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The meaning of independence: ENIL's monitoring of Article 19 as a struggle for hermeneutical justice

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Abstract

This chapter explores the efforts of disabled people's independent living movement to negotiate the meaning of independence. It focuses on the work of the European Network on Independent Living (ENIL) – a user-led, user-controlled initiative of disabled people and independent living organisations that has led the fight for independent living in Europe since 1989. I conceptualise ENIL's monitoring of the implementation of Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) as a struggle for hermeneutical justice. ENIL has challenged the conventional understanding of independence as self-sufficiency. This conventional understanding has undermined disabled people's right to live independently and be included in the community. In its stead, ENIL has promoted an understanding of independence stemming from the independent living movement and incorporated in Article 19 of the CRPD. According to this alternative understanding, independence means that one has choice and control in one's everyday life, including choice and control over one's support – rather than coping without support. This alternative understanding of independence has guided ENIL's monitoring of deinstitutionalisation reform and personal assistance schemes in Europe that are discussed in the chapter as instances of disabled people's organised collective struggle for hermeneutical justice.

Keywords: independent living movement, deinstitutionalisation, personal assistance, European Network on Independent Living (ENIL), hermeneutical injustice, hermeneutical marginalisation, Article 19

Introduction

For disabled people, as for other oppressed groups, negotiation of meaning is often a power struggle against social hierarchies and for individual and collective emancipation. A central element of this struggle has been the contest over the meaning of independence. In the modern period, independence has been understood predominantly as the ability to cope on one's own, without external support (Mladenov, 2016). Medical and other 'helping' professionals have reproduced this understanding in their treatment of disabled people. Professionals have put their efforts into fixing disabled people's bodies and minds so that disabled people become independent by becoming self-sufficient. Those who could not be fixed in this way have been confined to residential institutions or their homes (Oliver and Barnes, 2012).

The one-sided interpretation of independence as self-sufficiency is hermeneutically unjust. Hermeneutical injustice is a kind of epistemic injustice defined by the philosopher Miranda Fricker (2007: 158) as 'having some significant area of one's social experience obscured from collective understanding owing to hermeneutical marginalization'. The conventional understanding of independence as self-sufficiency obscures the experiences of interdependence that underpin self-sufficiency. Historically dominant groups such as men and abled-bodied people have benefitted from this obscurity because the infrastructures of interdependence have privileged them. For example, feminisation of care has privileged men whilst obscuring their dependence on women's caregiving (Fraser and Gordon, 1994); and ableist building conventions have privileged walkers whilst obscuring their dependence on environmental adaptations such as stairs (Oliver, 1993). Similarly to women, disabled people have historically been prevented from challenging the one-sided interpretation of independence as self-sufficiency due to hermeneutical marginalisation – their oppression has prevented them from participating on equal terms in meaning-generating practices such as research and policy-making (Oliver, 1992).

Women have been able to overcome their hermeneutical marginalisation by engaging in collective action for individual and social change. A key instance of such collective mobilisation has been the activity of consciousness rising through peer support. The practice of group 'speak outs' has helped to awaken 'hitherto dormant resources for social meaning that brought clarity, cognitive confidence, and increased communicative facility' (Fricker, 2007: 148). As a result of such collective hermeneutical efforts, women were able to overcome taken for granted interpretations of their experiences and 'to realize resources for meaning that were as yet only implicit in the social interpretive practices of the time' (Fricker, 2007: 148). A similar rise in 'cognitive confidence' and 'increased communicative facility' leading to realisation of new 'resources for meaning' occurred among disabled people when they started speaking out among themselves about their experiences of institutional care and their desire to have more choice and control in their everyday lives (Evans, 2002). Eventually, this gave rise to a new social movement.

The disabled people's independent living movement emerged in the late 1960 and early 1970s in the United States, spreading quickly to other parts of the world in the subsequent decades (DeJong, 1979; Evans, 20002; Ratzka, 1993). The movement has opposed the segregation of disabled people in institutions for social care and has advocated for personal assistance and other forms of user-led, community-based support that enable disabled people's full and equal participation in social life. A central part of this activism has consisted in challenging the one-sided understanding of independence as self-sufficiency, imposed on disabled people by medical and other 'helping' professionals, service providers, policy-makers, public

administrators, and the wider society. In this way, the independent living movement has initiated a process of rectifying a hermeneutical injustice suffered by disabled people. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) has been an important milestone in this struggle.

In their fight for hermeneutical justice, the activists of the independent living movement have insisted that independent living is not about self-sufficiency. It is not about one's ability to cope on one's own, without external support. Rather, independent living is about choice and control in one's everyday life that, importantly, includes choice and control over one's own support:

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. (ILI, n.d.: n.p.)

In its General Comment No. 5 on Article 19 of the CRPD, the Committee on the Rights of Persons with Disabilities (2017: 4) concurs: 'Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself.'

The spread of the independent living movement in Europe resulted in the creation of the European Network on Independent Living (ENIL) in 1989 by a group of visionary disabled activists (Evans, 2002: 13-14). Since then, the organisation has served as a user-led, cross-disability forum for disabled people, independent living organisations, and their non-disabled allies on the issues of independent living. Currently, ENIL has 72 full and 42 associate member organisations from more than 40 countries, most of them in Europe but some in Asia and Africa (see: <https://enil.eu/about-enil/our-members/>). ENIL's mission is to advocate and lobby for independent living values, principles, and practices such as the provision of personal assistance, deinstitutionalisation, barrier-free environment, and adequate technical aids. The organisation is financially supported by the European Commission, the Open Society Foundations, and its Nordic allies in Norway and Sweden.

ENIL has joined disabled people's struggle for hermeneutical justice by creating its own definitions of independent living and kindred disability policy concepts such as personal assistance, deinstitutionalisation, and community-based services (ENIL, n.d.). These definitions have been based on ENIL's monitoring, research, and advocacy work and have incorporated the testimonies and lived experiences of ENIL's members. They have been adopted by ENIL's Board in 2012 and since then have been actively disseminated and promoted by the organisation. ENIL's definitions have been aligned with Article 19 of CRPD and their aim has been to guide and enable the monitoring of disability policies on European and national levels. They have also been used to clarify misunderstandings and to prevent the hijacking of the language of independent living advocates:

the terms 'independent living' and 'personal assistance' have often been exploited and misused to profit organisations, charities and disability business which are not run and controlled by disabled people. These organisations do not appear to want to fully understand the concept of independent living as developed by the independent living movements across Europe and internationally. (Jolly, 2009: 2; see also Angelova-Mladenova, 2017: 11)

In addition to guiding and overseeing the deployment of the independent living discourse in Europe, ENIL has monitored the implementation of Article 19 of the CRPD by collecting and

assessing country-specific information about the translation of independent living concepts into social policy practices. The organisation has systematically gathered and analysed data on deinstitutionalisation reform and development of personal assistance schemes as key areas of Article 19's implementation. I will first discuss ENIL's definition of independent living and then present the organisation's work on deinstitutionalisation and personal assistance. My analysis will be guided by Fricker's (2007) concepts of hermeneutical injustice and hermeneutical marginalisation because the struggle over the meaning of independence has been a central concern of the independent living movement and, by extension, of ENIL's work.

Before proceeding, a note on my positionality. Although I have not yet identified as disabled, I have been involved in the independent living movement since 2000 and I consider myself an ally. In the period 2000-2009, I did action research and advocacy work for the Center for Independent Living – Sofia, and in 2017-2019, I was Marie Curie Individual Fellow at ENIL, where I was funded by the European Commission to conduct research on personal assistance in Europe. I am currently based in Scottish academia, at the University of Dundee, where I maintain close links with the independent living movement through my continuing collaboration with ENIL that has included the writing of this chapter. The views presented here are my own, but they have been informed by my work with ENIL, and my colleagues at the organisation have been consulted on and support this account of ENIL's monitoring and advocacy.

ENIL's definition of independent living

At the heart of ENIL's work is its understanding of independent living that has been captured in a definition (ENIL, n.d.). In order to pay heed to the significance of this definition for the organisation's struggle for hermeneutical justice, I will discuss it here statement by statement. ENIL's definition begins by suggesting that independent living is about the implementation of rights-based policies, in concert with Article 19 of the CRPD that frames independent living as a human right: 'Independent living is the daily demonstration of human rights-based disability policies.' (ENIL, n.d.: n.p.) In disability studies and activism, the rights-based approach to disability policy has sometimes been opposed to the needs-based approach, and the shift from 'needs' to 'rights' has meant a transition from charity to entitlement, from passivity to activity, and from professional domination to self-determination of disabled people (Oliver, 1996: Ch. 5). Indeed, the CRPD has been described on its official website as an embodiment of precisely such a hermeneutical shift by taking

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. (United Nations, n.d.: n.p.)

The second statement of ENIL's definition of independent living makes the point that independent living policies pursue two strategies simultaneously, in combination: 'Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives.' (ENIL, n.d.: n.p.) The first strategy is to design or modify mainstream environments – including buildings, housing, transportation, schools, and workplaces – to make them accessible and accommodating for disabled people. The creation of specialised services such as sheltered workshops or day-care centres, even when physically located within the community rather than on its margins, does not enable independent living but perpetuates segregation and exclusion (Angelova-Mladenova, 2017: 12).

Instead of such services, independent living requires personalised support in the community that includes personal assistance, communication assistance, and assistive technologies, among others. These solutions comprise the ‘individual factors’, the second policy-making strategy that makes independent living possible.

ENIL’s definition then emphasises that disabled people should be able to make ‘choices and decisions regarding where to live, with whom to live and how to live’ (ENIL, n.d.: n.p.). This point suggests that independent living excludes housing and servicing arrangements where disabled people are forced to live in designated buildings and groups, as well as to follow everyday routines determined by service providers or disabled people’s ‘helpers’. In policy terms, housing and support should be decoupled – otherwise, ‘people who need support are forced to accept a “group home” type living arrangement, and vice versa – people who need a place to live are forced to accept the support provided there’ (Angelova-Mladenova, 2017: 26). This is crucial when considering ENIL’s fight over the meaning of deinstitutionalisation, discussed below.

Independent living calls for redistribution of resources towards universally available and accessible services (positive measures), as well as for non-interference and respect of privacy (negative measures) – support should not be imposed through hard or soft power but freely chosen through informed consent: ‘Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life.’ (ENIL, n.d.: n.p.) Together with being universal and consensual, support should be flexible – its opposite are the rigid routines and one-size-fits-all solution of residential institutions and other provider-led services (Evans, 2002). This point will be revisited in the discussion of ENIL’s monitoring of personal assistance schemes.

The fifth statement of ENIL’s definition of independent living iterates the environmental factors and the individual factors that make independent living possible: ‘Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services.’ (ENIL, n.d.: n.p.) Finally, since independent living is a human right, support for it should be unconditional rather than restricted by identity categories or degree of needs: ‘It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.’ (ENIL, n.d.: n.p.) Here, we find a response to the common critique that the independent living movement prioritises physically disabled people of working-age (Westberg, 2010: 14-15) – rather, independent living is meant to be universally applicable, as also stated in Article 19 of the CRPD.

In sum, ENIL’s definition of independent living suggests that independent living is a human right that requires both mainstream adaptations and personalised solutions in which housing and support are decoupled and which are universal, consensual, flexible, and unconditional. From this perspective, to be independent means to have unrestricted access to mainstream environments and personalised support that is organised in such a way so that one has maximum choice and control in one’s everyday life. This understanding of independence excludes institutional care and rectifies the hermeneutical injustice suffered by disabled people when independence is one-sidedly interpreted as the ability to cope alone, without external support, or to be self-sufficient. To overcome their hermeneutical marginalisation and to assert their own understanding of independence, disabled people have organised in a social movement and have set up organisations such as ENIL.

ENIL's advocacy for deinstitutionalisation

The fight against disabled people's segregation in residential institutions has been a hallmark of the independent living movement since the time of its inception (DeJong, 1979; Evans, 20002; Ratzka, 1993). Institutions have been exposed by the members of the movement and their allies as sites of abuse and oppression that have deprived their residents of choice and control in their everyday lives. In concert with this struggle, Article 19 of the CRPD has been oriented towards challenging and preventing institutionalisation by asserting the right of all disabled people 'to live in the community, with choices equal to others'. Subparagraph (a) of Article 19 clarifies that this right presupposes 'the opportunity to choose their place of residence and where and with whom they live on an equal basis with others'. Since the 1960s, first in North America and Europe and later in other parts of the world as well, there have been various policy responses to institutional horrors and injustices that have been subsumed under the general heading of 'deinstitutionalisation' (Mladenov and Petri, 2020).

ENIL (n.d.: n.p.) has defined deinstitutionalisation as 'a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living'. The organisation has advanced deinstitutionalisation reform in Europe in a number of ways. Since 2008, ENIL has managed the European Coalition for Community Living (ECCL) – a Europe-wide initiative that has promoted community-based services as alternatives to institutional care (Parker and Bulic, 2010). ENIL has also been an active member of the European Expert Group on the Transition from Institutional to Community-based Care (EEG) – a coalition of advocacy organisations, international bodies and service providers established in 2009 and supported by the European Commission to guide deinstitutionalisation in the European Union (EU). As part of this collaboration, ENIL has led the development of two highly influential reports on deinstitutionalisation that have had a significant impact on deinstitutionalisation policies at EU level (EEG, 2012, 2014).

ENIL has also monitored the use of the European Structural and Investment Funds (ESIFs) for projects ostensibly committed to deinstitutionalisation in EU countries. ESIFs have been the main financial instrument used by the European Commission to help and/or nudge EU member states towards developing their economies and welfare systems in sustainable and socially just ways (European Commission, n.d.). ENIL has monitored the use of ESIFs by collecting and assessing country-specific information on deinstitutionalisation reform, which has resulted in a number of reports and policy briefings (e.g., Parker and Bulic, 2013; Parker and Bulic, 2010; Parker et al., 2016). In gathering evidence, ENIL has prioritised the testimonies of disabled people and their local organisations. Thus, rather than confining its monitoring to legal and policy analysis, ENIL has relied heavily on evidence generated on the ground by its members and stemming directly from the lived experience of disabled people. This has been a defining feature of ENIL's monitoring and has differentiated its policy work from that of other international organisations that have relied on expert fact-checking missions to develop their reports. Since 2016, ENIL has been doing this work in the framework of its EU Funds for Our Rights campaign, financially supported by the Open Society Foundations (Bulic and Kokic, 2018; Parker et al., 2017).

At the heart of these campaigning and monitoring activities one finds a fierce hermeneutical struggle over the meaning of deinstitutionalisation, which overlaps with the more general struggle over the meaning of independence. In Europe, deinstitutionalisation reform has routinely been framed by the most powerful stakeholders in the process – service providers, policy-makers, and big disability charities – either as a renovation of the old, large residential

institutions, or as a relocation of residents to newly created smaller institutions (Mladenov and Petri, 2020). These smaller settings such as small group homes, even when better resourced and placed within communities, have nevertheless reproduced key features of institutional life such as lack of control over one's assistance, rigidity of routine, bloc treatment, paternalistic approach to provision, and surveillance (for a comprehensive list of such features see Committee on the Rights of Persons with Disabilities, 2017: 4-5).

In addition, the providers of segregated services have appropriated the language of independent living to serve their own ends by claiming that their settings are 'independent living institutions' – for example, by offering training in 'independent living skills' (Jolly, 2009: 2-3), more appropriately described as training in 'daily living skills' (EEG, 2012: 128). Such appropriations have been criticised by independent living activists as misuse and misrepresentation of the concepts developed by the independent living movement (Jolly, 2009: 3). In its General Comment No. 5 on Article 19 of the CRPD, the Committee on the Rights of Persons with Disabilities (2017: 4) has also stated that neither large-scale institutions nor smaller group homes can be called 'independent living arrangements' if they deprive their residents of choice and control in their everyday lives through rigid routines, bloc treatment, surveillance and other practices characteristic of institutional care.

ENIL's hermeneutical struggle over the meaning of deinstitutionalisation has been a central aspect of its monitoring of the use of ESIFs. The organisation has repeatedly asserted that according to EU regulations, guidelines and reports, ESIFs should be used to promote independent living and inclusion in the community, in concert with Article 19 of the CRPD – accordingly, ESIFs should not be invested in building new residential institutions or renovating the existing ones, except in life-threatening circumstances and as part of ongoing efforts at deinstitutionalisation (Parker et al., 2016: 43). To rectify the hermeneutical marginalisation of disabled people in interpreting and assessing deinstitutionalisation initiatives, ENIL has advocated for the inclusion of disabled people's organisations in the monitoring of deinstitutionalisation programmes (Parker et al., 2017).

Hermeneutical marginalisation of disabled people has led to flawed deinstitutionalisation. ENIL's monitoring of ESIFs has revealed that many countries have used ESIFs to maintain and renovate institutional settings and/or to build new institutions under the heading of 'deinstitutionalisation' (Parker and Bulic, 2013). Most (although not all) of the cases of such misuse of ESIFs identified by ENIL have been located in newer EU member states in Central and Eastern Europe, including Croatia, Czech Republic, Bulgaria, Hungary, Romania, Latvia, Lithuania, Slovakia, and Slovenia (Bulic and Kokic, 2018: 9-10; Parker and Bulic, 2013). These countries have strong traditions in institutionalisation of disabled people, inherited from their state socialist past – although state socialism disintegrated in the region at the end of the 1980s, its legacy of institutional segregation has continued to shape disability policy over the following decades (Mladenov and Petri, 2020: 1206-1208). One way to maintain the status quo of segregated provision has been to interpret the creation of smaller institutions as deinstitutionalisation:

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

in mainstream services, such as housing, employment or inclusive education. (Bulic and Kokic, 2018: 7)

To summarise, interpreting deinstitutionalisation as maintaining old or building new institutions is a case of hermeneutical injustice inflicted upon disabled people. In this process, powerful stakeholders such as service providers have imposed an understanding of the shift from institutional care to ‘living independently and being included in the community’ (Article 19) that has served their own interests while depriving disabled people of choice and control in their everyday lives. ENIL has struggled to rectify this hermeneutical injustice by exposing the interpretations of deinstitutionalisation propagated by the dominant disability policy actors as false. In its monitoring of the ESIFs, ENIL has sought to overcome the hermeneutical marginalisation of disabled people in negotiating the meaning of deinstitutionalisation by formulating and promoting an understanding of deinstitutionalisation rooted in disabled people’s independent living movement. According to this (still) marginalised understanding, effective deinstitutionalisation requires access to housing, mainstream services, peer support and personal assistance (ENIL, n.d.: n.p.). The next section focuses on personal assistance, which has been yet another site of fierce hermeneutical struggle for independent living advocates.

ENIL’s advocacy for personal assistance

The activists of the independent living movement consider personal assistance (PA) to be key for independent living (Ratzka, 2004). Article 19 (b) of the CRPD concurs by stipulating that the states parties should ensure access to PA in order to realise disabled people’s right to living independently and being included in the community. However, the meaning of PA has been as contested as the meaning of independence and deinstitutionalisation (Jolly, 2009; Ratzka, 2004). ENIL has been involved in this hermeneutical struggle by creating its own definition of PA. This definition identifies PA as ‘a tool which allows for independent living’ and describes key features of PA such as: cash allocations; provision on the basis of individual needs and circumstances; rates of pay that ensure adequate salaries for the assistants and cover additional expenses such as employer contributions, administration, and peer support; and, ultimately, the right of PA users to recruit, train and manage their assistants (ENIL, n.d.: n.p.).

ENIL’s definition of PA builds on previous efforts at defining PA from the perspective of the independent living movement (Ratzka, 2004). Such user-led initiatives have contested provider-led interpretations which have branded as ‘PA’ support available only in kind and/or covering only a limited set of needs, with inadequate rates of pay and other restrictions – in essence, support that deprives its users of choice and control over recruitment, training, and management of their supporters. Independent living activists have insisted that provider-led, limited, conditional, and/or inflexible support schemes may amount to home care, or nursing, or companionship, but not PA (Westberg, 2010). By making such distinctions possible, ENIL’s definition of PA has been a vehicle for the advancement of hermeneutical justice – it has provided hermeneutically marginalised people with a means to challenge interpretations of individually provided support that may actually restrict disabled people’s choice and control under the guise of maximising them.

ENIL has used its definition of PA to guide its monitoring of PA services in Europe, the outcomes of which have been presented in several reports (ENIL, 2015, 2013; Mladenov et al., 2019). At the beginning of the 2010s, ENIL conducted a study of PA that included desk research of existing national legislative provisions, as well as a survey among disability experts from 22

European countries about the availability and the characteristics of PA schemes provided in their countries (ENIL, 2013). In this study, experts from 14 of the countries in the sample reported on the availability of relevant legislation, but the characteristics of the services provided under the heading of PA varied widely and in many cases, these characteristics were in contradiction with ENIL's understanding of PA. This analysis was updated in a follow-up study conducted in 2015 that identified lack of progress or deterioration of existing PA services:

The challenges that PA users throughout Europe meet nowadays have not changed much since 2013. Disabled people are still fighting to receive more hours of assistance, better salaries for their assistants and access to PA regardless of the type of their impairment. One of the main reasons for these challenges is financial, but not less important is the difficult transition from the medical to the social model of disability. Changing the mindset of society and decision makers is a challenge that needs to be tackled persistently. (ENIL, 2015: n.p.)

More recently, in 2018, ENIL developed and implemented the PA Checklist (Mladenov et al., 2019). Similar to ENIL's previous two studies of PA, the PA Checklist was designed at ENIL specifically for assessing PA schemes from the perspective of independent living. The tool included a set of criteria informed by ENIL's definition of PA and corroborated by PA users and independent living advocates in a preliminary survey.¹ The PA Checklist was piloted in eight European countries by local independent living experts who were also PA users. They were purposively selected by ENIL by considering their expertise in PA, and they were personally invited to assess PA schemes that they use and/or know well. Most of these experts have also participated in the development of the schemes they assessed. Based on their assessments, each PA scheme achieved an overall mean score, indicating the degree to which the scheme enabled or hindered users' choice and control. In addition to the overall scores, mean scores were calculated for five different dimensions of PA. Table 1 summarises the results – more detailed information about the study is presented in Mladenov et al. (2019), where the PA Checklist is also included as an appendix. It should be noted that the specific information provided by the experts in their assessments has not been cross-checked or further verified, so it must be taken with caution.

[insert Table 1 here – the table is given at the end of the text]

The results from the application of the PA Checklist confirmed a key finding reported in the previous two studies of PA implemented by ENIL (2015, 2013). This finding concerns the sheer variability of support schemes identified (in some cases misleadingly) as PA in different European countries. The checklist provided a quick, easy, and quantifiable way of assessing and comparing support schemes parading as PA, and it did so from the (hermeneutically marginalised) position of the independent living philosophy. The mean scores presented in

¹ The PA Checklist consists of 61 statements describing typical characteristics of PA which either enable or hinder the choice and control of PA users in their everyday lives. These characteristics were selected on the basis of a survey conducted among ENIL's members and subscribers of ENIL's newsletter during the initial stage of the project, in the period January – March 2018. The survey asked the participants to assign scores to a longer list of 138 characteristics of PA, formulated by the project leader based on literature review and consultations with colleagues at ENIL. The participants in the survey scored each characteristic of PA according to the degree to which they considered the characteristic to be enabler or hindrance to independent living. Of the 138 initial characteristics of PA, the 61 highest-scoring ones were included in the PA Checklist. An example of such a high-scoring enabler is: 'The users can keep their assistance when moving to another region or local authority within the country', and of a high-scoring hindrance: 'Under the scheme, assistance is bound to a location (for example, it is provided only at the user's home)'. The implementation and outcomes of the survey are reported in Mladenov (2019).

Table 1 allowed to judge at a glance whether a PA scheme conformed to a definition of PA created and supported by the members of the independent living movement in Europe. Thus, for example, the PA schemes available on the national level in Sweden and Serbia were assessed as highly compatible with this definition, whereas the PA schemes available on local level in Bulgaria and on national level in Ireland were assessed as incompatible. Instead of enabling disabled people's choice and control, the latter were actually suppressing them. Similar to flawed deinstitutionalisation, flawed PA deprives disabled people of their independence.

ENIL has continued the work of monitoring PA schemes by launching its first Independent Living Survey in June 2020 (ENIL, 2020). The survey contains general questions about independent living and more specific questions about PA that draw on its previous two studies (ENIL, 2015, 2013) and the PA Checklist (Mladenov et al., 2019). At the time of writing this chapter, the results of the Independent Living Survey were still being analysed. What is clear is that ENIL's latest study is yet another intervention in the negotiation of the meaning of PA. Through such interventions, ENIL has sought to advance hermeneutical justice in disability policy-making by asserting an interpretation of PA grounded in the experiences of disabled people who use support from others on an everyday basis.

Conclusion

In this chapter, I conceptualised disabled people's advocacy for independent living as struggle for hermeneutical justice that has sought to overcome the hermeneutical marginalisation of disabled people in meaning-generating practices concerning disability policy. These practices have traditionally been dominated by medical professionals, service providers, politicians and others occupying positions of power in areas such as disability-related research and policy-making that have affected disabled people but have historically excluded them. Powerful disability policy actors have perpetuated a one-sided interpretation of independence as self-sufficiency – an interpretation whose reproduction has constituted a hermeneutical injustice inflicted on disabled people. The conventional understanding of independence as self-sufficiency has been so pervasive that even prominent disability studies scholars have reproduced it: 'Dependence is the reality, and independence grandiose thinking.' (Davis, 2002: 31) Independence is grandiose thinking only when interpreted one-sidedly as self-sufficiency.

This interpretation has been challenged by the independent living movement through an alternative interpretation of independence that has rendered independence in terms of choice and control in one's everyday life, including choice and control over one's support – rather than ability to cope without support. To iterate, from the perspective of the independent living movement, to be independent does not mean to cope without support or to be self-sufficient but to have access to support that is organised in such a way so that the person who uses this support has maximum choice and control in her or his everyday life.

This alternative understanding of independence has been incorporated in Article 19 of the CRDP, which represents a major – although not decisive – achievement in disabled people's struggle for hermeneutical justice. The achievement of Article 19 has been consolidated by the Committee on the Rights of Persons with Disabilities (2017) in its General Comment No. 5 that has interpreted Article 19 along the lines of the independent living movement. However, it has not been a decisive achievement because there is still a lot of work to be done in order to translate the meanings implied in Article 19 into actual disability policies. The domination of 'helping' professionals and service providers in defining disability issues continues to be strong and it takes an organised and consistent collective effort to articulate, maintain and safeguard a

truly transformative and emancipatory reading of the CRPD that is in line with the values and principles of the independent living movement (Mladenov, 2013).

In her analysis of hermeneutical injustice, Fricker (2007: 174) points out that hermeneutical marginalisation results from unequal relations of power that exceed the domain of communication. The interpretation of independence as self-sufficiency is underpinned by material interests – most obviously, by the interests of providers of traditional services such as institutional care, who strive to maintain their competitive advantage over user-led, community-based alternatives. Hermeneutical injustice cannot be overcome by virtuous individual action alone – it is not enough that a decision-maker is willing to listen to the ideas of those who use services and to be convinced by their arguments or by their reading of Article 19 of the CRPD. The very structure of decision-making needs to change so that the members of the group whose interpretations have so far been marginalised become equal participants in meaning-generating practices. For this to happen, argues Fricker (2007: 174), collective political action is needed.

The work of ENIL represents such an organised collective effort at becoming an equal participant in the negotiation of meaning that guides contemporary disability policy. As a user-led, user-controlled initiative, ENIL has developed and promoted definitions of independent living and kindred disability policy terms such as deinstitutionalisation and personal assistance that draw on principles and values espoused by the independent living movement. In this way, ENIL has advanced hermeneutical justice in disability policy-making in Europe and beyond.

ENIL's monitoring of actual deinstitutionalisation and personal assistance policies has been part of this hermeneutical struggle. The organisation has used its interpretation of independent living in order to expose as flawed 'deinstitutionalisation' programmes that renovate institutions or move people to smaller institutions, as well as 'personal assistance' schemes that effectively amount to home care. Such policies have been exposed as flawed because they do not maximise disabled people's choice and control in their everyday lives. ENIL has advocated for their substitution with policies of deinstitutionalisation and personal assistance that reflect the meaning of independence elaborated by the activists of the independent living movement and incorporated in Article 19 of the CRPD.

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Table 1: PA Checklist – summary (reprinted from Mladenov et al., 2019)

Country, region	PA scheme (in local language in brackets)	Coverage ¹	Overall mean score	Mean score by dimension				
				Context	Funding	Needs assessment	Provision	Working conditions
Belgium, Flanders	Personal Following Budget (PVB Persoonvolgende budget)	regional	0.30	-0.23	1.05	0.89	-0.94	0.73
Bulgaria, Sofia ²	Assistant for Independent Living (Асистент за независим живот)	local	-0.71 / -0.91	-0.69 / -1.30	-1.87 / -1.87	0.23 / 0.20	-0.05 / -0.24	-1.19 / -1.33
Ireland	Health Service Executive Scheme	national	-0.61	-1.60	0.06	-1.32	-0.18	-0.03
Serbia	Personal Assistance Service (Usluga personalne asistencije)	national	1.13	1.98	-1.14	1.41	1.43	1.97
Slovenia	Independent Living (Neodvisno življenje)	national	1.03	0.88	-1.14	1.73	2.05	1.64
Spain, Andalucía	Pilot Project of Independent Living (Proyecto piloto Vida Independiente)	regional	0.03	0.76	-1.87	0.52	0.98	-0.23
Sweden	Personal Assistance Direct Payment (Assistansersättning)	national	1.34	0.64	1.87	0.18	2.08	1.96
United Kingdom ³	Direct Payment – Personal Budget	national (local funding)	-0.42	-1.33	-0.43	-0.43	-0.02	0.10

Notes

¹ All of the PA schemes included in the sample are publicly funded, although levels (national, regional, local) and forms of funding vary (i.e., they can be annual, project-based, social insurance based, requiring users' contributions, including charity contributions).

² Two assessments were completed in Bulgaria by two experts who assessed the same PA scheme independently of each other. Therefore, the corresponding cells of the table contain two values for mean score each.

³ The UK assessment concerns the national policy of providing 'direct payments' for PA as a whole, rather than any particular version of the policy implemented by a particular local authority.