



‘But We Are Always at Home’: Disability and Collective Identity Construction on Runet

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Abstract: The article analyses a Russian disability activism hashtag: ‘#AMyVsegdaDoma’ (‘But we are always at home’). The hashtag is explicitly organised around a collective ‘we’ of disabled people. In posting narratives under the hashtag, disabled people and their family members build collective identity around experiences of exclusion. This enables analysis of how the construction of collective identity is linked to the identification of injustice, and thus to both recognition and redistribution claims. The article thus makes two contributions. Firstly, it demonstrates how people’s interactions with a hashtag campaign build collective identity. Secondly, it demonstrates how collective identity construction drives claim-making.

Keywords: collective identity; injustice; claim-making; activism; disability; Russia

The Covid-19 pandemic sharply changed many people’s routines and brought periods of confinement.¹ However, in Russia, where disabled people often have limited access to material public space, the experience of confinement felt familiar to some. On 17 March 2020, as Russian regions and cities enacted lockdowns, Ivan Bakaidov launched the hashtag #AMyVsegdaDoma (‘But we are always at home’) on three social media platforms: VKontakte (VK),² Instagram and Facebook. A well-known disabled programmer and activist, Bakaidov sought to mobilise the discrepancy between the familiarity of confinement for disabled people and the strangeness of this experience for abled people.³ However, the hashtag

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² VK can be broadly understood as a Russian equivalent to Facebook, with some differences in features and use.

³ I use the term ‘abled’ to refer to currently non-disabled people. My use suggests alignment, conscious or otherwise, with ableism’s unspoken ideology of disability as deficit. My use seeks to indicate the often-unrecognised privilege held by abled people.

does not only indicate disparity. ‘But we are always at home’ immediately names a collective ‘we’, but also implies a collective ‘you’. This unnamed ‘you’ is suggested by the contrastive conjunction with which the hashtag begins (*a*, meaning ‘but’). The hashtag proposes a limited commonality; while ‘we’ are ‘always’ at home, now you are, too. In his online post launching the hashtag, Bakaidov makes this explicit: ‘the world can [now] experience (*oshchutit*’; feel) the conditions (*usloviia*) of disability’.

Confinement shifts the boundaries dividing disabled people from abled people. Bakaidov thus names a new collective ‘we’, impossible outside the conditions of confinement. He mobilises the extension of the collective ‘we’ to include both disabled and abled people as an opportunity to ‘get our situation across to people’. The extension (a) reframes disabled people as sources of knowledge which are valuable to abled people and (b) drive campaigns for changes which would positively impact disabled people’s lives. However, other disabled people and their family members do not necessarily recognise the same collective ‘we’. As they comment on Bakaidov’s original post and write their own posts with the hashtag, they negotiate the initial framework of his hashtag and post to transform how they identify their collective ‘we’ and make their own claims.

In this article, I argue that these users build collective identities through the hashtag, the original post and the subsequent posts and comments made with the hashtag. In this case, the hashtag explicitly elicits reflection on collective identity by centring on the contrast between a collective ‘we’ and a collective ‘you’. In response, social media posts reject, identify with and themselves propose collective identities by telling and retelling stories about the ‘we’ and the ‘you’. These narratives express how people ‘make sense of themselves, each other, and the world around them’ to ‘construct individual selves and collective cultures’ (Davis 2014: 504). I propose that their telling forms sites of interaction through which identities move from individual to collective, and the boundaries of these collectives are negotiated (cf. Davis 2002).

Building collective identity is itself a form of activism. With this claim, I draw on scholarship on new social movements (NSMs). NSMs are distinguished by their aim to equalise the moral worth of identities subject to unequal worth and cultural membership. This entails enabling people to ‘name themselves’ and thus claim collectively ‘the right to realize their own identity: the possibility of disposing of their personal creativity, their affective life, and their biological and interpersonal existence’ (Melucci, 1980 cited in Johnston et al. 1994: 10). Social media platforms are key sites in which collective identities are ‘created, channelled, and contested’ (Gerbaudo and Treré 2015: 866). Crucially, the act of building collective identity ‘involves a relationship between a social identity and an injustice frame’ (Horowitz 2017: 1). I therefore contend that narratives of posts and comments under #ButWeAreAlways-AtHome are instances of people naming themselves, and thus identifying an injustice and making claims to rectify that injustice.

I bring these sociological theorisations into dialogue with contemporary media and cultural studies of digital platforms to make two contributions. Firstly, I demonstrate how people’s interactions with a hashtag campaign build collective identity. Secondly, I demonstrate how collective identity building is linked to the identification of an injustice and thus, implicitly or explicitly, to claiming both recognition and redistribution. In doing so, I draw on the paradigm of recognition and redistribution as ways of making political claims from mar-

ginalised positions subject to injustice. Recognition claims focus on redressing misrecognition, or the denial of status of 'full partner in social interaction, as a consequence of institutionalised patterns of cultural value' (Fraser 2000: 113–114). Redistribution claims define and respond to distributive injustice. This argument advances theorisations of how recognition and redistribution claims function in practice (e.g., Alcoff 2007; Martin 2001). There have been numerous debates on analytical conceptualisations of recognition and redistribution (e.g., Butler 1997; Fraser 1998; Fraser and Honneth 2003; Lister 2007). However, consensus remains around the need for more complex analyses of how forms of oppression are interrelated and how we might arrive at a 'paradigm that could encompass both redistribution and recognition' (Fraser 2007: 299). The 'But we are always at home' hashtag demonstrates such a richer paradigm in action.

The remainder of the article proceeds as follows. Firstly, I introduce some context around disability in Russia. This context implies that the hashtag campaign negotiates a stigmatised identity. Furthermore, I note the importance of online space for building collectivity under conditions where the fragmented potential collective is fragmented and often excluded from material space. Secondly, I explain my methodology, presenting how I built and analysed the corpus of 75 comments and hashtagged posts. Thirdly, I analyse the narrative framework offered by Bakaidov's hashtag and its original post. Finally, I analyse other posts and comments made under the hashtag. I thus demonstrate how people use the hashtag to build collective identity and make claims.

1. Disability and online (self-)representation in Russia

Disability studies has identified pervasive ableism in societies. Ableism defines disability as a deficit, proposing an 'ideology of a healthy body, a normal mind, appropriate speed of thought, and acceptable expressions of emotion' and dividing the 'normative (and the normal individual)' from the other (Campbell 2015: 12). Disabled people are thus subject to misrecognition, which hampers positive identity formation (Hughes et al. 2005; Murugami 2009).

In Russia too, disabled people often experience stigmatisation and segregation (Iarskaia-Smirnova et al. 2015; Romanov and Iarskaia-Smirnova 2010). Dominant narratives around disability infantilise, exclude and ascribe permanent sickness to disabled people (Iarskaia-Smirnova et al. 2015). The material environment remains difficult to move around, both within and outside the home (Hartblay 2015b, 2015a, 2017; Kikkas 2001). Moreover, disabled people have been refused access to or asked to leave locations which are materially accessible, such as cafés or exhibitions (Verbilovich 2017: 206). In policy terms, Mladenov (2016: 104) describes how Soviet legacies combine with neo-liberalisation to create an exclusionary double bind. On one hand, Soviet legacies underwrite 'segregated service provision; medical productivist understanding of disability for assessment purposes; denial of disability on everyday level'. On the other, neo-liberalization has driven 'retrenchment of disability support through decentralization, austerity, and workfare; stigmatization of "dependency" through the discourse of "welfare dependency"; [and the] responsabilization of disabled people'. Another continuity in disability policy is the use of large-scale psycho-neurological

institutions (*psikho-nevrologicheskii internat*, PNI) and the limited availability of alternative, independent-living homes. Such smaller scale homes are largely run by civil society organisations.

Given this context, a hashtag organised around experiences of disability necessarily negotiates an identity subject to misdistribution and misrecognition. Disabled people's online self-representation may respond to stigma to construct new shared meanings and shift narratives around disability (Hill 2017; Reinke and Todd 2016). This has collective-building outcomes (Pal 2019). Disabled people both identify with narratives shared under the hashtag and write their own, thus moving from an individual identity ('my story') to a collective one ('our story'). In particular, disclosures of 'true experience' may create empathic bonds and affective recognition among a group who identify with that experience (Bargh et al. 2002: 35). Disclosures around a stigmatised identity, where met with support, may also create a sense of empowerment and positive collectivity around an experience (Berry et al. 2017; Folts and Danina 2019). While *collective* identity is not its primary focus, some research demonstrates this in Russia. For example, Verbilovich (2013) finds shifts in disabled people's status as possible in public arenas. Iarskaia-Smirnova and Verbilovich (2020) analyse disabled people's public, online story-telling about their sexualities as activism challenging dominant discourses about disabled people.

The possibilities of digital communication and access to online space have particular importance for fragmented groups with troubled access to material space. In these conditions, Bayat (2013: 23) argues that distanced, online networks assume greater importance in building mutual recognition. In the Russian context, Hartblay (2019) has developed the notion of the 'pixelization' of disabled people. This references the combination of (a) Soviet apartment blocks which divide people up, even while keeping them close together, with (b) an 'enlarged scale of digital social networks' (Hartblay 2019: 545). Digital communication enables people to come together in conditions of 'a kind of material separation of people with disabilities from one another and from the central spaces of the city' (ibid.: 545). As well as enabling access to the public sphere from the home, an online utterance can be accessible outside of a single point in time. This decreases pressure to adhere to less accessible, often-linear time dynamics of in-person, synchronous communication (Davis & Boellstorff 2016). Greater time to craft responses may allow greater control over meaning (Enochsson 2011).

One example from Russian disability activism illustrates the strengths of moving beyond a specific, material location and single time. The Women. Disability. Feminism Collective (*Zhenshchiny. Invalidnost'. Feminizm*) has created a website for the purpose of curating an online protest. Entitled '*Inva Protest*' (approximately, 'Disabled Protest'), the Collective introduces the website by stating, 'Not all of us have the possibility of leaving the home for protests or pickets. But we all have the right to speak. This site is an online protest against domestic violence against women with disabilities' (*Zhenshchiny. Invalidnost'. Feminizm* 2019). Updated with statements by women over time and constantly available online, the site exists outside of a single point in time, may be joined from any location and offers freedom to participants to choose the degree of anonymity or publicness with which they wish to participate. Here, online space clearly enables modes of collective participation which differ from those enabled by offline, material space. The 'But we are always at home' hashtag also benefits from this, as Bakaidov calls for participation in a collective campaign from the 'per-

manent quarantine' of participants' separate homes. In one concise comment, a mother sums up the role of the internet in conditions of material inaccessibility and her support for Bakaidov's representation: 'My son only has internet. Fourth floor, no lift. Mainly at home. You've thought of an excellent idea!!!'

However, online spaces are clearly not necessarily universally *more* accessible than the material public sphere. Rather, they are *differently* accessible. Access to online space is inflected by many factors, including a person's age and comfort with using technology, their socio-economic background and ability to access technology and internet provision, the presence of internet access in rural locations, their living situation and inaccessible interfaces and content once online. Despite these layered exclusions from access, online communication holds certain potentialities which communication in material space does not. Disabled people may thus leverage online communication to address a different public and gain greater control over aspects of their representation. Bakaidov's hashtag, the accompanying original post, and other posts under the hashtag are one example of using these potentialities.

2. Methodology

Bakaidov launched the hashtag on 17 March 2020 on VK, Instagram and Facebook. Several online media outlets reported on the hashtag (ASI 2020; Maksimovich 2020; Bondarenko 2020; Wonderzine 2020), and several non-governmental organisations (NGOs) and hundreds of individuals commented on and reposted the original posts across the three social media platforms. Individuals also made their own posts under the hashtag. In their comments and posts, these individuals primarily identified themselves as disabled people or as family members (largely mothers) of disabled people. I extracted 60 distinct posts and 15 substantive comments on Bakaidov's original posts, all publicly available, to compose my corpus.

In deciding which texts to include, I was driven by the goal of analysing their narratives and how they negotiate the framework proposed by Bakaidov's original text. I therefore excluded reposts of the original post that did not edit his image or text. I only included texts in my corpus which offered substantive comments, and thus a narrative reflection on the hashtag. Other comments of a few words or emojis only (e.g., '*otlichnaia ideia*' (excellent idea)) were included as dependents to corpus entries, rather than separate entries. Shorter comments do suggest the public reception of posts, which was often one of approval and agreement. These comments play a significant role in building a sense of common recognition of experience. They therefore support conceptualisations of the social media posts as building communities of recognition. However, they are insufficiently rich in narrative terms to allow further analysis in terms of my questions here.

Having compiled the corpus, I read the texts repeatedly with the aim of identifying (a) their claims, and (b) the relationship of those claims to how any collective 'we' and 'you' is identified. In offering this close reading, I take on the roles of reader, translator and analyst. The corpus posts negotiate the framework proposed by Bakaidov as well as my necessarily contingent interpretation. In translating, I offer multiple English alternatives to better convey the Russian, which I also make visible in some cases. I provide links to Bakaidov's original text for readers of Russian. In analysing hashtagged posts, I read other public posts on

people's social media pages to gain greater context. I also bring context to analysis via my own experience and research on disability in Russia. I do not quantify this experience further to avoid suggesting that such knowledge can be exchanged in return for a 'comfortable, transcendent end-point' (Pillow 2003: 193). However, such knowledge offers critical context to my subjective reading. Through back-and-forth reading of the corpus both before and while writing this text, I sought to hold myself accountable to the corpus texts as I represent them here.

In citing those who respond to or post under Bakaidov's hashtag, I use original pseudonyms or avoid naming altogether, rather than provide their offline names or online pseudonyms. Although their posts are publicly available, I thus maintain some anonymity at least within the bounds of the article. There is an argument that, given that social media users may have specifically decided to publish in the public domain, researchers should maintain their authorship (Grinyer 2007). This is strengthened by disabled actors' calls for voice and contentions that anonymity does not protect, but disempowers (Baez 2002; Moore 2012; Yanar et al. 2016). I aim to engage with this argument by using the article to amplify the claims made under the hashtag, as well as by considering whose experiences remain silent. However, posting publicly does not equate to consent to analysis and wider publication (Eysenbach and Till 2001). Furthermore, people posting differ in their awareness that their posts are open to everyone, including those who are not members of their networks.⁴ The exception is Bakaidov, whose text was already highly publicised and who gave consent for direct quotation from his original text as author.

My analysis neither seeks to produce any quantification of responses, nor to offer a comparison between platforms.⁵ Following Pal (2019: n.p), I rather 'gesture towards one possibility of what disabled activist work can look like'. In doing so, I foreground the construction of collective identities and how they motivate claim-making; my account is clearly analytically selective, rather than exhaustive. This selection aims to recognise the 'multi-voiced and complex accounts' (Cornish 2020b: 142) of this hashtag as a generative case which gives 'a new answer to a call from the past, and ... calls out new responses in the next reader' (ibid.: 149, see also: Cornish 2020a). The contingent answer I offer is to the questions from which I began: how do online posts and comments develop collective identity? How is collective identity linked to an injustice frame and, thus, to claiming both recognition and redistribution?

⁴ While focused on the U.S. and the U.K., Sugiura et al. (2017) and Hennell et al. (2020) offer further discussion of perceptions of public and private in online posting and the ethical questions which this raises for research.

⁵ As constructed, the corpus gives greater weight to posts made on Facebook and Instagram. This is due to a greater number of posts on these outlets being publicly available, and thus accessible to me. There are differences in the composition of users on VK, Facebook and Instagram (Panchenko et al. 2015) and the nature of their use (Bodrunova and Litvinenko 2014; Folts and Danina 2019). While narratives may differ between platforms, such difference was not suggested by my initial analysis of the hashtag.

3. #ButWeAreAlwaysAtHome

The hashtag was launched by Bakaidov, whose website describes him as a programmer, member of the Saint Petersburg boccia team,⁶ speaker, and 'person with problems of the musculoskeletal system and speech due to cerebral palsy' (Bakaidov 2018, my translation). Bakaidov is well-known; he was nominated for the UN World Summit Awards in 2018. In 2020, Forbes included him in their list of the 30 most promising Russians under the age of 30 in the 'Social Practices' category (Forbes 2020). Here, I offer a close reading of his text, as the initial elicitation which the other posts and comments negotiate. The text reads:

#ButWeAreAlwaysAtHome

I didn't go to my [boccia] training session today, the school [where training is] has gone into quarantine. I made myself a cup of tea and sat down to go about my normal business, proofread, read, write. I wasn't stressed at all, there was nothing that surprised me about it. And that's when I started thinking about how routine (*privychno*; habitual, usual) it is for people with disabilities and their families to live in a state of 'quarantine'.

Most of my disabled friends (*druz'ia s OVZ [ogranichennye vozmozhnosti zdorov'ia]*; lit.: friends with limited health possibilities) are also always at home because the environment is inaccessible (*iz-za nedostupnoi sredy*). For those people's parents, their children are always home too (even though these children might be twenty or forty years old). Basically, the world can [now] experience (*oshchutit'*; feel) the conditions (*usloviia*) of disability.

And I would like to call on people to sympathise (*sochuvstvovat'*) now with those who, because of their physical limitations (*fizicheskie ogranicheniia*), cannot leave the house. I would like you to make permanent those services which are now becoming most in demand (like food delivery or free online cinemas) for people with disabilities. Because the thing is, #ButWeAreAlwaysAtHome.

Also, I want to call on people with disabilities [to share] their lifehacks (*lajfkhaki*) and stories about life within four walls under this hashtag. Now is exactly the moment we will be able to get our situation across to people.

I came up with this protest (*aktsiia*, planned action, here: campaign) together with the Polytechnic Museum of Moscow and the museum's Accessibility Council, of which I am a member. I would like the greatest number of people possible to support it, as it will help us use the media frenzy (*informatsionnyi shum*, literally 'informational noise') for good. If you are a person with disabilities and you have faced isolation because of inaccessible environment and services, share your stories with the hashtag #ButWeAreAlwaysAtHome. It would be great if you could talk about the lifehacks you've acquired because of such isolation—now they could be useful for people without disabilities too.⁷

As in Bakaidov's text itself, I begin from the hashtag: #AMyVsegdaDoma, #ButWeAreAlwaysAtHome. The 'A' beginning the hashtag is a contrastive conjunction falling somewhere between 'and' and 'but' in English (Kreidlin and Paducheva 1974; Lakoff 1971). In informal

⁶ Boccia is a Paralympic precision ball sport, similar in some respects to bowls, bocce or pétanque.

⁷ I offer my translation of Bakaidov's original post in full particularly for those who cannot access the post in its original language. The Russian may be read here: <https://www.facebook.com/ibakaidov/posts/2706654382780430> (Facebook); https://vk.com/ibakaidov?w=wall20124065_7761 (VK); <https://www.instagram.com/p/B91gE7FqGeH/> (Instagram). All accessed 10.10.2020.

Russian, it typically begins utterances, providing a glide into the main thought. It can be interpreted as shifting ‘focus from one object of utterance to another’, connecting two foci while ‘semantically differentiat[ing] them’ (Dengub and Rojavin 2010: 150). Thus, it here functions to differentiate the ‘we’ (*My*) of the hashtag, always at home, with an unwritten ‘you’ of unnamed others who typically move freely beyond the home. However, another contextual subtext offers one caveated bridge to that distance. With quarantine announced, while still differentiated, the ‘you’ are drawn closer to ‘us’. The hashtag suggests ‘you are *now* at home, but we are *always* at home’. Bakaidov frames the Covid-19 pandemic as a situation which allows some equivalence between disabled and abled people. This is more fully delineated in the original post, which states that, in confinement, ‘the world can [now] experience the conditions of disability’. It is this new understanding and, therefore, enlarged collectivity which Bakaidov identifies as holding the potential to drive change.

The original post also elaborates on the differences between the experiences and roles of the hashtag’s collective ‘we’ and its silent ‘you’. Unlike abled people, Bakaidov emphasises that disabled people and their families typically stay at home due to the lack of accessibility in the material environment. The collective ‘we’ of disabled people is thus defined, as per the hashtag, as those who are ‘always at home’. Initially, Bakaidov positions this identity as one which is evocative of sympathy; it is because disabled people cannot leave the house that Bakaidov calls on abled people to sympathise (*sochuvstvovat*) with them. In urging this sympathy, Bakaidov perhaps steers close to well-worn images of pity (*zhalost*) for a distanced, disabled other (Verbilovich 2017: 209). Indeed, one user commenting on the Bakaidov’s original post takes issue with his choice of word, preferring a call for ‘attention’ (*vnimanie*) to one for sympathy (‘I would change ‘sympathise with’ to ‘pay attention to’. But, otherwise, you’re spot on (*vsio v tochku*)’).

Meanwhile, the call for sympathy is not passive; Bakaidov clearly names the action which sympathy should produce (‘I would like you to make permanent those services which are now becoming most in demand’). Bakaidov speaks to abled people, addressing the collective ‘you’, rather than the ‘we’ of disabled people (‘I would like *you* to make permanent’, emphasis added). Disabled people might thus be imagined in the role of service users or otherwise distanced from agency or power to affect change. Moreover, Bakaidov urges action from abled people based on sympathy, rather than through a demand framed in terms of rights or social justice. This is reinforced by the causal link which Bakaidov draws at this point between disabled people’s exclusion and their own ‘physical limitations’ (‘because of their physical limitations [they] cannot leave the house’). However, Bakaidov’s position is rather one of an extension of allyship in which abled people are asked to act for the benefit of disabled people based on sympathy stemming from their new experience of confinement. Bakaidov creates space for disabled people to make claims of abled people and, in his directive statement of what he wants abled people to do, models one way of doing so.

Bakaidov in fact complicates any categorical divisions between how disability is represented and claims made. Within a single post, Bakaidov moves between an apparently deficit-based, individualised understanding of disability (i.e., they cannot go out ‘because of their physical limitations’) and a social understanding of disability (i.e., they are ‘always at home because the environment is inaccessible’). The latter, social model of disability defines disability as a social justice issue located outside the individual and addressed by right-based

claims. It operates by drawing a distinction between impairment and disability, somewhat similar to earlier feminist distinctions between sex and gender (Garland-Thomson 2011). According to the social model, impairment is a physical condition while disability is created by a social process which 'gives meaning and consequences to those impairments in the world' (ibid.: 591).⁸ Disability studies have typically opposed the social model to representations which understand disability as individual impairment. However, here Bakaidov does not suggest that these two conceptions of disability are opposed. Rather, they coexist and are both mobilised to call for action. This indicates the messiness of representing experience and warns against any exported normative assumption about how activists (should) discuss disability and make claims. Particularly, it speaks to the criticism of the social model for externalising disability and failing to recognise its sometimes messy, sometimes troubling embodiment as a valid part of disability identities (Crow 1996; Snyder and Mitchell 2001; Wade 1994; Wendell 2016).

Furthermore, Bakaidov reframes disabled embodiment as a valuable source of creativity. Towards the end of his text, Bakaidov calls for disabled people to share their lifehacks, or tips or techniques for carrying out a task in a more simple or efficient manner (Merriam-Webster 2020). Wendell (2016) has attributed reluctance to recognise the complex embodied realities of disability to legitimate concerns to avoid naturalising representations of (a) disabled people as inherently vulnerable and (b) disability as uniquely a physical attribute and, often, a medicalised deficit. In calling for disabled people to share lifehacks, Bakaidov demonstrates another mode of recognising the realities of disabled embodiment; he identifies disabled people as sources of resistant creativity and agency which indeed grow out of embodiment or, per Bakaidov, 'physical limitations'. Kafer (2013: 141) has called for 'stories [of disability] that not only admit limitation, frustration, even failure, but that recognise failure as ground for theory itself'. Growing out of the limitation, frustration, and failure of being 'always at home' due to 'inaccessible environment' and 'physical limitations', Bakaidov both proposes and asks others for representations of a disabled identity which is agentic and creative.

This representation of disabled people thus illustrates a pathway away from disability as deficit which both recognises physical difficulties and simultaneously uses them to reverse disabled peoples' dominant positioning as passive or necessarily vulnerable. Disabled people rather are sources of lifehacks which, Bakaidov notes, could 'be useful for people without disabilities too'. I identify this as in itself a recognition claim because it aims to equalise worth between the two different groups (Lamont 2018); rather than in deficit, disabled people in fact have something to offer to abled people. This narrative shifts the balance of authority towards disabled people, who are identified as producers of knowledge which abled people do not, or cannot, possess. This analysis also demonstrates the contribution of disability studies to wider sociological theorising. Butler et al. (2016) have reframed selectively imposed and constructed vulnerability as a source of agency and power, rather than passivity. Analysis of Bakaidov's text demonstrates this in action; the call for lifehacks foregrounds agency precisely in response to 'limitations' and imposed isolation.

⁸ For one introduction to the complexity and multiplicity of the social model of disability, see Owens (2015).

Through the hashtag, Bakaidov organises online space for what Hogan (2010) refers to as positive self-exhibition. The original text proposes an active collective identity which foregrounds how ‘experiences of disability incite everyday creativity’ (Ginsburg and Rapp 2020: S6). These narratives form recognition claims, in that they seek to equalise worth by affirming a group’s positive qualities (Honneth 2014: 329). They call for disabled people to name themselves and thus realise their own identity, aligning with the activist work of NSMs (Melucci 1980). These calls are also interwoven with redistribution claims. Redistribution claims are grounded in the fundamental lack of equivalence between experiences of the collective, disabled ‘we’ of the hashtag and the collective, abled ‘you’, outside of conditions of the Covid-19 pandemic (‘how routine it is for people with disabilities and their families to live in a state of ‘quarantine’). Thus, Bakaidov draws attention to the inaccessibility of the material environment and calls for the permanent development of services which would facilitate his life. In his case, redistribution claims are ultimately galvanised by new equivalence (‘the world can experience ... disability’, ‘Now is exactly the moment we will be able to get our situation across to people’). He thus uses the conditions of confinement both to organise claims based on some equalisation of experience and to positively identify disabled people as sources of resistant, creative agency.

4. Negotiating collective identities

Disabled people and their family members wrote their own comments and posts in response to Bakaidov’s original post. These interactions, rather than the initial post in isolation, build collective identity. The initial post uses a collective ‘we’, evoking responses which consider that collective identity. However, collective identity building necessarily occurs via ‘interactive and shared definition produced by a number of individuals’ (Melucci 1996: 70). Collective identity is not a unitary product, but rather a ‘dynamic and open-ended process’ in which the membership boundaries of any group are continuously negotiated (Kavada 2015: 875). As people both write their own posts and comment on Bakaidov’s original post, their narratives demonstrate how they represent the collective ‘we’ with which they identify. They show a negotiation, rather than any direct and complete acceptance of what Bakaidov proposed in his text.

Some users suggested caveated agreement with aspects of the initial text. Bakaidov foregrounded new equivalences of experience between disabled and abled people and the new possibilities for active solidarity which he believes that this equivalence creates. Few users expressed that the common experience of quarantine could potentially bring disabled and abled people closer. Elena writes that it has a ‘double benefit: both healthy people (*zdorovye liudi*) and disabled people become closer, and, as well, the actual quarantine and fight with coronavirus’. These users felt that abled people having some small part of the experiences of disabled people might shift understandings and lead to change. For example, Aleksandra wrote:

Now, because of the compulsory measures, someone can, for a short while (2–4 weeks in comparison with 27 years—nothing at all (*ignia*)) feel and think about how a person with disabilities lives constantly. This is the point where a new conversation and new under-

standing can start and, perhaps (*vozmozhno*), some new solutions will appear which will allow people with disabilities to feel more comfortable in their permanent quarantine.

However, as Aleksandra indicates, even where the premise of quarantine's extension of common experience was broadly recognised, both equivalence of experience and hopes for change were caveated.

Disabled people and their family members indicated that, while quarantine might push abled people to consider the permanent isolation of disabled people for the first time, their experiences were far from equivalent. They felt that any new consideration of disabled people would be quickly forgotten as abled people left quarantine and returned to their normal lives. Alina wrote:

Yes, now all the 'joy' of our daily lives will be probably felt by all the others [i.e., abled people]. And maybe they can wince (*sodrognut'sia*, shudder) for a minute. But don't kid yourself (*ne obol'shchaites'*)—it won't be on our account. They're only going to feel sorry (*zhalet'*) for themselves. And, one way or another, for them this is all temporary. And it'll soon be finished and forgotten. But we—we'll just stay locked up in our world.

Criticisms like Alina's suggest that Bakaidov's claims create an illusory equivalence between abled and disabled people. Such false equivalences have been criticised as not requiring people 'to identify with the oppressor, [or to] identify [their] complicity in structures of power relations mirrored by the text' (Boler 1997: 258). Feeling that the suggestion of equivalence between themselves and abled people does not sufficiently recognise their struggle, people posting with this hashtag often reject equivalence and, thus, the extension of their collective to include abled people. Alina sharply differentiates her identification with a collective 'we', which will remain 'locked up', from the experience of 'the others'. Her opposition of the two groups is clear: 'maybe *they* can wince ... [but] it won't be on *our* account' (emphasis added).

Reinforcing their distance from abled people, disabled people and their family members build collective recognition of their common experience. This rejection of equivalence with abled people and development of solidarity with disabled people was most strongly present in disabled people's identification with Bakaidov's narrative of their permanent quarantine. This description resonated with disabled people and their family members, who clearly took it up: 'Quarantine is our normal life!!!', 'Most of the time we're in isolation, we've been in #quarantine for 12 years...', 'For people with limited health possibilities (*liudi s ogranichennymi vozmozhnostiami zdorov'ia*), quarantine lasts a whole lifetime', 'We really have been living in forced "quarantine" almost since being born'. Bakaidov provided a narrative framework which they felt captured their experience. Using this narrative via their own posts is a case of 'identification [with] and "cocreation" of a story' where 'the storyteller and reader/listener create a "we" involving some degree of affective bond and a sense of solidarity' by telling and retelling a story (Davis 2002: 19).

The description of the hardships of a forced, permanent isolation also develops the relationship between social identity and an injustice frame, which is part of building collective identity (cf. Horowitz 2017). Many people emphasised continuity of their experience, saying that the announcement of quarantine changed nothing or little about their lives. This is con-

trasted with the experience of abled people. In one user's post, the contrastive conjunction with which the hashtag begins ('But', or 'a') reoccurs to differentiate between their self-isolation and that of abled people: 'But my self-isolation will never end'. In another example, Galina writes:

For some reason, it's commonplace (*priniato*) to talk about self-isolation only now and only in one context, but there are people who have been spending their life locked up for months and years. And yes, there're lots of people like that. Unfortunately. #But-WeAreAlwaysAtHome. Not all of us go away from the world of our own will (*dobrovol'no*). For some of us, a life like that is dictated by external factors. This is my huge pain. And how often I've heard from healthy people (*ot zdorovykh liudei*), 'How great that you're at home'. Yes, imagine, for years. ... And now of course I don't leave the house at all. Consciously and voluntarily. But there's a difference. For me, nothing has changed.

Galina points to 'external factors' which force disabled people to permanently stay at home, and the lack of difference which the pandemic has therefore brought to her life. She clearly defines an injustice which causes her suffering ('my huge pain'). Galina also indicates the lack of understanding from abled people ('how great that you're at home'). Sharing experience of constant isolation is directed towards informing others who do not know ('And yes, there're lots of people like that'). It also builds collectivity around sharing, recognising, and discussing a common experience of injustice among disabled people and their family members.

In contrast to their own exclusion, users described abled people's quarantines as minor, temporary and creating disproportionate panic. For example, Angelina said, 'I don't understand why people get so angry when they're forced to spend a little bit of time at home so they don't get ill? ... It's already the 12th year that #ButWeAreAlwaysAtHome'. Kristina writes, 'And [because of the quarantine] people are in shock, they're drawing and posting demotivators, looking for support in groups. And I look at it all, evil, like, "Mwah-ha-ha-ha! Welcome to my life!"' In his post, Viktor says, 'But there are people, and I'm one of them, for whom quarantine has changed practically nothing. I'm talking about people with disabilities—not all of them, but many of them. ... So, when you're complaining about having to stay home, remember that there are people for whom it's a routine experience which lasts their whole lifetime—and that's without any viruses'. Thus, people again name an injustice by distinguishing between a temporary, justified quarantine ('so they don't get ill') and an unchosen, forced and permanent quarantine. As Viktor does, many address abled people directly to urge them not to forget those who experience permanent quarantine.

Using the hashtag, people discussed what isolation meant to them beyond the pandemic: remaining constantly at home with limited social contact, leisure activities and holidays; the impossibility of leaving the home independently; feeling unprotected and lacking a social security net; and fearing the future. Close to the initial focus of Bakaidov's text, they often described how their isolation is constructed by the physical inaccessibility of their material environment. They noted the lack of curb cuts, staircases without railings, broken, unusable or inexistent ramps and lifts, unsuitable accommodation and roads and paths uncleared in autumn and winter, making them impassable for wheelchair users. Although people posting did

not explicitly refer to the social model of disability, their mode of externalising barriers to point out injustice echoes the social model's argument that the environment, not the disabled person, is responsible for exclusion. Emphasising the constructed nature of exclusion facilitates demands for change; it suggests that it is the environment, not the disabled person, which must be altered to resolve the issue. Disabled users and their family members again highlighted the injustice of inaccessibility by differentiating the experiences of their collective with that of abled people. For example, Evgeniia writes, 'Feeling the impossibility of going out when you want to—that's one thing. It's another when you want to, but the world is shut to you because of its inaccessibility'.

Users also went beyond Bakaidov's framework to name other barriers to accessibility. They described other forms of exclusion: whispers, pointing and being refused entry to various otherwise physically accessible establishments on the basis that other clients are not prepared to see them or be in the same place as them. For example, Tat'iana said, 'Our society is not ready to see children *like that*. Looks, whispers or, on the contrary, turning away. And children with their naiveness can say Something [bad] (*'skazat' chto-nibud' Takoe'*) because their parents haven't taught them'. Irina reached similar conclusions: 'As they say, welcome to our world, where families with children with disabilities live in a non-stop regime of social isolation just because "society is not ready for you"'. One user stressed that such social isolation is especially the case for disabled adults, who are no longer accepted as 'cute little ones' (*'milye малыши'*). People related others' assumptions of lack of intelligence based on their physical impairments, demonstrating the strength of the 'myth of global incapacitation' (Wendell 2016: 17) and how others' misrecognitions deny them 'the status of a full partner in social interaction' (Fraser 2000: 113–114). Maksim commented:

For society, people with limited capabilities (*liudi s ogranichennymi vozmozhnostiami*) sometimes just don't exist, they just aren't recognised as a person, as an individual with their own desires and demands. They aren't hired for jobs, they aren't taken seriously, people don't speak directly to them (like when you go to the medical clinic and the dentist for some reason asks the person accompanying you which of your teeth he should treat). In Russia, any ethics of relating to people like us is completely missing. 'If a person moves around differently, that doesn't mean that they've got no brains'.

Again, people differentiated the experiences of two different collectives. They mobilised the space of the hashtag to name the injustices to which abled people subjected them, while simultaneously building collective recognition of the treatment of their collective (e.g., 'people like us', 'our world', emphasis added).

Differentiation from abled people was also conveyed by posts focusing on the discontinuities of the pandemic. People described the pandemic's exacerbation of issues which they felt more keenly than abled people: the impossibility of isolating when daily care necessitates proximity; needing to enter hospitals for treatment, and thus increased risk of infection; concerns around being unable to access necessary care and services given the increased pressure on the health care system; and the loss of even the rare outings and occasions to socialise which they formerly had. Anger was sometimes expressed at those who presented the pandemic as a 'challenge' or 'adventure'. More rarely, Bakaidov's use of 'lifhack' also drew anger. Alina criticised it as too frivolous and light-hearted given their situation:

Lifehacks, you say? Which ones? 33 ways of climbing up the walls? 100 shades of the meaninglessness of existence? How to stay sane when not leaving the house? ... For you, it's a 'challenge' (*chellendzh*), an adventure, the chance to organise a webinar, training at home, cook-off battles and so on [but] for us, it means the cancellation of rehabilitation, an important operation, the impossibility of getting assistive tech, the voucher to go to the sanatorium you waited for 5 years for going out of date...

Users' narratives of unjust exclusion and misrecognition call others to recognise their situation, and thus implicitly also demand change. More explicitly, people called directly for abled people to accept and welcome disabled people and for the adaptation of the built environment to facilitate access to their own homes, as well as public space and services. Others urged an end to the segregation of disabled people in PNI and the development of supported living services. Some posts made by both disabled people and parents (largely mothers) of disabled people use the hashtag to raise money for treatment or equipment. Their posts indicated that the state does not cover these costs. They emphasised the increased burden on them to ensure access to expensive items which are simultaneously necessities for them and unknown to abled people. NGOs drew attention to difficulties of organisational survival given limited financial resources. One NGO emphasised the precarity of their situation: '[we're] not a state centre, we are held together by the enthusiasm of parents, we don't have any permanent support except one-off subsidies and rare grants'. Description of unjust difference suggests that some equity may be gained by support from abled people, who are not subject to this increased burden. Differentiation thus aimed to reach beyond those typically or directly affected to use pandemic's new solidarity, if not its new equivalence, to drive donations and other work to address current injustice.

The hashtag's collective 'we' also holds silences. While building collectivity by priming people to share their own experience, the original text elicits relatively little reflection on the members of the collective 'we' of disabled people who are not represented in posts or comments. Laying aside technological inaccessibility, Bakaidov's initial framework largely focuses on motor impairments and material exclusion. Some people surpass this focus, particularly in discussing exclusion through stigmatisation. However, the focus remains on physical disability and exclusions created by inaccessible material environments. Neurodiversity and neurodivergence, intellectual difference, invisible disability and psycho-social disability receive little to no discussion. Family members responding to the hashtag largely identify as mothers, enacting an accepted maternal role and carrying another tale of the gendered division of labour (Iarskaia-Smirnova et al. 2015). Few people wrote about PNI; nobody identified themselves as writing as a PNI resident. Finally, while posts often expressed anger and frustration, many people also struck a positive tone, emphasising overcoming and using time productively. Here the lifehacks for which Bakaidov called resurfaced, largely as lists of activities which could be done from home. People managed the perceived transgression of disability by limiting further transgressions, including by defending themselves from imagined accusations of negativity or complaint. Tatiana ended her post by commenting, 'I ask you not to read this text with the feeling that I'm complaining, I'm [writing] with the desire to get across (*donesti*), to get through (*dostuchat'sia*), so that people hear (*chtoby uslyshali*)'. Finally, this example suggests the multiple audiences and purposes of the narratives shared

under the hashtag; users share experiences to convince abled people of injustice, simultaneously building collectivity through the recognition, definition and retelling of narratives of isolation and exclusion among the hashtag's 'we'.

5. Conclusion

The hashtag elicited a community of recognition among disabled people by providing a new narrative framework (i.e., constant quarantine) to describe experience. Through their posts and comments, disabled people and their family members built collectivity through mutual recognition and retelling of this constructed exclusion. In doing so, they use online connectivity to transform experiences of isolation and fragmentation into a source of community. The hashtag thus curates an opportunity to transcend aspects of exclusion.

However, their narratives do not just speak to each other. Rather, in describing the injustice of their constant quarantine, disabled people and their family members also address abled people to demand their recognition of disabled people's situation as indeed an injustice. The identification of an injustice frame is not only part of building collective identity. It is also a recognition claim which asserts equal moral worth, as injustice is identified where unequal conditions meet those with equal worth. In identifying injustice, disabled people and their family members implicitly claim equal moral worth.

Building collective identity thus develops the foundations for multiple claims, demonstrating how recognition and redistribution claims are interwoven. Bakaidov initially proposed an extended collective 'we', aiming to drive redistributive change through the solidarity built by lockdown's temporary enlargement of the group which experiences confinement. He made a recognition claim by both claiming equivalence with abled people and framing a positive, creative disabled identity. In the reception and negotiation of his hashtag, other users largely built a collective 'we' of disabled people via differentiation from abled people. Their recognition claim was grounded in the unjust impossibility of equivalence. This drove descriptions of how their exclusion is constructed, motivating claims addressing structural and institutional discrimination, such as those for accessible environment and against distribution inequalities. The hashtag addresses multiple audiences simultaneously, building recognition and community among disabled people, demanding recognition from abled people and claiming redistribution action from abled people and state actors. Bringing disability studies online thus centres analysis of how people may contest stigmatisation and develop collectivity out of the very condition of material exclusion from public spaces.

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