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Steppingstones in larger struggles. How can we combine colliding struggles in the care crisis?

Puntos de apoyo en luchas más amplias. ¿Cómo podemos combinar las luchas que colisionan en la crisis de los cuidados?

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Steppingstones in larger struggles. How can we combine colliding struggles in the care crisis?

Puntos de apoyo en luchas más amplias. ¿Cómo podemos combinar las luchas que colisionan en la crisis de los cuidados?

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Abstract: The question of whether to increase the caregiver benefit is a controversial one among policy experts and movement actors. It is criticized as counterproductive to the emancipation of disabled people and women. At the same time, it becomes the goal of organizing campaigns as it provides immediate solutions, particularly to low-income families. This spotlights two

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questions: 1. How can activists fight for large-scale, transformative outcomes and achieve real, tangible changes in people's lives? 2. How can a constituency fight for its liberation without leaving other constituencies behind? Drawing on the analysis of the Hungarian caregivers' struggle, I reveal prospects for an emancipatory resolution of these two questions. I suggest seeing the struggles of affected constituencies as different dimensions of the care crisis and propose an organizing framework that engages with the deep structural underpinnings of capitalism and takes the issues of power and control inherent in care relations seriously.

Keywords: Social movements, caregiving, disability rights, women's rights, capitalism, organizing, emancipation.

Resumen: La cuestión del aumento de la prestación para personas cuidadoras es un tema controvertido entre los expertos en políticas y los actores del movimiento. Se critica que es contraproducente para la emancipación de las personas con discapacidad y de las mujeres. Al mismo tiempo, se convierte en el objetivo de las campañas de las organizaciones, ya que proporciona una solución inmediata, en particular, a las familias con bajos ingresos. Esto pone de manifiesto dos cuestiones: 1. ¿Cómo pueden los activistas luchar por resultados transformadores a gran escala y conseguir cambios reales y tangibles en la vida de las personas? 2. ¿Cómo puede un colectivo luchar por su liberación sin dejar atrás a otros colectivos? Basándome en el análisis de la lucha de los cuidadores húngaros, propongo una resolución emancipadora a estas dos cuestiones. Sugiero que se consideren las luchas de los grupos afectados como diferentes dimensiones de la crisis de los cuidados y propongo un marco organizativo que se comprometa con los profundos fundamentos estructurales del capitalismo y tome en serio las cuestiones del poder y control inherentes a las relaciones de cuidados.

Palabras clave: Movimientos sociales, cuidados, derechos de las personas con discapacidad, derechos de las mujeres, capitalismo, organización, emancipación.

Introduction

On September 17, 2018, in Hungary, a few family caregivers disrupted the opening day of the Fall parliamentary session. They demanded that the government raise their benefit. They hung a banner and held a press conference from the speaker's podium, claiming their care work should be recognized as labor and honored with the minimum wage (Sebály 2020). During the years leading up to the 2018 protest, the caregiver benefit was generally less than half of the minimum wage, even though caregivers did not have many other support services to draw on (KSH 2021b). Even though fair remuneration for caregivers has been a priority for the disability movement since the 1989-90 transition, activists and advocates did not reach a breakthrough for a long time. However, the struggle rebounded after 2013. A new movement organization led by family caregivers used its resources well and reacted strategically to the political environment. This finally led to a policy change. After five years of campaigning, in 2019, the Fidesz-KDNP government raised the benefit to almost 70 percent of the minimum wage for one-third of the caregivers and put their benefit on a path to parity with the minimum wage. The result was a hitherto unseen scale of increase in the allowance for more than 18,000 families, along with a more modest rise for another 30,000 families (MEOSZ 2019).

This measure broke –though not solved– an almost 30-year vicious cycle of exploitation. Family caregivers, most of them women, not only earn significantly more now but acquired an empowering experience. They successfully fought for political recognition under Prime Minister Viktor Orbán's authoritarian government. The victory was widely hailed among social justice organizations and movements in Hungary and Eastern Europe. At the same time, there were a few explicit criticisms: 1. women's rights advocates argued that women as primary caretakers would be more likely to opt out of the labor market, which would increase their isolation in the domestic sphere (Betlen 2018), 2. disability rights advocates anticipated the further isolation and subordination of people with severe disabilities instead of increasing their self-determination (Verdes 2014), and 3. policy experts pointed out that higher cash transfers are only partial solutions; in addition, different groups of caregivers did not equally benefit from the raise (Verdes, Scharle, and Váradi 2012: 27, MEOSZ 2019). All in all, their criticism boiled down to one thing: incrementalism. In their view, the state should invest in institutions and support services that can handle special needs (public education, transport, housing, etc.) and provide personalized support to assist disabled people in independent living.

For them, organizing to increase the caregiver benefit was a distraction, a struggle counterproductive to protecting the human rights of both women and people with disabilities.

The Hungarian case spotlights two broader questions:

1. How can activists fight for large-scale, transformative outcomes and achieve real, tangible changes in people's lives? It is not straightforward how to do justice to both orientations. The first wants to see «the world as it should be». It pursues a comprehensive, rights-based agenda, often with little intention to adjust it to the actual political context. The second orientation is more sober about the prospects of «the world as it is». It defines a goal that could have the largest possible impact on people's lives if attained under the current organizational and political conditions. It aims to achieve real changes in people's lifetimes; thus, the efforts often lead to partial results. This creative tension between these two orientations sometimes manifests among rights organizations and constituent-based organizations (e.g., Nicholls, Uitermark, and van Haperen 2000).
2. The second question derives from the inherent contradictions of social change struggles. How can a constituency fight for its liberation and realization of rights without leaving other constituencies behind or advancing its emancipation at the expense of others? The history of social movements provides us with ample examples of this dilemma. For instance, third-wave feminism was a response to the fact that feminists in the 1960s and 1970s had focused primarily on the problems of white, typically middle-class women (Hull, Bell-Scott, and Smith 1982). Almost 40 years later, Arruzza, Fraser and Bhattacharya (2019) problematize that unaffordable housing, poverty wages, etc. affecting poor and low-income women, are still not a high priority on the women's movement agenda.

In this article, I aim to reveal prospects for an emancipatory resolution of these two questions. I suggest an organizing framework that engages with the deep structural underpinnings of capitalism and takes the issues of power and control inherent in care relations seriously. My approach is not theoretical but draws on the case of Hungarian caregivers. Following Nancy Fraser's footsteps and her conceptualization of the capitalist crisis, I will look at the impact of neoliberalism on the solidarity fabric between constituencies within the disability movement. As Meyer (2004: 125) says, «social movements make history, albeit not in circumstances they choose». Usually, organizers and activists must wrestle with tight resources, redefine their struggle to keep their base engaged and adapt strategies considering the political and cultural realities. This political environment is dominated by neoliberal governments and corporations that are reluctant to ease the strain on care or affective labor and increase spending on support services. This is what Fraser (2016) calls the crisis of care, and caregivers and disabled people absent broad institutional support and adequate remuneration are heavily affected by it. In this context, caregivers' struggles for moral and financial recognition are the emancipatory expressions of their discontent and desire for a better life. The Hungarian story also reveals how the crisis of care is connected to the crisis of democracy. The post-socialist neoliberal democratic governments found every way to avoid accommodating caregivers' demands for fair financial remuneration by giving minor concessions. Ironically, it was the authoritarian-capitalist regime of the fourth Orbán government that eventually gave in to movement pressure and significantly raised the benefit for a subset of caregivers.

The article has the following structure. First, I present the care debate against the backdrop of neoliberal policies in general and review the arguments in favor of and contra the caregiver benefit from the perspective of women, disabled people, and caregivers. Then I introduce the development of the Hungarian caregiver benefit policy in relation to the democratic-capitalist transition and the autocratic shift. This is followed by the story of the emancipatory struggles of Hungarian caregivers in response to the care crisis. Whether these struggles constitute a path to a larger social change depends on how leaders can build the connective tissue between hard-fought but relatively short-term solutions and more ambitious goals, build larger coalitions and specify the steppingstones for a larger vision. The final section proposes an organizing framework that can be a tool to accomplish this.

1. **Methodology**

In my research, I primarily used qualitative methods, which I supplemented with the analysis of social policy data. I conducted six semi-structured interviews with six representatives of four disability organizations (four presidents/executive directors, one former president, and one lawyer). I analyzed the change in the amount of the caregiver benefit in relation to the minimum wage. I gathered survey data from seven organizations, asking them about their policy claims, tactics, and allies in the caregiver benefit struggles. I reviewed more than a hundred newspaper articles related to movement activities between 1990-2019 and studied minutes of parliamentary meetings in two relevant legislative periods, 2004-2005 and 2012-2018. Using these data, I mapped out the phases of movement activities related to caregiver benefit policies and traced the connections between these actions and changes in caregiver policy. Last but not least, I relied on my participatory observation (ethnographic data); through my organizing work in the Hungarian Civil Liberties Union (HCLU) and the Civil College Foundation (CCF) between 2013-2018, I gained insight into the activities and internal dynamics of the disability movement.

2. **Arguments pro and contra caregiver benefit**

Family caregiving came into the spotlight in the 1980s as a result of the neoliberal turn spearheaded by Ronald Reagan, in the U.S., and Margaret Thatcher, in the U.K. The retrenchment of the welfare state was wrapped up in a language that promoted the replacement of impersonal services and residential institutions with localized policy solutions and the involvement of the family in caring (Young, Wodarski, and Giordano 1982, Keith 1992, Mladenov 2015, Brown 2019). Deinstitutionalization and government funding to contract out care services to for-profit and non-profit providers were presented as a flexible, humane alternative to the state-administered care of the mentally ill, the disabled, and the elderly. However, this radical restructuring of care arrangements came with a gradual decrease in funding (or scarce resources in the first place) (Mechanic and Rochefort 1990, Koyanagi 2007). This resulted in the uneven geographical distribution of services and disparities in quality, which often shifted more responsibility to families (Segal 1979, Mladenov 2015).

This increased role of families in caregiving raised serious concerns among feminist researchers and practitioners. Policies implicitly or explicitly promoting caregiving within the home were seen as cementing the role of women as primary caretakers providing unpaid or underpaid labor (Finch and Groves 1980). The shift increased the risk of women's isolation in the domestic sphere, reinforcing economic and personal dependence on men and setting back recent decades' equal opportunities achievements (Finch 1983, Lister 1990, Keith 1992). Care work also became a prominent dimension of the debates over reforming welfare and employment systems. Fraser (1994: 601-610) summarized the mainstream reform approaches as the universal breadwinner and caregiver parity models. The first one (represented mainly by U.S. feminists and liberals) primarily aimed to achieve gender equity by promoting women's employment and shifting care work to the state and the market. The second one (mainly attributed to Western European feminists and social democrats) aimed to liberate women by elevating care work to parity with formal paid labor, where flexible work arrangements enable caregivers to transition between supported care work and formal employment. The argument for this approach was that the fair remuneration of caregiving would reduce poverty for women who are the most vulnerable (Fraser 1994: 607-608); women who are disadvantaged by their caregiving role, i.e., have less access to well-paying jobs on the market but have care duties (Gheaus 2020: 2).

Contradictions in caregiving within the home also prompted criticisms from disabled people. Neoliberal aspirations to dismantle state-administered policy solutions provided a window for disabled people's struggle for equal opportunities and independent living in the 1970s. Disabled activists resonated with some of the neoliberal language defying patronizing, top-down, centrally organized support structures. Deinstitutionalization and opportunities for self-determination, choice, and control over services were seen as a trajectory to independent living (Mladenov 2015). However, activists found the neoliberal promotion of family caregiving as counterproductive to this goal. It was essentially seen as a practice that increases dependence, confines disabled people to the private sphere instead of enhancing their independent living, and does not provide them with the economic basis to choose the support they need (Keith 1992, Barry 1995, Mladenov 2015). These concerns were reinforced by the academia and practitioners (often disabled people themselves) who pointed out that disabled people were often described as passive or helpless in the care debate. Their state of oppression and dependence received less attention than caregivers (Keith 1992, Barry 1995). Critical voices highlighted that care should be understood as a partnership between the caregiver and the care recipient where conditions are negotiated over the process (Fisher and Tronto 1990, Barry 1995).

Family caregiver policies evolved under the influence of these debates over the decades and took hybrid and complex forms, heavily shaped by countries' local histories and agencies. Today family caregiving is considered progressive when it enhances both the recipient's and the caregiver's autonomy and self-determination. First, care recipients are not passive receivers of care but active contributors whose experience as a member of a generation, class, gender, and ethnicity influences their needs (Fisher and Tronto 1990, Keith 1992, Barry 1995). Therefore, institutions and support services that enable the disabled person to go to school, participate in the life of the community and live independently as an adult are crucial components of caregiving. In-cash support should also provide real and effective choices for both groups. No matter whether the caregiver benefit goes to the caregiver or the care recipient; if it does not allow the caregiver to combine care and employment, or if the amount is too low (in relation to the comprehensiveness of the available support services), or the disabled person does not have the chance to switch to formal care when preferred or support services that enable independent living, the caregiver benefit does not provide the means for an autonomous life (Triantafillou *et al.* 2010).

However, the reality is often messier and does not live up to these human rights standards. Usually, care systems are fragmented and have low capacity. The lack of well-staffed, accessible services often requires that family members –primarily women– reduce their working hours or withdraw from the labor market to care for their relatives. The risk of income loss, impoverishment, mental deterioration, and isolation of both the caregiver and the care recipient is high, which results in strenuous efforts to keep up with life. Since states will not create a comprehensive care arrangement from one day to the other, affected groups sometimes come across as competitors in the fight for resources. High-intensity caregivers fighting for higher benefits may be seen as working against low- and medium-intensity caregivers, or caregivers' struggle for moral and financial recognition may come across as hindering the emancipatory efforts of disabled people and women.

Are the rights and needs of these groups indeed mutually exclusive? Or are they simply the different dimensions of the same crisis? The latter may be a way to see the interests of the affected constituencies concurrently. Fraser (2022) provides a conceptual framework that lays out this broader context. She points out that we live in a world of multiple crises. These crises have three strands, 1. the economic, 2. the non-economic, and 3. the political. The first refers to the capitalist reorganization of society, in which morals, ethics, and politics have been subordinated to self-regulating markets. The second strand exposes the freeriding of the capitalist state on care work and nature –the state and corporate disinvestment from social welfare and the exploitation of nature– devolving the responsibilities and harms back onto households and communities. Finally, the root of the third strand is identified in the contradiction that capitalism needs public powers to provide the conditions for the operation of capital; however, to maximize accumulation, its self-interest lies in hollowing out democracy.

The emancipatory struggles of caregivers and disabled people are situated in this complex reality, and their struggles either combine or collide in the different dimensions of the care crisis. This paper suggests that it is more productive to present their struggles from a complex organizing framework that engages with the deep structural underpinnings of capitalism and takes the issues of power and control inherent in care relations seriously. In the next section, I will introduce the development of the Hungarian caregiver benefit policies against the backdrop of the country’s neoliberal social transformation and expose how the lack of social protection went hand in hand with the hollowing out of democracy. Then I present the caregivers’ struggle for emancipation and show to what extent disabled people were involved. Finally, I will suggest a complex organizing framework to enhance the interconnectedness of these struggles and provide a pathway for the future of united cooperation.

3. The policy context. Hungary as the poster child of a freeriding state

Post-socialist states soon adopted the doctrines of neoliberal restructuring in Eastern Europe. This heavily influenced the development trajectory of institutions and support services for disabled people from the early 1990s. The state and its relationship to society had to be remodeled to facilitate the expansion of global capitalism. In this new setup, the state delegated much of its social responsibility to civil society, which was expected to find ways to alleviate the harms derived from the socialist legacy and the new capitalist transition (Dagnino 2011). Facilitated by legal changes, state funds, and private donors, the third sector became the provider of services, manager of development programs, and executor of public policies. The emergence of the disability sector is a good example of these social processes. The new NGOs were often established by people with disabilities or their family members, as they had first-hand experience with marginalization and low level of services.

However, this increased role of NGOs in service provision has not been accompanied by sufficient funding, which made the future of people dependent on these services unpredictable and put the organizations in a vulnerable position. The new democratic-capitalist regimes gradually improved access to support services and fair conditions, albeit in a piecemeal manner. Inadequate funding resulted in the uneven geographical distribution of services and disparities in quality (Kovács 2020, Kozma, Petri and Bernát 2020, Petri 2020, Mladenov and Petri 2020), which often shifted more responsibility to families (Könczei 2009, Bass 2009, Mladenov 2015). In Hungary, for example, people with multiple severe disabilities have practically no or minimal access to education and housing (i.e., independent living or small group homes) (Márkus 2009: 123, Verdes 2009, Verdes 2010, TASZ 2017, MEOSZ 2018a, Kovács 2018, Mladenov and Petri 2020). Therefore, they are often left with very limited choices; they can either move to residential institutions or live with their family (Esztári and Márkus 2009: 17, Bass 2009:46).

At the same time, instead of adequately compensating family caregivers until support services became widely accessible, the post-transition regime chose to freeride on care work from as early as 1993. Since it is cheaper to provide low caregiver benefits than build powerful institutions, states often spare money at the expense of family caregivers and compensate them with a fraction of the social value they create (KFIB 2016). This freeriding strategy, wrapped in seemingly favorable, but incremental raises, can be traced in the development of Hungarian caregiver benefit policies.

Immediately before the transition, in 1990, policy-makers demonstrated an effort to acknowledge family caregiving at parity with formal care work. The amount of financial compensation fell between the pay levels of formal caregivers and the minimum wage.[2] However, the restructuring of cash transfers in 1993, after the regime change, reflected the neoliberal vision of a «small state» (Ferge 1998: 13). The Social Care Act of 1993 tied the caregiver benefit to the lowest possible benchmark, the old-age pension (*öregségi nyugdíj*), despite the absence of an extensive formal care system. This policy decision had long-standing consequences as it maintained a vast gap between institutional care costs and the cost of cash-for-care transfers up to the most recent times (KFIB 2016).

As Figure 1 shows, between 1993-2000, the caregiver benefit (tied to the old-age pension) was about 70 percent of the minimum wage; however, this was when the minimum wage fell between 29-33 percent of the gross average income. In 2001, when the minimum wage substantially increased, family caregivers were excluded from the gains. The old-age pension was not adjusted to the minimum wage; therefore, the value of caregiver benefits substantially dropped.

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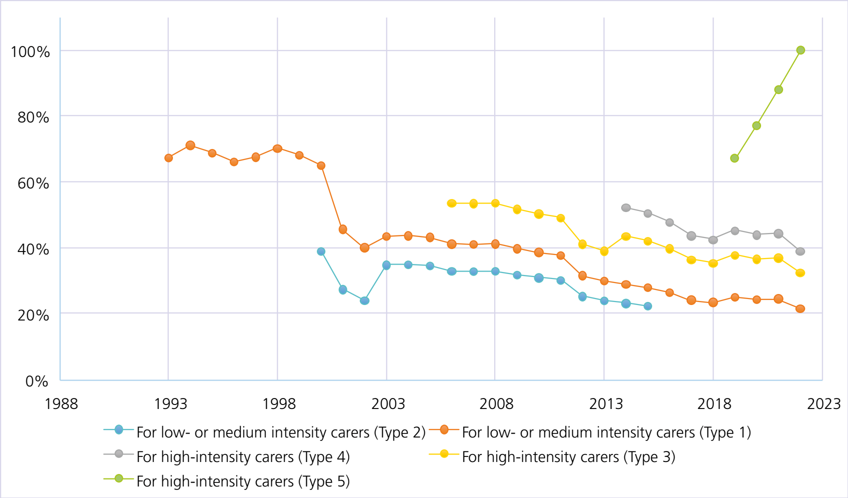
[2] According to the Decree of 33/1990. (II. 25.), caregiver benefit tied to people with severe disabilities over the age of 2 or permanently ill under the age of 18 was identical with the minimum wage. The compensation of caregivers of permanently ill over the age of 18 or those of elderly people was set between the highest value of a professional caregiver's honorarium and the minimum wage.

Figure 1

Caregiver benefit by type as a percentage of the minimum wage between 1993-2022



Source: author. Data obtained from KSH datasets 20.1.1.69, 25.1.1.21, and Act III of 1993 on social administration and social benefits.

Another crucial policy change occurred in 1999 when decision-makers distinguished between caregivers of persons with severe disabilities and those of permanently ill adults. This was another way to demonstrate the state's freeriding strategy. Instead of increasing the compensation for the care of persons with severe disabilities by taking the highest (Type 1) benefit as a benchmark, they regarded this benefit as a cap and introduced the new (Type 2) benefit at a much lower rate. As a response to movement claims, policy-makers occasionally narrowed the gap between the benefit and the minimum wage. However, as Figure 1 demonstrates, they did this in a piecemeal manner by introducing new types of benefits to a reduced number of beneficiaries (in 2006 and 2014) and phasing out older types (in 2015).

Besides its tokenistic value, the Hungarian caregiver benefit lacks an empowering character due to its entitlement structure. In Hungary, only family members receive the caregiver benefit, and only if they work no more than four hours per day in the labor market (see Table 1 for an overview of the benefit types). If the family decides to hire a professional caregiver to enable the family caregiver to go back to paid employment, the household loses the benefit. Essentially, the family needs to cover caregiving from their budget, or a family member must give up full-time work (unless they choose the low-quality state-funded nursing and residential care). In other words, leaning on Fraser (2016: 104), care is «commodified» for those who can pay for it and «privatized» for those who cannot.

Table 1

Types of caregiver benefits

	Benefit name	Intensity of caregiving	Care recipient	In effect
Type 1	«Basic» caregiver benefit (*alapösszegü*)	Low and medium*	(1) persons with severe disabilities over the age of 2; (2) permanently ill under the age of 18; (3) until 1999: permanently ill over the age of 18	1990-
Type 2	«Special» caregiver benefit (*méltányossági*)	Low and medium	Permanently ill over the age of 18	2000-2015[1]
Type 3	«Increased» caregiver benefit (*emelt összegü*)	High*	Type 1 + care recipient suffers from at least three limitations of daily activities	2006-
Type 4	«Highly increased» caregiver benefit (*kiemelt*)	High	Type 3 + care recipient cannot meet their own needs	2014-
Type 5	Caregiver benefit tied to children (*GYOD*)	High	Type 4 + care recipient is the caregiver's child or foster child regardless of age[2]	2019-

* low- and medium intensity: < 20 hours weekly.

** high-intensity: > 20 hours weekly.

[1] From 2015, the provision of the Type 2 benefit falls within the competence of local governments.

[2] In the first phase of the implementation, several high-intensity parent caregivers were excluded from this benefit due to ill-defined eligibility criteria. This has not been completely remedied up to now. See the letter of Lépjünk to Minister of State Attila Fülöp (Lépjünk 2019) and the report of AOSZ (2019).

Source: author. Data obtained from the Act III of 1993 on social administration and social benefits.

Compared to other types of benefits, the recently introduced *GYOD* (Type 5) –the 2018 policy victory of the movement highlighted in the introduction of this paper– raised the benefit to almost 70 percent of the minimum wage for one-third of the caregivers and put the benefit on a path to parity with the minimum wage. Although Hungarian caregiver benefits, in general, are still considered low in European comparison, beginning in 2022, *GYOD* pays the minimum wage for more than one-third of the caregivers (about 22,000 people) (KSH 2021b). At the same time, it received a lot of criticism because eligibility is contingent on a parent-child relationship.

The analysis above shows that policy interventions of the last decades were ad hoc, and decision-makers did not intend to carry out a comprehensive reform. Facilitated by both external and internal pressure for privatization and fiscal austerity, coupled with the rent-seeking of elites, the structural adjustment reforms of the '90s led to a political transition that lacked emancipatory character for many, in particular, disabled people and caretaking relatives.

The Hungarian example epitomizes what Fraser calls the crisis of democracy. The post-socialist governments found ways to avoid accommodating movement demands for fair financial remuneration by giving minor concessions and making fine promises to caregivers that were never fulfilled (Sebály 2020, Section 6.3). The authoritarian-capitalist regime of the fourth Orbán government eventually yielded to movement pressure. The organizations pressing for an increase in benefits made the most of the Orbán regime's pragmatic character and ideological emphasis on families, which has almost always manifested in allocating more resources to better-off households than low-income families. In alignment with the government's emphasis on family, the new *GYOD* benefit policy differentiates between high-intensity caregivers based on their family relations. More precisely, even though two caregivers provide care for people with the same degree of disability, one will receive the Type 4 benefit unless the care recipient is their child or foster child. If the cared-for is the caregiver's child or foster child, the household will receive the Type 5 benefit. This is what Szikra (2018: 223) calls «eclectic policy-making».

4. Colliding struggles and emancipatory responses to the crisis of care

The lack of moral and financial recognition created resentment among caregivers and put many at risk of impoverishment. Therefore, the caregiver benefit reform has been on the agenda of the Hungarian disability movement since the regime transition. Over the last thirty years, with varied intensity but demonstrated continuity, organizations kept claiming moral and financial acknowledgment for households with disabled people. These emancipatory efforts affected the future of several constituencies –disabled people, older people, caregivers, and women– which often resulted in the convolution of interests. As Fraser (2013: 129) puts it, emancipation «produces not only liberation but also strains in the fabric of existing solidarities» –the gains of one constituency can be understood as the loss of another. The struggles of caregivers for moral and financial recognition have been the expressions of their discontent and desire for a better life.

This section demonstrates how these contradictions of perspectives are inherent in emancipatory struggles and provide evidence for the need for a complex organizing framework (to be laid out in the next section). Between 1990-2019, six disability organizations –*ÉCSJE, ÉFOÉSZ, Hand in Hand, HSSZ, Lépjünk*, and *MEOSZ*[3]– took a leadership role in the fight for the caregiver benefit reform, and altogether, more than 60 organizations were involved to a lesser or greater extent. The story also underscores the fact (true for many disability movements) that the leadership role of people with autism, intellectual disabilities, or multiple severe disabilities has been very limited (Petri, Beadle-Brown, and Bradshaw 2021a, Petri 2021). This prevents the movement from launching complementary campaigns organized by various constituencies. Taking the neoliberal context and temporality seriously, this section shows how the outcomes of earlier struggles influence the ambitions and achievements in the future. Whether these struggles eventually constitute a path to a larger social change depends on how leaders can build the connective tissue between hard-fought but relatively short-term solutions and more ambitious goals, build larger coalitions and specify the stepping stones for a larger vision.

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[3] The abbreviations stand for the Advocacy Association of Persons with Intellectual Disability and Their Families (ÉCSJE, *Értelmi Sérültek és Családjaik Jogvédö Egyesülete*), the Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ, *Értelmi Fogyatékossággal Élök és Segítöik Országos Érdekvédelmi Szövetsége*), the Association for Parents of People with Multiple Severe Disabilities (HSSZ, *Halmozottan Sérültek Szülöszövetsége*) and the National Federation of Disabled Persons' Associations (MEOSZ, *Mozgáskorlátozottak Egyesületeinek Országos Szövetsége*). Lépjünk stands for «Step so that They Can Step!» Association (*Lépjünk, hogy Léphessenek! Közhasznú Egyesület*). Hand in Hand Foundation is the English name of *KézenFogva Alapítvány*.

4.1. *1999: Distinction between caregivers of disabled and elderly people*

Before 1993, the caregiver benefit was set between the highest value of a professional caregiver's honorarium and the minimum wage, depending on the type of care recipients' condition.[4] However, in 1993, as part of the neoliberal reconfiguration of the state, the benefit suffered a major cutback, and the value was universalized across caregivers (see Section 4). This prompted a mix of disabled-led and caregiver-led organizations (including *MEOSZ* and *HSSZ*) to advocate the increase of the benefit. Based on the intensity of caregiving, they demanded the introduction of a new type of benefit that distinguishes between caregivers of persons with severe disabilities and those of permanently ill adults and compensates the former group at a higher rate.

The enactment of the Disability Rights Act in 1998 created leverage for the movement. In 1999, a distinction between the two types of caregivers was enshrined in law. However, neither of the two groups benefited from the new policy. As discussed in Section 4, compensation for the care of persons with severe disabilities was held at a low level, and the benefit for caregivers of permanently ill people was even lower. Neither increased in relation to the minimum wage.

4.2. *2005: Elevating high-intensity caregivers*

In subsequent years, increasing the caregiver benefit and securing employment status for caregivers of people with multiple severe disabilities (i.e., high-intensity caregivers) became the movement's primary goals. Advocacy followed two courses at the beginning of the 2000s. Hand in Hand, a service and advocacy organization, drafted an overarching policy proposal in 2003 concerning the rights and needs of people with multiple severe disabilities and their families. They addressed a broad set of policy areas from education through employment to institutional care, including the financial compensation of caregivers. Hand in Hand recommended that the caregiver benefit should be differentiated based on the condition of the care recipient, and the benefit of those who care for persons with multiple severe disabilities (a subset of Type 1 benefit recipients at that time) should be raised to the minimum wage. Hand in Hand thus promoted a comprehensive policy change that concerned the

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[4] See Footnote 1 in Table 1.

rights and needs of both disabled people and caregivers. The organization had several negotiations with relevant ministries in the next two years until 2005.

Parallel to this advocacy process, but independently from it, a few organizations started a mobilizing campaign. In November 2004, *ÉCSJE*, a self-help advocacy organization of families, launched a popular initiative to raise the Type 1 benefit to the minimum wage and create employment status for caregivers. According to the then Hungarian law, when at least 50,000 signatures were collected to support the initiative, the government was obliged to place the claim on the parliamentary agenda. Supported by *MEOSZ* and *ÉFOÉSZ*, *ÉCSJE* collected the necessary signatures, and the popular initiative landed on the parliamentary agenda in December 2005. The issue gained some media coverage when an affected family was interviewed on a popular TV show. However, on the day of the vote, the governing coalition turned down the initiative, and the movement had no strategy for the «unsuccessful vote» scenario. Instead of the minimum wage and the employment status, the decision-makers introduced a benefit for high-intensity caregivers at 54 percent of the then minimum wage, which they devalued in the following years (Type 3, see Figure 1 and Table 1 in Section 4). This created concessions for about 10,000 people, about one-fourth of the caregivers.

4.3. *2018: Policy breakthrough for high-intensity caregivers and the change of public perception of caregivers and people with multiple severe disabilities*

The campaign gained new momentum in 2013 when *Lépjünk*, an organization of primarily female caregivers with children with multiple severe disabilities took on the caregiver cause. Like their predecessor, they demanded employment status and an increase of the caregiver benefit to the minimum wage for their constituency. *Lépjünk* used the community organizing approach, which places the story of self, constituency building, cutting issues, and the dynamic use of conflict and negotiations at the heart of advocacy (Ganz 2009, Whitman 2018). *Lépjünk* focused on such policy goals that their leaders could effectively influence, given their scarce organizational resources. In other words, they tried to define a goal that could have the largest possible impact on people's lives if attained under the current organizational and political conditions. After a multi-year base-building effort and many public events to elevate the needs of caregivers, *Lépjünk*'s partnership with an online organizing platform, *aHang,* finally led to a breakthrough in 2018. The two organizations launched a petition which went viral in May 2018 and was signed by more than 50,000 people (aHang 2018). They demanded that the government allocate funding for an immediate increase in the benefit and expressed their claims emphatically through demonstrations.

Caregivers gained significant public attention, and the demonstrations provided previously unforeseen visibility to people with multiple severe disabilities who joined the protests. However, similarly to 2005, the government turned down the movement's demands in July 2018, on the day of the parliamentary vote over the 2019 budget. But this time, the movement did not stop. *Lépjünk* and its allies raised the stakes. They organized more demonstrations, mobilized more public support, and implemented more confrontational tactics. They even disrupted the opening day of the parliamentary assembly on September 17, 2018 (the direct action this paper highlighted in the introduction). Caregivers felt empowered to share their stories in the press by letting journalists in their homes or by giving interviews at demonstrations. This disclosed their everyday life, induced sympathy, and commanded respect.

Altogether, a few hundred families went public by attending these events. This significantly shaped the perception of both the caregivers and people with multiple severe disabilities. Caregivers, primarily women, appeared as spokespeople. They came across as self-conscious of their choice to care for their children and the value of their care work and, at the same time, demanded appreciation from society. This portrayal of women was typical in the five years of the campaign and encouraged more female caregivers to come out of the closet and share their stories. Moreover, people with multiple severe disabilities appeared in previously unforeseen roles –as protestors. Movement leader and the president of *Lépjünk*, Anett Csordás's son Erik Attovics was a particularly active participant in the campaign and often took part in movement meetings, protest events, or press interviews.

Parallel to this organizing process, but independently from it, *MEOSZ* demanded a comprehensive reform. They wanted the government to substantially increase the benefit of all types of caregivers, not only high-intensity caregivers (MEOSZ 2018b) and started separate consultations with the government in alliance with other disability organizations. The combination of these insider strategies of *MEOSZ* and its allies, and the primarily outsider strategies of *Lépjünk* and its allies, together with *Lépjünk*'s successful framing strategy, the movement could create a political space in which a top government official could support the cause with little political risk.[5]

Finally, on October 11, 2018, the Minister of State for Family and Youth Affairs announced that caregivers of children with multiple severe disabilities would receive a new benefit (GYOD) of 100,000 HUF from 2019, which would be gradually raised to the minimum wage by 2022. This measure increased the benefit of a group of high-intensity caregivers (about 18,000 people, one-third of all caregivers) to 70 percent of the minimum wage and put the benefit on a path to parity with the minimum wage. The victory of caregivers, who fiercely criticized the government during the campaign, was also an empowering moment for opposition parties and activists and the emancipatory manifestation of a democratic social order many Hungarians wanted for the country.

5. **Organizing framework in the crisis of care**

Movement actors in Hungary have taken different approaches to address the complexity of the care crisis. Advocacy organizations have often proposed complex solutions, demanding the overhaul of the whole caregiver benefit system or large-scale institutional changes that would benefit both disabled people and their relatives. Though their claim-making and framing were not entirely absent of competitiveness between affected groups, they demonstrated a relatively comprehensive policy perspective. On the other hand, caregiver-led organizations (run by people affected by movement gains) aimed at fixing one component of the care system at a time instead of waging a fight against the whole policy structure at once. Thus, they had somewhat narrower claims. These claims did not lack ambitions but drew on the needs and rights of the constituency to which leaders belonged.

The Hungarian case spotlights two broader questions: 1. How can activists fight for large-scale, transformative outcomes *and* achieve real, tangible changes in people’s lives? 2. How can a constituency fight for its liberation without leaving other constituencies behind? This paper demonstrated that these questions could not be adequately addressed without engaging with the deep structural underpinnings

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[5] The scope of this paper does not allow to lay out the evolution of the caregiver struggle in Hungary and the reasons that led to the political outcomes in 2018. For a case study on this, see Sebály (2020, Section 5).

of capitalism. Affected constituencies are situated in this complex political-economic reality, and their perspectives often collide in the different dimensions of the care crisis. The challenge for constituency-based organizations and movements is to stay anchored in the interests of their members while building the connective tissue with other constituencies and tying short-term solutions to larger, more ambitious movement goals.

This section presents an organizing framework that can be a tool to accomplish this. I lay out three organizing principles that engage with the structural contradictions of capitalism and take the issues of power and control inherent in care relations seriously. The section aims to help movement leaders and funders build a strategy that strengthens the movement infrastructure (relationship between and capacity of movement actors) and be an asset for those who strive for large-scale, transformative outcomes and real, tangible changes.

5.1. *The crisis of care is multidimensional. Enhance a complementary, not a competitive, relationship between constituencies*

The rights and needs of caregivers and disabled people –or caregivers and women with emancipatory efforts– are often presented as mutually exclusive, which leads to an unproductive polarization. If these constituencies could see their situation as the different dimensions of the care crisis, their struggles would become complementary and could be combined. This necessitates an empowering, politically engaged learning environment that helps disabled people and caregivers reflect on the power dynamics defining their position in society and relationship with each other. Such a learning process could help build the necessary mechanisms into their work to maintain an emancipatory experience for all parties.

This is particularly important because chances to enter the public arena are far from equal. Emancipatory struggles might happen at different times or paces for different constituencies, which can result in leaving some groups behind or realizing emancipation at their expense. To enhance complementarity and solidarity instead of competition and division, it is crucial to invest in organizing, i.e., creating empowering space where marginalized groups can build relationships, construct collective identities and agendas, gain legitimacy to voice demands, and nurture new leaders (Stall and Stoecker 1998, Cornwall and Coelho 2007). If organizations representing caregivers and people with disabilities are able to embrace this integrated approach based on the structural contradictions of capitalism, these constituencies could be part of the same struggle and amplify each other's voices.

5.2. *The crisis of democracy is part of the problem. Engage with the deep structural underpinnings of capitalism*

In most countries, there is no political leadership wholeheartedly advancing a comprehensive care agenda. The neoliberal restructuring of care arrangements often led to scarce resources or a gradual decrease of funding in the U.K. and the U.S., to start with. Post-socialist leadership also decided to remodel their countries to facilitate the expansion of global capitalism, leaving these states with very few resources to alleviate the harm derived from the socialist legacy *and* the new capitalist transition. Instead of investing in institutions and support services that would allow an autonomous life for disabled people and their families, governments decided to freeride on care work and delegate much of their social responsibility to civil society. This created a service-heavy movement infrastructure of NGOs.

However, things rarely move without social pressure, and constituency-led organizations which invest in leadership development and base-building provide leverage (Andrews 2001, Ganz 2004, Shorbagy 2007, Whitman 2018, Han, McKenna, and Oyakawa 2021). The Hungarian case epitomizes how their social struggle for more adequate services is intertwined with the crisis of democracy. As Drzyek (cited by Cornwall and Coelho 2007: 7) argues:

> Democratization […] is not the spread of liberal democracy to ever more corners of the world, but rather extensions along any one of three dimensions […]. The first is franchise, expansion of the number of people capable of participating effectively in collective decision. The second is scope, bringing more issues and areas of life potentially under democratic control […]. The third is the authenticity of the control […]: to be real rather than symbolic, involving the effective participation of autonomous and competent actors.

This complex perspective on the role of the disability struggles and their relationship to defending democracy provides an opportunity for a larger vision.

5.3. *Embrace the narrative. Specify stepping stones for a larger vision*

How to combine struggles through building a larger vision is not straightforward. Family caregiving lies at the intersection of several policy fields, and emancipatory efforts result in the convolution of interests of disabled people, elderly people, caregivers, or women. In addition, organizations often juxtapose the perspectives of various constituencies to reflect on the power and control inherent in care relations or focus solely on the rights and needs of their represented constituency (Keith 1992, Barry 1995). In response to this complexity, the human rights framework envisages 'the world as it should be;' it puts forward a vision that activists can gain inspiration from and imagine that another social structure is possible. On the other hand, organizers are often more sober about the prospects of 'the world as it is'; they take context seriously and fight to deliver the best possible solution under the given circumstances. This often generates creative tension between these two orientations.

However, a shared critique of capitalism embraced by leaders suffering from multiple forms of the care crisis can reconcile the tension between political strategies. It exposes their work in terms of immediate campaigns and a long-term vision that moves power and resources from those who have them to those who do not (Healey 2015, Chmelík *et al.* 2021: 13-14). In this regard, the rights orientation and the organizing orientation can reinforce each other. While the first one defines long-term goals and helps imagine activists the «world as it should be», the second can articulate a strategic pathway and define campaigns and milestone achievements as stepping stones towards structural reform. As a result, we would see imperfect struggles and partial solutions rooted in recognition and redistribution, constituting a path to a larger social change. The idea that different types of organizations that employ different strategies and tactics can productively complement one another in the public arena is known as movement infrastructure (Andrews 2001), the ecosystem of organizations, movement ecosystems, or in the democracy literature, the democratic ecology of associational life (Warren 2001).

Conclusion

The crisis of care is one of the major issues of our age. The problem is not the lack of policy proposals but the absence of political will to implement them. Social movements are one of the sets of actors that can advance the cause of a just care infrastructure. But where movement organizations should begin and how they should work together is less obvious.

This paper spotlighted two broader questions in this regard: 1. How can activists fight for large-scale, transformative outcomes and achieve real, tangible changes in people's lives? 2. How can a constituency fight for its liberation without leaving other constituencies behind? Drawing on the case of the Hungarian caregivers, I revealed prospects for an emancipatory resolution of these two questions. I suggested seeing the struggles of affected constituencies as different dimensions of the care crisis and proposed an organizing framework that engages with the deep structural underpinnings of capitalism and takes the issues of power and control inherent in care relations seriously. This framework can be an asset for movement leaders and funders to build a strategy that enhances a complementary relationship between constituencies, connects the crisis of democracy to the care crisis, and turns 'ideals' and 'pragmatism' into strategic allies.

The 2018 organizing for the caregiver benefit reform will certainly not be the last one in the history of the movement in Hungary. Several organizations already started advocating for better-designed eligibility criteria and a more comprehensive caregiving reform (AOSZ 2019, Lépjünk 2019, 2020, MEOSZ 2019). In addition, the Hungarian Civil Liberties Union (HCLU), a civil rights advocacy organization, and *Lépjünk* cooperated to extend respite care services (TASZ 2019). Organizations pioneered by *Lépjünk* also made progress in laying down the foundations of inclusive quality education for children with multiple severe disabilities[6].

In 2018, a disabled people's self-help group, Living Independently-Living in Community (*Önállóan lakni-Közösségben élni* in Hungarian), presented their participatory action research on the possibilities of independent living (Kovács 2018). Moreover, a group of low-intensity caregivers, encouraged by the success of the 2018 victory, joined the caregivers' organizing committee. Last but not least, the president of *Lépjünk* attempted to establish the political representation of the movement when she ran for a seat in the Parliament in 2022 –albeit unsuccessfully.

It is a challenge for every movement to build the connective tissue between constituencies and create a space where movement actors can reflect on power dynamics in their emancipatory struggles. But if

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[6] See: www.aholnapiskolaja.hu

this happens, people can create the potential for converting short-term victories to long-term structural changes, which can have profound consequences for reclaiming democracy.

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