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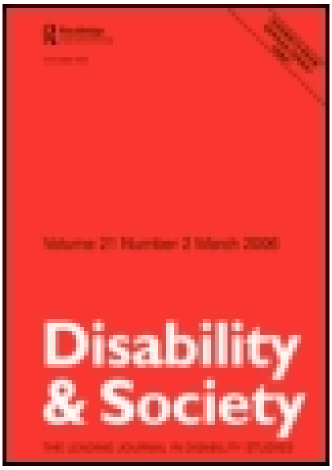

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Organizing survival and resistance in austere times: shifting disability activism and care politics in Ontario, Canada

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Following the 2008 financial crisis, all levels of Canadian government implemented austerity measures that dramatically restructured welfare, employment, and social service infrastructures. This has significantly affected how disabled people access services. We argue that this restructuring has been an impetus for new forms of disability activism and care politics in Ontario as disabled people fight for services necessary for survival. We discuss examples of politicized forms of care and resistance in Ontario, namely self-care, the Ontario Direct Funding programme, and collective forms of care. We contend that while these examples of care can be practical modes of resistance, they can all be co-opted and restructured to suit neoliberal ideologies and must therefore be continually interrogated.

Keywords: austerity; Canada; care; disability movements; Independent Living; neoliberalism

Points of interest

- There is a new policy and economic context in which disabled people are unevenly affected by ‘austerity’ cuts.
- New forms of disability organizing, such as disability justice, are a response to service cuts, other austerity measures. Disability justice builds on the successes and limitations of other forms of disability activism.
- The issue of ‘care’ is political because of an ongoing history of institutionalization and stereotypes about ‘women’s roles’. This article presents three cases where care is political: self-care, direct funding, and care commons.
- We identify the limitations of care models that heavily emphasize ‘choice’ and ‘independence’.
- We explore the potential of alternative care models to support disabled people and to challenge the existing policy frameworks.

Introduction

Disability activism throughout North America and the United Kingdom is becoming more diversified and complicated in light of highly uncertain political and economic

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changes. Following a brief period of economic stimulus in the wake of the global recession in 2008, neoliberal policy agendas have expanded quickly and abruptly through the implementation of austerity measures that disproportionately affect disabled[1] and ill people. These cuts target social programmes designed to support people with disabilities in financial, physical, and other ways. Meanwhile, disability continues to be taken up in both political and cultural arenas as a superficial indication of liberal progress under discourses of 'inclusion', 'accessibility', and 'diversity' in ways that erase the material effects of living with disabilities. McRuer elaborates these trends, labelling the former 'disability, incorporated' where disability is 'corporealized, destigmatized, identified, and integrated *as such* (out and proud) into the circuits of global capital' (2014, 274; original emphasis), and this trend is dependent on the state securitization and incarceration of disabled bodies. The austerity framework in combination with glossy notions of inclusion creates a context characterized by what Goodley, Lawthom, and Runswick-Cole term 'neoliberal-ableism' where 'neoliberalism provides an ecosystem for the nourishment of ableism' (2014, 981).

Against this backdrop, programmes and services that provide support in daily life for disabled and ill people are threatened as potential avenues for cost-savings. In Canada, health and social spending predominantly fall under provincial jurisdiction. In the province of Ontario, provincial and municipal governments simultaneously implement austerity measures and promote a liberalized inclusion of disabled bodies through accessibility legislation with a weak implementation strategy that was further scaled back in 2015.[2] Recent Ontario-based austerity measures that target disabled people include recommendations to merge Ontario's welfare system 'Ontario Works' with the long-term income support mechanism, the Ontario Disability Support Program (Lankin and Sheikh 2012), and will probably reduce access to income support. Already, expedited reviews of over 30,000 files are underway, creating challenging scenarios for recipients who are not able to respond fast enough and risk losing their benefits (Pflug-Back 2014). These changes mirror austere restructuring efforts in the United Kingdom that left thousands of disabled and ill people in life-threatening poverty (O'Donoghue 2013). Moreover, the Canadian healthcare system is moving towards a two-tiered system of public and private services through mechanisms such as public–private partnerships, subcontracting, medical tourism schemes, and corporate fundraising (Whiteside 2009, 2011). Disability service providers that are dependent on government funding are pressed to demonstrate greater 'efficiencies' in their budgets, encouraging them to restructure services to align better with neoliberal ideologies. As health and social services are restructured and shuffled across and between government and non-profit providers, disabled and ill people – particularly those who are immigrants, homeless, poor, racialized, and/or queer – are often at the greatest risk of losing services, while facing other forms of discrimination and dispossession (see Dossa 2009).

Disabled people and their allies have not remained silent as the twin trends of economic austerity and neoliberal-ableism have developed. Disability activists in Canada are long known for a successful history of challenges in legal and political realms (Chivers 2007; Prince 2012; Stienstra and Wight-Felske 2003; Vanhala 2011), commonly connecting back to the inclusion of physical and mental disability as defendable categories in the Canadian Charter of Rights and Freedoms in the early 1980s. Policy-based and legislative styles of activism continue to take place even during precarious times. For example, in 2012 a group of people with intellectual disabilities who had lived in government-funded, large-scale residential regional centres between 1945 and 2009 successfully reached a landmark class action settlement against the Ontario government. This settlement provided financial compensation for the abuses and harms of the institutional model of 'care' to those who lived in the centres or to their surviving relatives (Crawford Class Action Services 2014).

New forms of disability activism have also emerged, or been brought to light, in reflection of new economic and social realities (Reville and Church 2012; Withers 2012). New political frameworks for disability activism, such as 'disability justice', interweave the politics of cultural recognition with radical visions of a new society. Disability justice is a vibrant intersectional approach to disability politics that emerged and was named in San Francisco, California and seeks to respond to some of the limitations of Independent Living and other more mainstream disability organizing (for a broader description, see Hande and Mire 2013; Mingus 2010). For example, disability justice organizers support interdependent notions of care, make deep links with other social movements, and refuse to simplify the complex identities most people with disabilities embody. The group in California, however, perhaps only provided a name for this new wave of disability politics as there is evidence that frustration with mainstream disability activism and socio-economic factors led to similarly complex and creative activism in Ontario (Kelly 2013b). Regardless, disability justice frameworks also enable disability activists to play a greater role in cross-issue, mass protests including the G20 protests in Toronto, austerity protests in the United Kingdom in 2010, the Occupy movements in 2011, and the Québec student movements of 2012 (Blouin Genest under review), and other forms of artistic and radical activism that take place beyond legal or policy realms (Kelly and Orsini under review).

We contend that the shifting contexts of disability activism and austere, neoliberal restructuring efforts transform each other and are pushing the politics of care to the forefront of political struggle. The loss of disability support services forces both individuals and advocacy groups to develop alternate survival strategies. These survival strategies can depoliticize or discourage disability activism, particularly when activists are disciplined with threats of further funding cuts. However, these survival strategies can become a critical dimension of new forms of disability activism that reconfigure care in compelling ways. In this article, we explore how individual and collective orientations around 'care' are politicized and translate into policies and practices of support for disabled people in Ontario. Further, we trace how care politics are linked to the shifting arena of activism in Canada, and how they are historically situated reactions to the current austere policy climate.

The politics of care

Care, for many disability scholars and activists, is a highly contested concept (Kelly 2013a, 2014; Morris 2004; Silvers 1997; Thomas 2007). The history and ongoing legacies of care are structured by exploitive and oppressive relations, from subtle coercions played out on the microscale between disabled people and those who support them, to mass institutionalization of disabled bodies undertaken in the name of 'caring for' people with disabilities. The oppressive legacies of care also encompass exploitive structures that coerce women, especially women of colour, into what Glenn (2010) terms 'racialized gendered servitude'. There have been a number of community and policy responses that represent practical resistance to the ongoing oppressive legacies of care. We discuss examples of this practical resistance in Ontario – namely politicized notions of self-care, the Direct Funding programme, and collective forms of care – to help consider the importance of ensuring that people's tangible, material needs are met, while also creating spaces for building alternative services that radicalize care relations. In austere times, we contend that while each of these examples of care are politicized and can be used as practical modes of resistance, they can all be co-opted and restructured to suit a neoliberal ideology, and must be continually interrogated.

Self-care

Chandler and Rice, among other critical health and disability studies scholars, argue that the emphasis on individual responsibility for health operates as a 'biopedagogy' which is:

> the loose collection of information, advice, and instruction about bodies, psyches, health, and well being, often moralizing or lecturing in tone, that works to control people by using praise and shame alongside 'expert knowledge' to urge their conformity to mental and physical norms. (Chandler and Rice 2013, 231)

'Self-care' can operate as a biopedagogy that is presented as a neoliberal solution to coping with stressful or unhealthy work environments, and proper amounts of self-care are presumed to be a crucial part of successful living. As austerity measures intensify and affect healthcare spending, it is perhaps unsurprising that the neoliberal emphasis on individual responsibility results in increasing attention to 'self-care' in and beyond policy contexts. In Ontario, government policy documents (see Government of Ontario, 2011; Harrison 2014, discussion) as well as national health promotion agencies and organizations (for example, ParticipACTION 2013; Public Health Agency of Canada 2005) demonstrate growing encouragement for individuals to take more responsibility for their own health and well-being by reducing stress, exercising regularly, and eating healthy, rather than demanding significant changes to the conditions of modern work, healthcare, and social services.

Self-care, as it circulates in public and radical discourses, represents contradictory concepts and practices ranging from a politics of individual responsibility for embodied reactions to socio-economic pressures to a potentially transformative praxis and starting place for social change, as endorsed by disability justice activists. The contradictory discourses surrounding self-care cut across lines of disability, class, sexuality, and race, to name a few. For example, critics of self-care emphasize the individualized, neoliberal underpinnings implicit to self-care and endorse 'community care' as a superior model (see Loewe 2012). However, for disability justice organizers, an uncritical embrace of community care is especially dangerous for disabled women, trans people, and people of colour, potentially reinforcing their exclusion from activism and political organizing spaces. Piepzna-Samarasinha (2012) argues that without explicitly focusing on the politics of care and the importance of self-determination in care provision, ableism remains invisible and disabled people's struggles for just forms of care are trivialized, reproducing historical trends of segregation and oppression.

Community care has very different connotations for disabled activists than for non-disabled activists. Rather than political strategies for building community resilience and strong movements, ‘community care’ models often remain as institutional, medicalized, and individualized modes of care in the forms of publically or privately run homes or services for people with disabilities. In many instances, community care (also linked to or referred to as ‘community living’ or ‘supported living’) has been proposed as an emancipatory alternative to institutionalization, but can maintain an institutional, medicalized character, and includes discouraging statistics about propensity for abuse and maltreatment (Nosek et al. 2001). In fact, community living may point to what Drinkwater (2005, 229) calls ‘a new dispersal of power relations, one that is entirely in keeping with the modern drive to greater efficiency’. Hence, what appears to be a strategy at building greater community engagement for people with disabilities may translate into creating similar institutional settings that foster dependency and medicalized models of care, while relying on less funding to maintain services. Given this history, it is clear that not all applications and conceptualizations of community care are ethical or politicized alternatives to self-care, but rather demonstrate other deployments of neoliberal care, pathologization, and violence.

Disability justice activists are arguably at the forefront of conceptualizing and practicing a self-care that is neither neoliberal nor apolitical. They emphasize that self-care has been a rallying cry for political activism, particularly for feminists. Prior to the neoliberal implications of self-care, Audre Lorde commented: ‘Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare’ (1988, 131). Self-care is frequently taken up by social justice activists and organizers as they become ‘burnt-out’. As online media activist Spectra Speaks explains, ‘Self-care, for me, isn’t a luxury by any means; it is a basic need, a necessary part of my being’ (2012, n.p.). Self-care becomes important for activists to continue their organizing work and to develop relationships that strengthen the movements which they are building. In fact, explicitly policitizing self-care and linking it to political organizing, as Lorde and Spectra Speaks do, becomes crucial for avoiding practices of care that fit too comfortably with the neoliberal celebration of the individual.

In attempts at building political movements that actively address austerity, ableism, and the ongoing legacies of exploitive care for disabled people, the important relationship between self-care and community care must be treated with political nuance. Anti-poverty and disability activist A.J. Withers argues that self-care and community care are both integral, not only for disability organizing but for any form of transformative justice:

> I think there’s always stuff that we need to do [to take care of] ourselves. That’s important and there needs to be space for that. But, also, we need to think about and value collective care and value the cultural shifts that we have to produce to stop articulating this ‘Oh, you’re burnt out. You go away for a while and then come back.’ Stopping burnout is a collective thing. It’s not an individual thing. (Interview for OPIRG Toronto *Action Speaks Louder* newsletter, 2013)

While neoliberal policy and ideology typically frame care as individual, Withers reminds us that care must be conceptualized in terms of long-term and short-term goals that are always individual and collective at the same time. Withers’ argument resonates with feminist work around relational autonomy, where scholars posit that caring relationships are necessary for one to move about the world with a sense of autonomy (Clement 1996). This work largely does not critique concepts of care in the ways that disability scholars do, but it nevertheless provides some insights for conceptualizing forms of self-care that are rooted in notions of community and perhaps echo some of the intentions behind Independent Living and collective approaches to support discussed below. Relational forms of self-care are not contradictory, but require disability activists to attend to immediate material care needs of disabled and ill people while also creating space to think about alternative models of practice and broader aims of transformative justice.

These debates around self-care and community care among activists emphasize the tension between fighting against exploitive disability care relations by addressing systemic injustice (i.e., capitalism) and by maintaining a variety of immediate care options for disabled people, such as direct funding. For disability justice activists, self-care and other alternative modes of care provision must be linked to interwoven structural forms of exploitation and injustice such as ableism, racism, patriarchy, colonialism, capitalism, homophobia, and so forth. This means critically examining how care is discussed and how practices of care are structured by these oppressive relations, and how they might be transformed through practice and struggle. From this perspective then, both self-care and community care must be practiced and envisioned as part of complex relations of oppression and as key parts of transforming care.

Independent Living, direct funding, and consumer direction

An oft-cited history of Independent Living developed as a political movement and critical orientation towards 'care' in Berkeley, California in the 1970s and spread into Canada in the 1980s. Alongside deinstitutionalization movements led by people with intellectual disabilities and their allies, Independent Living emerged out of necessity for alternatives to institutional approaches to daily support. Independent Living promotes 'consumer-control' of services for disabled people, from administrative control of attendant service programmes to individual control of support interactions. The emphasis is on choice and control, and Independent Living includes tangible recommendations for how service models should be organized (Parker et al. 2000).

Direct funding represents a form of politicizing care, or more accurately of rejecting 'care' and replacing it with concepts of services and supports (Kelly 2011). Under direct funding, people with disabilities who require support with the activities of daily living are given cash to personally hire individuals to work as their attendants. This policy mechanism is utilized in a number of different sectors, from education to childcare and especially in home care and attendant services (Adams, Rohacek, and Snyder 2008; Carnoy 1998; Ungerson and Yeandle 2007). Direct funding is a clear example of neoliberal downshifting to the level of the individual, yet at the same time remains an essential and even transformative experience of support for those who are able to meet the eligibility criteria and use the funding successfully.

In the United Kingdom, the Direct Payments scheme was introduced in 1997, and is growing in an austerity context. In contrast, the national Independent Living Fund provides top-up cash for personal assistance for the most profoundly disabled people, and will be eliminated in June 2015 as part of austerity measures. There has been an active campaign to 'Save the Independent Living Fund' in the United Kingdom since the decision was announced in 2011, but the reallocation of the programme funds to the local councils seems inevitable. The closure of this programme will probably result in more experiences of ‘assessment’ for disabled people and less support, because there is no guarantee that individuals receiving support from the Independent Living Fund will receive the same level under new arrangements.

In Ontario, the Direct Funding programme was developed around the same time as the UK Direct Payments programme and is administered by an Independent Living Centre in Toronto. The programme serves approximately 750 people with disabilities, and included a large increase in capital from the provincial government in 2014 that should allow for another 300 people to access the programme (CILT 2014). The development of Direct Funding in Ontario involved a number of politicized strategies, largely working ‘within the system’, including finding allies within the government, participating in consultations, and running and evaluating a pilot programme (Parker et al. 2000; Yoshida et al. 2004). The Special Services at Home (SSAH) programme served as a valuable precedent during these efforts, and SSAH has its own history of advocacy from parents and recipients as well as a formal coalition. The SSAH programme is used by families with children with disabilities and provides funds for respite care and other eligible expenses. In a different ministry, there is a Passports programme for adults with intellectual disabilities that uses similar criteria to SSAH and has also been expanded in recent years.

It is noteworthy that over the course of proposing, piloting, and eventually securing the Direct Funding programme, it was supported by all three major political parties in Ontario during different election cycles and elected terms. This does not necessarily suggest the rights-based or cultural messages embedded in the programme that reject conventional understandings of ‘care’ were universally compelling. It is more likely that the cost-effectiveness, ‘smaller’ role of the government (i.e. an oversight role instead of a service delivery role) and emphasis on individual responsibility aligned with the broader neoliberal ideologies shaping contemporary governance. However, in the midst of health care restructuring and provincial government changes during this period, it is no small feat that this programme was, and remains, administered by the Independent Living Centre. Further, the programme has been able to maintain politicized messages about disability and ‘care’ within administrative materials. Within a context of fiscal austerity, support for this ‘cost-effective’ model of service delivery is rising, but this is not simple ‘progress’ for disability in Ontario.

The Ontario Direct Funding programme is open to individuals with physical disabilities who require assistance with eating, bathing, or dressing, and can demonstrate the ability to ‘self-direct’. Those who access the programme must administer their own funds; that is, a guardian or family member cannot do the administration, and partners or roommates who are also direct funding users must not formally pool their resources. The programme is not open to people with intellectual disabilities, mental health concerns, and low literacy. There is some concern, then, that direct funding attendant services privileges people with physical disabilities, especially individuals with more social capital and education. It is unclear whether this is happening in the Ontario programme; however, in the much larger direct payments programme in the United Kingdom, which does allow for assistance managing the funds, researchers and policy-makers actively work to promote higher rates and more diversity in the uptake (Barnes 2007; Ridley and Jones 2003).

As previously mentioned, different ministries within the Ontario government administer the SSAH programme for children with disabilities and the Passports programme for adults with intellectual disabilities. These programmes have very different political histories, parameters, and available funds (e.g. Direct Funding can only be used for attendant services, whereas Passports can be used for a broader range of activities). Unlike Direct Funding, SSAH and Passports are not administered by a community organization with a disability history and the different ministry locations reinforce divisions between physical and intellectual disabilities. The Ontario government is fully committed to this style of service delivery as represented through funding three separate direct funding programmes related to disabilities and is launching pilot programmes to deliver directly-funded home care to older adults in Ontario in the fall of 2015.

Like Independent Living more broadly, the direct funding approach to revisioning care relationships are essentially individualized approaches to care. However, this complicates critiques of neoliberalism as Direct Funding users in Ontario and in other contexts advocate strongly for this model and report high levels of satisfaction, including increased freedom, flexibility, and sense of empowerment, especially in contrast to other forms of service delivery (Benjamin, Matthias, and Franke 2000; Carlson et al. 2007; The Roeher Institute 1997). Further, people with disabilities, disability organizations, and their allies deployed collective strategies to obtain and expand direct funding options in Ontario.

Neoliberal discourses of choice and the primacy of the individual are mobilized in complex ways, towards empowering models of support on the microscale, while also undermining larger claims for social justice and enacting forms of exclusion through hiring practices and eligibility requirements. Neoliberalism and austerity are, like care, complex means of repression and, confusingly, may also include individualized experiences of empowerment and dramatically reoriented support interactions that are examples of potentially transformative models of care.

The tensions of care evoked by direct funding programmes also implicate the attendants working under the programmes. Attendants largely report high levels of emotional and relational satisfaction in these positions (Clark, Hagglund, and Stout 2004; Dale et al. 2005); however, direct funding dramatically changes the material working conditions of care. More institutionalized settings (and even other home care arrangements) are and were often unionized, whereas direct funding programmes explicitly distance attendants from other care workers in both geographical and rhetorical senses. Direct Funding users and administrators seek out workers without formal training, bucking against trends towards tracking, consolidating education standards, and discussions of care worker regulation taking place in the broader political arena. While this has interesting cultural ramifications in terms of distinguishing attendant services and Independent Living as unique alternatives to ‘care’, it also has tangible consequences for the attendants by creating a highly precarious and difficult to monitor group of people. Of note, direct funding attendants were explicitly excluded from the (small) wage increase for care workers announced by the provincial government in 2014. In some respects, this means Independent Living in Ontario has been successful at maintaining control and a distinct approach to attendant services in the provincial sphere, yet at the expense of a wage increase for their workers.

There are ongoing tensions between labour and disability perspectives with regard to direct funding and care more broadly. In 2013, the Ontario Red Cross orchestrated a two-week home care strike, leaving 48,000 recipients across the province to scramble to find other arrangements (Clarke and Boyle 2013). The strike resulted in arbitration, and eventually a wage increase, but it left thousands of people in the lurch for services that are essential for daily survival. Similar tensions are highlighted when large-scale institutions close, and union organizers raise concerns about the employment options for their employees without considering the ramifications of indirectly promoting institutionalized life (Globe and Mail 2013). These contradictions between quality care and quality work emphasize how exploited, marginalized workers and people with disabilities are pitted against each other (Cranford 2005). These examples highlight the limitations of conventional labour organizing to protect disabled people from life-threatening loss of services or to protect precarious care workers (Rinaldi and Walsh 2011).

Collective forms of care

Given the inherent contradictions of commodified care for disabled people and underpaid care workers, as well as numerous disabled people who are excluded from direct funding or formal care options, some disabled people are forced to develop other survival strategies. A unique response to this is the concept of care commons (Hande 2014), which are informal unpaid care supports from family and friends or more organized forms of care communities such as 'care collectives' or 'planning circles'. Care collectives are often explicitly political, developing in communities of poor, trans, and queer people of colour. These communities have been ill-served by both disability services and labour unions. They are organized to meet immediate care needs including emotional support, acupuncture, and toileting. The communities also aim to 'socializ[e] the experience of illness, pain, grieving and the care work involved, in this process reclaiming and redefining what it means to be ill, to age, to die', and, it is important to add, to be disabled (Federici 2012, 253–254). Many care communities have developed as a response to gendered, racialized, and sexualized care situations which are neglected or mishandled by formal care services. These situations range from the spread of HIV/AIDS (Federici 2012), sex reassignment surgery, homophobic attendant services (Loree Erickson personal communication, 10 July 2013), and rampant sexual and physical assault in care homes, particularly towards women (Morris 1991). Closely tied to the emergence of disability justice organizing across North America, 'care collectives' have become popular political projects that are often linked with other social movements. These collectives combine the political commitments to self-care as well as politicized notions of interdependency and disability solidarity that are very different from the community care options offered through the public and private homes.

In Toronto, Ontario, Loree Erickson's care collective has been held up as a model of radical care politics and a nexus of radical disability organizing (Hande and Mire 2013). Loree Erickson is a queer femmegimp[3] activist and has been managing her care collective for over 16 years. She is intimately connected with the members of her collective as they help her get in and out of bed, bathe, prepare food, and use the bathroom. When she moved to attend school in Virginia, she relied on inadequate care provision and spent years fighting her care agency to get adequate 'care hours'. Many of her care workers were homophobic and reluctant to come to her queer collective house, which doubled as a meeting space for political organizing. The inadequacy of hours, the unreliable 'randomness' of care providers arriving at her home, and their homophobia prompted her friends to simply take on the care labour themselves. For Erickson, this initially felt like a survival strategy to get through her day-to-day life, not a conscious effort at organizing or anti-capitalist commoning. However, she gradually learned about other care communities around North America and their political potential. When she moved to Canada as a graduate student, she learned that she was not eligible for permanent residency (and in extension, publicly-funded care arrangements), and nor could she afford adequate private care provision as a disabled international student. When she started up a care collective in Toronto, it became a key aspect of her politics and organizing (Hande and Mire 2013). In her academic work, Erickson makes pornography that sexualizes and politicizes her relationships with other members of the care collective, who are predominantly queer, trans, racialized, and/or disabled activists (Erickson 2005, 2007).

Other examples of collective care can be found internationally. Sylvia Federici (2012), for example, talks extensively about the importance of developing alternative forms of elder care, pointing to the 'solidarity contracts' formed by elderly Italians as examples of communal living organized around the care needs of those who cannot afford a caregiver and wish to avoid institutionalization. Other North American care collectives are temporary and can be organized around the sickness or surgery. For example, Toronto disability activist A.J. Withers organized a care collective when they were dealing with particularly acute fatigue and pain (interview for OPIRG Toronto *Action Speaks Louder* newsletter, 2013). Travel can be difficult to arrange for some disability organizers due to such things as physical inaccessibility and high costs of attendants and extra accommodations. Care collectives can help alleviate these barriers, helping disabled people engage more fully and frequently in political organizing, while also reorganizing social relations and communities to see care and disability political necessities for transformative justice.

These practices explicitly politicize both care and disability, abruptly challenge distinctions between public/private, self/other, and construct a commons space that is decidedly different from professional or domestic care settings. Further, these practices have the potential to generate new modes of transformative anti-capitalist organizing. Nevertheless, just as with self-care and direct funding, the tension between survival and conscious resistance undergirds work the political work of care collectives, and no simple conclusions can be made about how truly radical care collectives are (Hande 2014).

While rapidly intensifying global austerity may force disabled and sick people into situations to take more responsibility to reproduce their own care or organize with others to do so, it is not clear how these alternative solutions attenuate the larger problems of healthcare financialization and a rapidly eroding welfare infrastructure. In fact, similar to the ways in which self-care is easily refashioned into biopedagogies that depoliticize care and disability and serve neoliberal ideologies, care collectives can be neatly co-opted into the systemic, neoliberal austerity agenda as this informal care work is removed from the paid labour sector. On an even larger scale than the administration required by direct funding users, care collectives require endless hours of organizing and physical and emotional labour simply to 'get through the day'. This leaves limited energy and time to focus on other political projects and tackle broad socio-economic processes like austerity and neoliberalism that have forced them into these conditions to begin with. Moreover, many disabled people would not have the resources or political support to create or even join a collective – especially cognitively and severely disabled people, who are often overlooked as exceptions to disability solidarity and rights projects (Erevelles 2011; Withers 2012). Nevertheless, intentional care communities explicitly politicize care concepts and practices, and underscore the staggering limitations, contradictions, and ironies of neoliberal disability-related policies and privatized care provision. These politicized care communities not only explicitly facilitate disabled people's engagement with other anti-austerity social movements but this engagement may forge stronger solidarity across disabled and non-disabled activist communities and broaden the struggle against neoliberalism.

Politicizing care

Global neoliberalism and austerity measures have had dramatic effects on disabled people and care workers by rearranging how care is accessed, who receives or needs it, and the working conditions for those providing it. Political struggles around self-care, community care, Independent Living, and collective care have also undergone significant changes, as these care models are reformulated to suit neoliberal goals for labour flexibilization, funding cuts, and individual responsibility over collective interests and actions. At the same time, individual disabled people and disability justice activists have been at the forefront of fighting against co-optations, grappling with the tensions we outline in this article.

As we have discussed in this article, concepts of 'self-care' and 'community care' in political organizing are contentious for disabled people. Models of transformative healing and 'collective well-being' are discussed and practiced in activist organizing. Yet 'community care' has a different history for disability organizers. Some disability justice organizers emphasize that it is not acceptable to dismiss 'self-care' as unimportant or subsidiary to conventional forms of political action. Indeed, this rationale underscores the importance of direct funding as an essential political strategy to enable disability organizers to practice self-care. Erevelles (2011) and Kelly (2014) discuss the problematic aspects of emphasizing 'choice' in managing care and the provision of care, particularly for those with profound or intellectual disabilities who may be deemed incapable of proper decision-making and may have family members or trustees to make decisions for them. Erevelles (2011) argues that the over-reliance on the neoliberal notion of choice creates tensions within disability communities – creating unnecessary fractures and antagonisms. However, 'community care' models are no simple substitute (Ben-Moshe 2014).

The family and the state are no longer predominately organized in ways that they will, or can, take on the care needs of most disabled and ill people. The political consciousness of disability organizing has developed in such a way that disability is now being linked not only to resistance against pathologization and institutionalization, but, more and more, young disability organizers in Ontario are engaging in cross-issue politics in mass protests such as Occupy, the Québec Students' movements, and the G20 protests. Indeed, it is in these cross-issue political movements that the care collectives and radical forms of self-care described in this article were developed. Such care practices are often organized to address the potentially disabling conditions of long-term political organizing and to ensure that disabled and ill people can fully participate in these political projects.

Conclusion

The challenge of new forms of care politics is to move beyond 'survival strategies' to cope with dwindling social resources, towards a conscious political resistance to the neoliberal policies that go hand-in-hand with austerity and the restructuring of disability benefits and care resources. There is a new wave of disability politics in Canada and elsewhere, represented by changes in tactics, orientation, and issues of disability activism. This wave, as we argue, also includes a revisioning around 'care' politics, new visions that build on and do not dismantle the important advances of deinstitutionalization, Independent Living, and radical alternatives to care. The renewed politics of care is cognizant of the ongoing and historical legacies of oppression and exploitation of people with disabilities as well as the current social–political climate in which disabled people must survive. Goodley, Lawthom, and Runswick-Cole (2014, 983) implore: 'How else might we live together to support, care and enable one another? What do we gain when we fail to meet neoliberalism's normative labouring standards?' As critically re-imagined and politicized, 'care' is a historically wrought tension deeply implicated in socio-economic trends. Centring this understanding opens possibilities for life beyond survival and radical forms of service that include supporting both care workers and disabled people in ways which not only imagine but move towards new material realities.

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Notes

1. There are ongoing debates in academic networks, policy circles, community organizations, and among individuals around whether to use the phrase 'person with disability' or 'disabled person' (and sometimes other terms) in writing and politicizing disability. Some individuals feel very strongly about each term, and thus to acknowledge the lack of consensus and diversity in personal identification we elected to alternate between the terms in this article.
2. The Accessibility for Ontarians with Disabilities Act ambitiously aims for an 'accessible' province by 2025. This Act, however, does not include a monitoring function, consequences for non-compliance, requirements to retrofit existing structures, nor does it address the availability of services and supports.
3. Erickson describes this as a queer, sexual, disabled identity that is considered 'abnormal, yes, even monstrous, by many in the normative community' (2007, 44), but is defiant, reclaimed, and flaunted.

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