Book Section:

Handbook on Society and Social Policy

Social Policy and Social Divisions - Disability

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Abstract:

Disability policy is yet to receive substantial attention from scholars operating within social policy discourse. This has led to a continuation of policy practice that prioritises individualised, overtly medical approaches to providing support to disabled people. Often leading to institutionalised, segregative, and residual care systems. Disability Studies scholars, disabled activists, and disabled people's social movements remain critical of these systems and the overall direction of contemporary disability policy. There is the possibility of change, evidenced in Disability Studies literature, contemporary policy-making processes, and the ideas emerging from disabled activists and their organisations. This chapter employs the concept of Independent Living, as defined by disabled people's social movements, to understand how disabled people are positioned as active welfare citizens participating in social policy and producing, as well as using, welfare. The chapter critically reviews three issues: the realisation of Independent Living within existing social policy; existing assessment methodologies that (are supposed to) provide social protection to disabled people; and disabled people's influence and engagement with the social policy process. The chapter argues that there remains substantial failings with current social policy aimed at supporting disabled people's access to and participation within society. If the issues explored within this chapter remain dismissed by scholars and policymakers, disabled people's emancipation will never be realised. Independent Living remains a useful lens for critically analysing contemporary social policy that affects disabled people's lives.

Keywords:

Assessment Methodologies; Care and Support; Disability; Independent Living; Representation; Social Model of Disability

Introduction

The question of how disability policy is determined is a crucial one in the current global context. Disabled people, across the world, are marginalised in their attempts to access services and gain social protection. There are repeated claims that opportunities to progress disabled people's rights is in jeopardy due to the political and economic objectives of States (Hauben *et al.* 2012). The continuation of austerity measures within Europe provides an example of disabled people and their families struggling to receive the right level of support to meet health, social care, and education needs (Horridge *et al*. 2019). Similarly, the majority of disabled people in the global South struggle against oppression perpetuated by poverty, inaccessible environments and the consequences of historical and contemporary violent colonial action (Grech 2016).

More recently, there is an emphasis to understand disabled people's position within society as one rooted in social inclusion and justice. Policymakers have attempted to develop policies on the basis that they promote disabled people's opportunities to be valued, supported, and active members of society - such examples will be explored later in the chapter. The introduction of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), in 2006, illustrates the importance of promoting disabled people's rights and ensuring disabled people have support and resources to make decisions about how to live their lives. According to Harpur (2012) the UNCRPD highlights existing rights that disabled people should be in a position to claim, and provides insight as to how disabled people's rights should be realised within the existing structures within society. The Convention, along with the UN Agenda 2030, European Disability Strategy 2010-2020, and Council of Europe Disability Strategy 2017-2023, are examples of agendas and mechanisms that prioritize full participation and equal opportunities for disabled people.

Social policy is designed to challenge the intrinsic aspects of political, social, and economic structures that are commonly subjected to violations. Attempts to build inclusive education practices (Slee 2019; de Bruin 2019), support for disabled people to enter and remain in meaningful employment (Bonaccio *et al.* 2019), and inclusive strategies to ensure access to and across the transport system (Jeekel 2019) are examples of how social policy can be utilized to protect and support disabled people. However, social policy remains a paradox. It is used to undermine and deny disabled people access to fundamental freedoms. The continued use of institutions (Kozma, Mansell, and Beadle-Brown 2009), segregated schooling initiatives

(Finnvold 2018), and health policies that promote eugenicist principles (Hansen, Janz, and Sobsey 2008) are testament to this.

This chapter employs the concept of Independent Living to understand how disabled people are positioned as active welfare citizens participating in social policy and producing, as well as using, welfare. The justification for using the concept is found within its centrality in disability activism and social movements (Griffiths 2019), as well as human rights treaties (United Nations Committee on the Rights of Persons with Disabilities (UNCRPD), in particular: Article 19) and national policy agendas and statutory guidance. The UNCRPD (2017) and the Equality and Human Rights Commission in the UK (2019) have both highlighted concerns that disabled people's right to Independent Living continues to be eroded due to the ever-changing political, economic, and social objectives of the state.

The chapter critically reviews existing evidence surrounding the realization of Independent Living, as articulated by disabled activists and prominent social movements. In order to realize Independent Living within social policy, it is important to explore existing assessment methodologies that provide social protection to disabled people. This is useful for understanding how disability is positioned within existing policy formation, implementation, and evaluation, as well as the proportion of resources and expenditure placed on facilitating disabled people's inclusion within society. Finally, the chapter considers disabled people's influence and engagement with the social policy process. This is necessary for considering how social policy dismantles historical, and traditional, forms of services and 'protection' – policies that often leads to institutionalized and segregated practices.

The chapter argues that despite attempts to ensure social policy addresses the marginalization and oppression experienced by disabled people, there remains substantial failings with current social policy aimed at supporting disabled people's access to and participation within society. The reasons for these failings are extensive and go beyond the parameters of this chapter. However, the issues explored within this chapter engage with critical issues that remain pivotal for realising disabled people's emancipation. Social policy discourse must encapsulate the contemporary ideas emanating from disabled people's social movements and engage, proactively, with the extensive literature surrounding inclusion, social justice, and - in particular - Independent Living, which emanates from Disability Studies and activist networks.

Understanding Independent Living and Disability

The conceptual basis of Independent Living has its origins in the activities and ideas of disabled activists and disabled people's organisations. Independent Living is predominantly associated with challenging oppressive infrastructures that deny disabled people choice and control over how to live and be supported within the community. It resists traditional notions of care, which position disabled people as passive and vulnerable individuals in need of segregation and rehabilitation. Independent Living has developed to critique the provision, resources, and management of support required by disabled people to be active and valued members within society. Furthermore, it engages with social policy areas relative to the organization and functioning of an accessible, just, and inclusive society - such as access to financial services, employment, transport, and education. Priestley (2007) provides a useful historical review of disability policy at the European level.

Academic and 'grey' literature demonstrates how organizations managed and coordinated by disabled people have developed a concept that engages with macro- and micro-level social policy practice. Evans (2011), for example, explores Independent Living within the context of developing personal assistance schemes, the implementation of anti-discrimination legislation, and challenging austerity policies that dismantle and reduce disabled people's support mechanisms. Bulic-Cojocariu and Kokic (2018) use the concept to critique how EU structural funds can accelerate or decelerate the deinstitutionalization programmes across Europe, and Mladenov (2017) considers Independent Living useful for establishing practical policy alternatives to the neoliberal rationality in Eastern Europe. Importantly, Berghs (2015) draws attention to how Independent Living is primarily conceptualized within an Anglo-American understanding of disability, citizenship, and support; therefore, as a way to identify various conceptualizations of Independent Living, literature and empirical research from the global South must be considered alongside the dominant discourse found within the West. Meekosha and Soldatic (2011) go further, arguing that Northern discourses of disability rights have influenced existing human rights tools and the experiences of disabled people in the global South remain detached from the dominant Northern analysis of disability.

This chapter embraces the UNCRPD position within Article 19 as its definition of Independent Living: 'the equal right of all persons with disabilities to live in the community, with choices equal to others, and [...] full inclusion and participation in the community.' Emphasis is on ensuring disabled people have access to a place of residence, on an equal basis with others, and

are not forced to live within institutionalised or group based living arrangements, as well as access to community support services, which includes but is not limited to, personal assistance, and does not allow for segregation from the community.

Calls to develop proposals to incorporate Independent Living into domestic law and social policy are extensive; however, there is a requirement to expand the literature and further the discourse surrounding Independent Living if it is to remain a useful lens for evaluation and overhaul of existing policy directions pertaining to disability. Distinguishing between narrow and holistic definitions of what Independent Living offers to social policy is important, for two reasons. Firstly, it can be used to protect and further opportunities for disabled people to - for example - own an accessible house, ensure common rules and standards on accessibility of goods and services (such as with the European Accessibility Act), and restructure the assessment procedures for identifying and providing for disabled people's needs. Secondly, Independent Living can challenge analysts to consider how policy affects the social position of disabled people within society. Will policies continue/return to a reinforcement of traditional, paternalistic understandings of disability? Will Independent Living be operationalized to prevent disabled people from disrupting the existing, normative ideas and actions that contribute to the structuring of society? On the other hand, can the concept be mobilized to ensure social policy unpacks the complexity surrounding disabled people's marginalization and challenges notions of an individual's value, contribution, choice, and autonomy within society?

Developing social policies to address disabled people's marginalization requires clear identification as to the cause and nature of disability. This is a particularly complex issue. Oliver and Barnes (2012) provide a comprehensive account of the various positions taken to articulate what disability is. However, for the purpose of this chapter, the *individual* and *social* models of disability are particularly relevant. It is important to distinguish between the ideas of the social model, as formed by activists, and the later academic interpretation that continues to be instrumental in Disability Studies. The core values of the social model were first established by Paul Hunt (1996) and later came to be considered fundamental to the principles of the Union of the Physically Impaired Against Segregation (1975, p.4). Disability would be considered a product of social conditions, requiring a holistic assessment of existing barriers:

> Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing, etc.

From this, the social model becomes a device to describe the experiences of disability. For Oliver (2008), who articulated the term 'social model', it remains a practical tool to improve disabled people's lives, providing policymakers with insight as to how the organization of social structures and collective activity within society can perpetuate the marginalization experienced by disabled people. Barnes (2012) argues the social model is a *heuristic* device, which highlights the limitations of traditional practices and policies that prioritize medicalized and rehabilitative interventions to address disability. Such interventions were, and continue to be, justified on the basis that welfare states articulate disability as the tragic, functional limitations of people with health conditions and impairments.

The individual model locates the problem of disabling barriers with the individual and within the functional limitations to arise from being categorised as disabled. As such, it is problematic to consider the health of a disabled person to be the primary reason for discrimination and disadvantage. This often results in policy that seeks to address disabling barriers by compensating the individual for their 'identified' limitations and providing institutionalized or residual care. More importantly, it means social policy fails to facilitate disabled people's inclusion within society and dismisses the important notion that disability is a social justice issue.

The social model remains significant for challenging existing policy that positions disabled people as dependent individuals, vulnerable to the existing organization of society, and unproductive to the economic pursuits of the State. However, if social policy is to engage critically with disability and bring about radical and progressive change, it needs to consider disabled people as active welfare citizens who engage with the policy-making process. Beckett and Campbell (2015) suggest understanding the social model as an oppositional device, which explores the ways in which the social model can assist activists in developing resistance-based practices to the processes that produce and sustain disablement.

Within a policy context, the social model as an oppositional device provides analysts with opportunities to consider what it means to oppose/resist, how that is realized, and the implications that occur from resisting. What happens when disabled people resist existing disability policy? Is disabled people's collective resistance challenging the distribution of resources to meet disabled people's needs significant enough to realize change? In this way, the social model can be used to draw attention to the policies and practices that perpetuate

disabled people's oppression, such as sheltered employment opportunities and segregated education systems. As argued by Beckett and Campbell (2015, p.275), the social model as an oppositional device allows for the identification of practices, programmes and rationalities that are unjust. It harnesses practices of resistance towards such programmes, procedures and rationalities, and introduces counter-rationalities and strategic activity by disabled people. Creating oppositional devices is a means of opening possibilities, of identifying and challenging the structures that demand and regulate conformity (Holmes 2007).

Attention now turns to the key issues associated with ensuring social policy reflects the aspirations and values found within Independent Living discourse.

The Pursuit to Realize Independent Living

As outlined above, Independent Living is complex within the context of social policy. It should not be limited to a specific focus on developing policies to meet the assessed care needs of disabled people. This narrow definition of Independent Living has, unfortunately, plagued much of social policy discourse surrounding disabled people's right to choice and autonomy. Within the UK, there is much concern with regard to the definition transitioning from the ideas and vision outlined by disabled people's movements globally to one that underpins New Right policy values. Clements (2008) illustrates this concern by exploring the expansion of the personalization agenda, a rollout of mechanisms - like direct payments and personal budgets - that the individual (disabled person) takes control of and acquires commissioning power in the local community. Independent Living, when adopted by a state enacting policies supportive of neoliberal values, becomes synonymous with an agenda rooted in expanding privatization, commodification of services, and an emphasis placed on individual responsibility to manage one's needs.

There is no suggestion that disabled people should be denied choice and control over the level of support, and how that support should be provided, to be part of their community. Rather, it is essential to understand how the pursuit of Independent Living is reimagined based on the dominant agendas of those who coordinate and influence the policy direction. Care, within a neoliberal context, has its foundations in individual autonomy and responsibility (Wrenn and Waller, 2017), with a residual approach taken by the state.

Policy developments to national and international events can reshape the aims and objectives to realise disabled people's right to Independent Living. Hande and Kelly (2015) illustrate this shift in Canadian policy following the 2008 global financial crisis. With changes to the eligibility criteria to access welfare and social security services, disabled people returned to the activism and resistance found in the development of the Independent Living agenda. This led to new, policy-driven visions of care and assistance to explore. A significant point in Hande and Kelly's argument is their concern about policymakers co-opting and restructuring the ideas and visions of disabled activists to suit neoliberal ideologies. Independent Living, care, and assistance remain inherently political. They exist within the context of institutionalization, residual forms of support, assessment procedures typically focused on individual limitations and medical prognosis, and notions of self-sufficiency. It is naïve to assume that policies directed towards the expansion of individual choice and independence will unequivocally deliver services reflective of disabled activist's notion of Independent Living.

Social policy is required to adopt a holistic definition of Independent Living, one that moves beyond existing debates surrounding concepts of service provision and support. Developing policies to engage with issues, such as the deinstitutionalization programme, remain essential, particularly when research suggests that EU structural funds are used to continue with restrictive, group-based support services across Europe (Parker and Clements, 2012; Kuuse and Toros, 2019). However, pursuing Independent Living is about repositioning disability policy to be primarily focused upon social justice and inclusion of disabled people within society. This means interrogating specific policy recommendations and strategies to determine whether proposed or existing policy practice, in the broadest sense, engages with the struggles experienced by disabled people, as defined by disabled people.

To achieve this, it is useful to consider the commentary provided by UN Committee on the Rights of Persons with Disabilities in relation to article 19 of the UNCRPD (*review* General Comment 5, 2017). In their guidance to States committed to realizing Independent Living, they highlight notable gaps in policies aimed at providing disabled people with opportunities to live independently in the community. In particular, the Committee raise concerns with regard to disabled people being denied opportunities to decide about living arrangements and the community; inadequate budget allocations to achieve independent living; and disparity between local authority implementation of strategies to provide appropriate support and infrastructure for disabled people, often arising from policies failing to consider decentralization challenges.

Within the global South, policy-making to advance independent living has required exploring the link between poverty and experience of disability (Cleaver et al., 2018). Scholars, such as Palmer (2011), have argued for emphasis on the economic resources required to address the material deprivation experienced by disabled people. Palmer continues by suggesting that policymakers need to differentiate between the basic needs of disabled people experiencing poverty and the resources needed to alleviate poverty long-term. This highlights the importance of implementing policy to address the specific needs associated with a disabled person's access to the community, such as personal assistance, assistive technology and accessible housing, as well as the wider strategies to address the overrepresentation of disabled people in poverty, such as the development of an inclusive education system. Quarmby and Pillay (2018) suggest policies must also take account of the intrinsic aspects associated with disability and nutrition. Food security frameworks, which address needs that emerge from the intersectional relationship between disability and nutrition, remain paramount to ensure that disabled people have access to the appropriate support and services that will guarantee food security and assistance. This, they argue, is particularly relevant to humanitarian emergency contexts.

The pertinent issues arising from the global South context draw attention to the necessity for social policy to respond to the intersectional aspects associated with disabled people's experiences of marginalization. Constructing an effective and socially just welfare system requires acknowledgement that disabled people are not homogenous. Systems and structures need to respond and take account of the specific needs arising from the connection between disability and, for example, ethnicity, gender, sexuality, or age. Research by Jung Kim, Parish, and Skinner (2019) draws attention to the importance surrounding policy evaluation and intersectionality. Rather than examining the target population affected by specific policy intervention, it is necessary to consider the impact of disability policy upon variations in identity characteristics. In their research, analysis of contemporary UK government disability policy highlights the increased hardship by disabled women to access appropriate levels of support to engage in the labour market. Exploring intersectionality and social policy remains a focal point for social policy discourse (Hankivsky and Cormier, 2011), with limited examples referencing disability (Liasidou, 2012; Price and Goya, 2016).

The Academic Network of Disability Experts (ANED) provide useful thematic reports and datasets to consider the progress made to realise Independent Living. Crowther (2019), in his assessment of disability policies within 35 European States, concluded that institutional care remains the traditional mechanism to meet disabled people's needs. Expenditure on

institutionalized practice surpasses the investment in community-based support, irrespective of age. Countries, such as Slovenia (Rafaelic, Ficko, and Flaker, 2017) and Belgium (Leyseele, 2019) are reported to spend more on institutions than on community-based support. Of all 35 European States reviewed by ANED, Finland reports higher spending on community-based assistance instead of institutionalized care (Crowther, 2019). Furthermore, where policies are developed to transition disabled people out of institutions and into the community, this often results in an overreliance on congregate living. Effectively, smaller-scale institutionalized facilities that continue segregated practices and reduce disabled people's choice and control over the level of support received and how it is provided.

This illustrates the significance of social policy incorporating the obligations and guidance from the UNCRPD in order to realize Independent Living. Crowther (2019) continues by suggesting States prioritise measures to reduce numbers of people residing in institutional care, rather than developing policies that incorporate wider strategies to improve disabled people's access to living and participating in the community. This is reflected in Sumnikov's et al. (2018) research, which explores disabled people's living conditions across European countries. Their argument centres upon three distinctive areas that contribute towards restrictions in the pursuit of Independent Living: lack of ambitious policy, complex and limited social care and support systems, and a lack of advocacy and awareness surrounding community living.

Questions remain as to how aims and objectives are identified during the policy-making process. Remaining with Sumnikov et al. (2018), they present a review of factors associated with the successful implementation of policy to realize community-based support. For example, in Switzerland it is considered essential that the UNCRPD was ratified in order to allow for a comprehensive approach to ensure disabled people's needs are met. In Italy, the cooperation between public administration, service providers, and disabled people's organizations is necessary to influence existing policy. Such factors affect the overall direction of policy to improve disabled people's living conditions, and determine the aims and objectives of policy agendas.

Ensuring policy is aligned with the aspirations of the UNCRPD Article 19 requires understanding of the methodologies used to assess disabled people support needs.

Different Approaches to Social Protection

States across the globe implement different assessment procedures in order to identify the needs of disabled people. The reasons for such variations in the approaches taken is reflective of the different ways in which social policy conceptualizes disability and Independent Living. Factors such as the prevalence of disability as a political issue, the emphasis placed on social justice, and the position of disability as a consequence of how society is organized - or the functional limitations of the individual - affect the approaches taken to identify and provision support for disabled people.

Prior to considering the variations in assessment methodology to meet disabled people's needs, it is useful to review public spending on disability. States have responsibility for the organization and financing of social protection systems. The amount spent on disability will help to understand the approach taken by the State to provision disability support within government agendas. Furthermore, it places into context the assessment procedures and the available options for the provision of support to disabled people. According to the OECD (2019a) dataset, public spending on incapacity is defined by the amount of spending in relation to sickness, disability, and occupational injury. This incorporates cash benefits, which are a response to the decision that a person is unable to access the labour market meaningfully - at all or partially. In addition to cash benefits, spending on incapacity can also include social transfers in kind (for example, the provision of rehabilitation services, day care places, and personal assistance within the home). Measured as a percentage of GDP, there are differences across continents and the globe.

Within the global South, Mexico's expenditure is 0.03 per cent of GDP and Chile is 0.74 per cent. In the European Union, public spending ranges from 1.3 per cent of GDP (in Germany) to 3 percent of GDP (in Denmark). Expand the geographical reach to the G-7 and the range is 0.6 per cent (in Japan) to 1.75 per cent (in Italy). The amount spent on disability does not indicate success or failure of policies to deliver effective and efficient support to disabled people. This very much depends on the social welfare regime adopted within the specific country or area under investigation. As highlighted in the previous section, considerable amounts of money are spent on the provision of expensive institutionalized care that will achieve nothing with regard to the realization of disabled people's right to Independent Living. Richardson et al. (2019) argue that welfare regime characteristics are a determinant factor in disabled people's experiences of accessing support. It is necessary to review existing welfare

regimes in order to improve the provision of support to disabled people. This requires consideration of state expenditure on cash benefits and services, but - similarly – there is a need to consider social security contributions by the individual (OECDb 2019), as well as the types of support available.

Typologies to identify welfare state regimes provide an overview of the disability assessment methods employed to identify and meet disabled people's needs. Scholars (Bambra and Eikemo, 2009; Vanhoutte, 2012) have sought to provide descriptive traits to illustrate the comparative and contrasting approaches taken by different countries across the globe to organize welfare. This illustrates the extent of redistribution surrounding services and cash benefits, and brings to attention the distributional effects of tax expenditure as a way of reducing inequality for marginalized groups (Avram, 2017). Within the context of disability, how public spending is redistributed is as important as the volume of what is to be redistributed.

Turning attention to the assessment procedures to identify and provision support, de Boer et al. (2008) suggests there is commonality in how assessments throughout Europe have tended to conceptualize disability. Emphasis is placed on the individual's functioning and ability to perform tasks associated with entering or remaining in the labour market, with medical professionals positioned as the authoritative figure in determining access to support. This is deeply problematic from an Independent Living perspective, as attention turns away from the barriers within society that restrict disabled people's participation. Instead, the procedures scrutinize the productivity of the individual, review individual ability to integrate into existing social structures within society, and attempt to classify the identified limitations of the individual's ability to function - the latter point explored comprehensively by Stone (1984). As an example, there are convincing arguments that UK disability policy has embraced a biopsychosocial model approach to reform benefits and restrict eligibility criteria to access disability support (Shakespeare, Watson, and Abu Alghaib, 2017). According to Berger (2014), it serves to broaden understanding of limitations in order to take account of psychological and social factors associated with marginalization. Put simply, the individual will take responsibility (or blame) for the barriers experienced in daily life, and support centres upon prompting the individual to engage with existing economic, political, and social structures.

This emphasis on using assessment procedures to individualize disability, and provision support on the basis of an individual's limitations of functioning, is also highlighted in the global South. Chaudhry (2019) notes that, within South India, social work assessments do little

to engage with the structural aspects that perpetuate disabled people's marginalization. Typically, outcomes are associated with an individual's attempt to gain empowerment - often using self-help groups. Chaudhry argues that this approach to assessment and provision reinforces the individual's notion of responsibility to overcome barriers within the social and economic context. The disabled person enters a process of assessment in order to determine what is required to remain/become productive to the functioning of society. This approach is evidenced throughout South Asia, realized through the domination of organizations - such as the World Bank - that are closely related with the development and implementation of projects associated with addressing disability issues.

Waddington, Priestley, and Sainsbury (2019) highlights five key points when reviewing the variations of disability assessments across Europe. First, assessment methods can centre upon a medical diagnosis with emphasis placed upon the individual's health conditions and impairments.   Second, they can be context-based. Focusing on functional capacity, the assessment explores an individual's needs within different contexts (employment, self-care, economic hardship). Third, assessments incorporate and combine different procedures to identify and provision support. Fourth, there remains procedural differences across the assessment approaches. This is in the case of how evidence is collected and the role of medical professionals and assessment teams. Finally, there is a necessity to consider how closely aligned state assessment procedures are to the UNCRPD aspirations. This is in response to concerns raised by the UN Committee on the Rights of Persons with Disabilities about incorporating definitions of disability as a determining factor in providing benefits and support, at the expense of understanding the support needs required by disabled people to participate in the community.

Assessment of a disabled person's needs may lead to community-based support and produce opportunities to participate within the community. However, assessment procedures are not reflective of the values and ideas underpinning the Independent Living approach. Policy-making, overall, has failed to provide a comprehensive approach to identifying the barriers within the organization of society that deny and restrict disabled people's participation – barriers that transcend the functionality of the body and deny disabled people an accessible home, financial support, and transport system. The chapter will now consider the significance of involving disabled people within the design, development, and delivery of policy to address disabled people's marginalization.

Disabled People's Representation in Social Policy Formation

Critical policy analysis has drawn attention to the importance of examining key actors within social policy formation. According to Diem et al. (2014) there is a need to investigate who influences the implementation and evaluation of existing policy practice. Whilst this is useful for determining the direction of policy, it highlights the individuals, organizations, and communities who are denied opportunities to influence policy-making processes. This is evidenced in Byrne's (2019) assessment of inclusive education policy across the globe, who argues for disabled children to have opportunities to influence and promote inclusive education strategies.

Disabled people's social movements often campaign under the slogan of 'nothing about us without us' (Charlton, 1998). This serves as a demand to ensure the inclusion of disabled people within the policies and strategies that have an impact on living conditions and participation within the community. Whilst activists are united in their call for representation, it is a continuous struggle for disabled people to be included in the policy-making process. Nevertheless, the requirements outlined in the UNCRPD (notably Article 4) call for States to actively involve disabled people in the legislation and policies implemented to realize the Convention. With states obliged to establish mechanisms to monitor progress towards implementing policies that realise disabled people's rights, there is a clear attempt to position disabled people as active welfare citizens participating in policy and the production of welfare systems. In Europe, research shows that States need to expand opportunities for disabled people to participate in public life (Priestley et al. 2016). Currently, disabled people encounter legal and administrative barriers to participating in the political and policy arenas. Disabled people are denied access to voting in political processes, and the lack of organized disabled people's coalitions to influence local, regional, national policy platforms, serve as examples that restrict opportunities to contribute to policy formulation.

Disabled people's organizations from the global South have called for the involvement of disabled people within the implementation and monitoring of policies aimed at improving living conditions. Research by Lang et al. (2017) shows how disabled people in Africa struggle for non-tokenistic inclusion within policy formation. It is determined, through their analysis of African Union policies, that disabled people and their organizations are denied opportunities to contribute at the very start of policy design. Where there is involvement, this is largely

tokenistic (to satisfy media attention or to demonstrate commitment to transnational principles of participation and representation).

Lang et al. make an important distinction between policy agendas that seek to engage with disability issues, and policy processes that do not incorporate the views and perspectives of disabled people. Whilst effort to promote discussion and action on disability-related issues is apparent, this is often undermined by the lack of representation of disabled people within the formation process. Prioritizing disability within public policy discourse does not, in its own right, result in disabled people being represented in the design, development, and delivery of social policy.

Conclusion

Disability policy remains a focal point within policy analysis. Approaches to improve disabled people's living conditions vary across the globe, at a time when there is extensive marginalization and oppression experienced by disabled people. To engage critically with contemporary policy practice, it is useful to employ the concept of Independent Living - as defined by disabled people's social movements. The concept provides insight into the oppressive infrastructures that deny and restrict disabled people's access to services and systems of support. Support that is essential for facilitating disabled people's participation within the community.

Mobilizing the concept of Independent Living is useful for exploring the extent and direction of social protection and welfare provision. The concept can be utilized to reflect on holistic ideas of social justice, inclusion, and fairness, as well as the specific impact it can have through narrowed policy practice, such as access to housing, transport infrastructure, employment opportunities, and the availability of social care.

To realize Independent Living, within a social policy context, the chapter has considered how policy formulation has positioned the concept of Independent Living and embedded it within current political, economic, and social structures. To achieve this, the chapter has examined the position of disability within existing assessment methodologies that aim to provide social protection to disabled people. Assessment procedures illustrate how disability is framed and understood by policymakers, which affects the proportion of resources and expenditure offered to improve disabled people's inclusion within society. Finally, the chapter has offered a

commentary on representation within the social policy process - highlighting fragmented engagement with disabled people in their pursuit of realizing Independent Living.

The chapter argues that disability policy remains a paradox within social policy discourse. On the one hand, policies are enacted to provide support to disabled people in order to participate within their local communities; however, this is undermined through the expansive policy agendas that promote institutionalized care facilities, segregated education and employment systems, and a focus on individualized functioning over the identification of societal barriers. Independent Living provides a useful lens to understand this paradox.

For social policy to be effective in realizing disabled people's rights, it is necessary to engage with contemporary ideas emerging from disabled people's social movements, such as Independent Living.

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