent norming, consolidation through interventions in material reality, and dissemination of new ideas and practices. These various contributions constituted an archive that would eventually become a key source of strategic insight, affective support, and policy guidance for subsequent generations of IL activists. We evidenced this through

a close reading of young disabled activists' responses to questions concerning their activism. Thus, our analysis redefined the function of social movement archives, positioning them not as passive repositories of memory but as active, affective engines of intergenerational prefiguration. By treating the archives as dynamic workspaces, contemporary activists are able to engage in a transtemporal collaboration that transforms the 'here-and-now' of prefiguration from a local experiment into a cumulative, enduring political project.

To avoid any potential misunderstanding, it is important to emphasise that the ILM has never been content with creating alternative futures here-and-now and at the small scale of local CILs. From its very inception, the movement has sought wider policy changes – first national, then international and, ultimately, global. The ILM has been successful in this more traditional form of activism, considering the widespread adoption of the CRPD and its progressive incorporation into national legal codes and policy practices throughout the world. As argued in the introduction, the CRPD has embraced the basic tenets of the ILM. However, the Convention's persistent and ubiquitous misappropriations and misinterpretations by policymakers, professional, service providers, and even disability activists (Mladenov, 2024, 2025) suggest that CRPD's adoption needs to be carefully monitored and corrected. ILM prefiguration is a source of authenticity that could provide a foundation on which genuine IL policies can be built, while also serving as an antidote to professionalisation and institutionalisation that may stifle ILM's creative energies.

Our findings thus suggest that prefigurative initiatives are not separate from political change but can serve as 'translators' that connect grassroots experimentation with formal legal and political tools (Barros & Rose, 2023). ILM prefiguration is dialectically related to the instrumental dimension of IL activism. Such a relationship is essential for every successful form of social movement activism, especially when it is understood from an intergenerational perspective. Wider social transformation necessitates small-scale niches and free social spaces that allow prefigurative politics to emerge and flourish (Törnberg, 2021). From the perspective of the young disabled activists quoted in this article, the ILM is valuable when creating spaces to enact horizontal forms of participation supported by the IL archive. Localised spaces like CILs and associated self-help groups enable new claims and everyday practices to emerge, empowering the activists to resist paternalist care, segregation, and ongoing disablement in their everyday lives. Attempts at high-level advocacy and policy making following the CRPD's progressive realisation principles are bound to remain abstract or easily sidetracked without the prefigurative enactment of IL at the level of personal lives and local communities.

The pioneers of IL at CIL Berkeley and elsewhere did not wait for legislation to be adopted to start living independently – they organised to enact IL here-and-now (Evans, 2002; Heumann, 2004; Ratzka, 1996; Zukas, 1975). Young IL activists demonstrate a desire for such a prefigurative approach. This should not be taken to mean that they are not interested on policy advocacy or campaigning for societal change. Youth participation in ILM prefiguration should be considered as a ground on which traditional policy engagement could emerge. Our key finding is that prefigurative action is as much needed for the vitality of the ILM now as it was in the 1970s. For public policy, this means encouraging prefigurative consolidation by supporting small-scale, local IL initiatives like CILs and peer support networks. For the ILM, facilitating prefiguration means

developing the IL archive while continuing to encourage self-learning, ongoing norming and dissemination, and, most importantly, bold experimentation.

Note

1. For the purposes of this study, Armenia, Georgia, and Turkey were reassigned from the M49 category of Western Asia to Southern Europe to allow for consistent regional comparisons.

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Notes on contributors

Teodor Mladenov is Senior Lecturer at the School of Humanities, Social Sciences and Law, University of Dundee, UK. Previously, he was Marie Curie Individual Fellow at the European Network on Independent Living (2017-2019), and Leverhulme Early Career Fellow at the Centre for Public Policy Research, King's College London (2013-2016). Teodor has expertise in disability studies and activism, international social policy, postsocialism, and critical theory. He is author of *Critical Theory and Independent Living* (2024, Manchester University Press), *Disability and Postsocialism* (2018, Routledge), and *Critical Theory and Disability: A Phenomenological Approach* (2015, Bloomsbury). Since 2017, Teodor has been coordinating the Independent Living Research Network, a research collaboration hosted by the European Network on Independent Living. In the period 2000-2009, he was actively involved in campaigning for disability rights in Bulgaria, working closely with the Centre for Independent Living – Sofia.

Miro Griffiths is Associate Professor of Social Policy and Disability Studies at the University of Leeds and Director of the Centre for Disability Studies. His research focuses on disability politics, activism, social policy, and the ways disabled people organise collectively to challenge exclusion and inequality. He has worked with governments, public bodies, international organisations, and disabled people's organisations across the United Kingdom and Europe, contributing to policy development, research, and public debate. His work has explored youth disability activism, resistance practices, independent living, violence, and the politics of assisted dying and suicide. He is the author and co-author of books and academic publications on disability politics, including *Ableism and Violence* (Policy Press) and *Youth, Disability, and Resistance* (Routledge). Alongside his academic work, Miro is committed to strengthening disabled people's political participation, supporting collective organising, and ensuring that lived experience, scholarship, and activism meaningfully shape public policy and democratic debate.

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