The London School of Economics and Political Science

Disability Organising in Russia: Legitimacy, Resistance, and their Limits

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A thesis submitted to the Department of Social Policy of the London School of Economics and Political Science for the degree of Doctor of Philosophy, London, August 2021

Declaration

I certify that the thesis I have presented for examination for the MPhil/PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

I warrant that this authorisation does not, to the best of my belief, infringe the rights of any third party.

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Abstract

This thesis investigates Russian civil society organising around disability. It seeks to demonstrate the construction of legitimacy through depoliticization, and its opportunities and threats for disability organising. It proposes an analytical framework of resistance which foregrounds actors' intent and meaning-making to identify resistance which strategically aims to evade perception.

Civil society research has characterised the Russian state as relating to civil society in two broad ways: (1) encouraging its action as a partner of state which responds to legitimised social welfare needs and (2) restricting action which it perceives as politically threatening. Within this research, disability organising has largely been naturalised as belonging to the first category. However, just as the categories of legitimised and delegitimised civil society are more fluid than the above binary might suggest, understandings of disability organising as legitimate are also contingent. This raises questions about how disability civil society organisations (CSOs) enact, negotiate, and instrumentalise legitimacy, and how the category of legitimacy interacts with constructions of disability.

I explore these questions through four empirical chapters, based on interviews with actors involved in disability organising. The first chapter asks how people organising around disability perceive their environment and how this influences action. Their perceptions of risk result in strategic management of action to appear compliant. They link compliance to depoliticised social action. In the second chapter, I ask why this works in relationship to disability organising. I demonstrate how disability, and thus disability organizing, have been naturalized as apolitical via association with the private sphere, medical expertise, charity, vulnerability, and dependence. I show that assumptions of vulnerability are instrumentalized by some actors to resist; organizing from within the disability sphere manages the risk of sanction by benefitting from the sphere's assumed depoliticization. In the third chapter, I explore the everyday, ambiguous forms that resistance takes so as not to trouble apparent compliance. While some actors strategically avoid identification by the state of their action as contentious, research does not need to reach the same conclusions. Rather, I argue for the need to extend the forms of action which we recognise as resistance under these conditions. In the final empirical chapter, I look to how normatively politicized LGBTQ+ identities interact with normatively depoliticized disability identities. I demonstrate that legitimization as a civil society actor is contingent on perpetuating the misrecognition of disabled people as non-agentic, passive, and desexualized. I thus demonstrate how apparent compliance structures unequal recognition and exclusions. Analyzing how LGBTQ+ disabled actors negotiate this through strategies of fluid identity management and community building extends our understandings of resistance.

Through the thesis, I unite civil society and disability literatures to make three main contributions. First, I challenge the notion that enacted compliance is forced or passive; it is rather highly strategic. Second, I demonstrate that apparently social action cannot be understood as non-resistant and apolitical. In doing so, I highlight actors' instrumentalization of assumed vulnerability as a resistant strategy and uncover a range of forms of resistance which aim to evade dominant perceptions. Finally, I show how enacted compliance both functions as strategy and struggles to address existing power relationships. These findings call for research which recognises and values a wider range of resistance, and for organizing which is reflexive about and responsive to how its strategies may replicate exclusions.

Acknowledgements

My first thanks go to all the people who so generously shared with me as part of this research. I met one participant at a shopping centre near her house. After a few hours, I wanted to give her an out and checked whether she needed to get back home: 'Oh no, this is the only time I have without the kids this week. I'd rather stay here with you!' The people with whom I spoke were juggling hectic and often unpredictable schedules with multiple responsibilities. That I was offered that participant's only time off that week encapsulates the generosity and weight of the hours I took for these interviews. I am so grateful to all the participants who gave me their time and energy.

I thank my supervisors, Dr Armine Ishkanian and Dr Tania Burchardt, for their unfailing and encouraging support, patience, and guidance. I have been lucky to work with and learn from them, and the huge amount I still have to learn is reflected in their examples. I am grateful to have them.

I am grateful to the Economic and Social Research Council for the funding which allowed me the privilege of doing this research. I am thankful for the generosity of my hosts for the research portion of my PhD, Dr Christian Fröhlich and Dr Elena Iarskaia-Smirnova at the Higher School of Economics (HSE) in Moscow. For my academic visit, I thank for their welcome and helpful reflections on my work Dr Anne Revillard at the *Observatoire sociologique du changement* (OSC), Sciences Po and Dr Françoise Daucé at the Centre for Russian, Caucasian and Central European Studies (CERCEC), EHESS. I thank the administrative teams at LSE's PhD Academy and Social Policy Department, HSE's Visa Office and Sociology Department, and the OSC and CERCEC's secretariats for all their essential organisational and problem-solving work. I thank all my officemates in the Old Building at LSE for their friendship and care.

I thank my families: Mullins, Rosenfeld, Goldhurst, McGill, McCutcheon, and Sèvres. And my friends, non-exhaustively and non-alphabetically: Ken, Šima, Margherita, Phaedra, Claire, Flavia, Otto, Luisa, Orsola, Rana, Ginevra, Ellie, Ewa, Vicky, Luca, Rachael N.-D., Catriona, Laura, Nadir, Paula, Chris J., Flora, Katia F., Lena R., Elena J., François, Olivier, Sofia, Clara, Katja F., Julius, Karolina, Ena, Matteo, Sarah, Abi, Orna, Ale, Narine, Marta O., Miguel, Jelena, Rachel W., Lisa, Klaus, Teresa, Georgia, Mathilde, Dasha, Marta P., Geoffrey, Howard, Emma-Tina, Nathan, Donny, Katie, Ruth, Ayesha, Keziah, Yvonne, Alex, Kola, Chris M., and Tomek and all the team at Salle Boston.

‘Ну, просто если это не обсуждать, то истина не родится.’
‘Well, just, if it isn’t discussed, then the truth (*istina*) won’t be born.’
Aleksandra, founder of a registered civil society organisation.

One opening question I asked at interviews was, ‘How did you end up doing this?’ This question gave me some frame of reference. It referred to a story which participants knew and had, perhaps, already told – to themselves or to others. In that sense, it was conceived of as an ‘easy’ question.

Sometimes, the answers were not particularly easy. People described depression, family breakdown, having no access to information, and feeling hopeless and alone.

They have been resourceful, courageous, and resilient. They should not have been forced to be so.

I dedicate this thesis, with immense gratitude, to those without easy answers.

Overview Contents

Detailed Contents

Chapter One

Introduction

1. Introduction

> The 'Foreign Agents' Law[1] specifies that '*political activities do not concern*, for instance, culture and art, health care and healthy ways of life, maternity assistance and child care*, social support of the disabled*, and charity' (Kulmala, 2016, p. 207, emphasis added).

> '…the figure of the child is used to render *certain positions as extra-political, as beyond the realm of politics*, and I suggest that *the disabled body performs a similar function*' (Kafer, 2013, pp. 96–97, emphasis added).

This thesis brings together literature on civil society, social movements, and disability with qualitative, interview-based research to explore disability organising in Russia. It does so to challenge two misperceptions that affect how we understand disability organising and, more widely, resistance. The first: the association of the social sphere with depoliticization. The second: the characterisation of disabled people as extra-political, or beyond the political sphere (Kafer, 2013).[2]

In doing so, I argue for the recognition of a strategic infra-politics of resistance in restrictive conditions. I also demonstrate that assumptions of inherent vulnerability and depoliticization may be strategically mobilised as a source of agency and power. Finally, I sketch the limitations of these strategies in conditions where actors strategically avoid risk of sanction. These strategies remain dependent on ambiguity and liminality, and structure erasures of aspects of identity which may perpetuate the misperception of disabled people as passive, infantile, and inherently vulnerable. Where the action of and access to disability civil society organisations (CSOs) is predicated on replicating these misperceptions, patterns of exclusion

[1]Federal Law No.121-FZ of 20 July 2012 'On Introducing Amendments to Legislative Acts of the Russian Federation regarding the Regulation of the Activities of Non-Commercial Organisations Performing the Functions of a Foreign Agent.'

[2]Here and throughout, I use extra-political and apolitical in broadly similar ways to indicate dominant perceptions of the disassociation or removal of an identity (e.g., disabled) or organising area (e.g., disability organising) from the political sphere, or from a space of 'contestation and agonistic engagement' (Swyngedouw & Wilson, 2014, p. 6). I use apolitical without the connotations of apathy or antipathy which it can sometimes hold. Rather, I simply mean that an object, person, or topic is characterised as unrelated to the political realm.

and erasure within the disability organising sphere operate unequally to exclude certain groups. How disability is misrecognised thus offers both opportunity for infra-political action and reinforces power imbalances and exclusions. Exploring how legitimacy of actions and identity is created, instrumentalised, and resisted in Russian disability organising therefore contributes to debates on the nature and challenges of infra-political resistance.

I address these questions in the context of Western, largely urban Russia, through the experience of civil society actors based in and around Moscow, Saint Petersburg, and Nizhny Novgorod. As I discuss initially below (Section 4) and further in situating the thesis in this setting (Chapter 4), the Russian context productively supports analysis of both infra-politics and the construction of disability as extra-political. I include actors who participate in a wide range of organising spaces (Chapter 2). Within the thesis, I use civil society organisation (CSO) as a pragmatic shorthand including, unless otherwise specified, a range of organisational and non-organisational forms, social movements, and communities.

I am particularly concerned to explore resistance as identified by actors themselves, based on their claimed meaning-making and intent. While I understand the interviews fixing these claims as co-constructed, contingent accounts (Chapter 2), I take the feminist standpoint that we should believe and listen to participants' accounts, rather than understanding participants as not recognising their own realities (Lamont et al., 2016, p. 6). By exploring intent and meaning, I counter the tendency of research on social movements and civil society to lean on overt, collective, in-person action at a particular time and place (Véron, 2016). Instead, I focus on everyday, infra-political, ambiguous action which, as I will discuss (Section 3.2.), is characterised by a desire to avoid the perception of dominant parties. This form of action seeks change to shift power relationships by changing meaning-making and consciousness in everyday life (Polletta, 1997; Staeheli, Ehrkamp, Leitner, & Nagel, 2012), change which is by its nature long-run.

Therefore, in exploring questions of the meanings and problems of action to the actors themselves, I lay aside questions of tangible, wider impact as beyond my scope. This is not least because of the relatively short temporal span of this project, which problematises analysis of such outcomes. It is also because the focus on meaning-making and intent of quiet, everyday resistance is the most appropriate to develop knowledge. This focus challenges characterisations of disability organising in Russia as non-contentious and extra-political.

Through this approach, I call attention to organising which we would undervalue were we to characterise it uniquely as, for example, 'parochial' and 'inward-looking' (Crotty, 2006, p. 1319)[3] for not achieving change along measurable axes. Such characterisations would not recognise apparent compliance as subversive strategy, the meaning-making and resistance which lies behind it, and the value and potentially transformative quality it holds for those individuals involved. What some research sees as 'parochial' can also be understood as being protective and transformative for a certain group. Nonetheless, I also remain critical in exploring the moments where such infra-political, apparently compliant resistance encounters limits and replicates existing power inequalities.

In the remainder of this chapter, I first present my research questions. I then situate them in relationship to debates on depoliticization, infra-politics and ambiguity, and the construction of discursive norms. I outline how my thesis relates to Russia as its empirical context. This context allows the exploration of the theoretical possibilities I suggest and gives them precise form. However, I also note how understandings and control of both disability and civil society mean that aspects of my explanations go beyond Russia alone. Finally, I present the contributions of the thesis and the structure of its remaining chapters.

2. Research Questions

Throughout the thesis, I draw on my empirical findings to discuss the following research questions (RQ):

> **RQ.1.** How do people organising in disability CSOs perceive their environment? How do they consequently enact compliance?
>
> **RQ.2.** Why is disability organising dominantly perceived as social and, therefore, legitimised? How do some actors subvert and instrumentalise that positioning of disability?
>
> **RQ.3.** How do actors enact resistance while remaining apparently compliant?

[3]I note that the cited article's conclusions on environmental organising are entirely legitimate according to its terms. Here, I use it only to call attention to the possible gap created by limiting ourselves to this approach. When we do not look behind what could be characterised as failure to achieve certain types of change (e.g., when we think only in terms of policy change), we miss exploring the meanings and workings of a whole host of action. Furthermore, claims of elitism and hoarding of social capital within an in-group are mitigated or even turned on their head when that group turns inwards precisely for reasons of self-protection and support in a hostile environment. Considering these factors shifts how we value inward-turning, ambiguous action.

RQ.4. How does strategically ambiguous resistance relate to existing power relationships?

RQ.5. How do ambiguous, non-overt strategies of resistance and enacting legitimacy exclude LGBTQ+ people? How do they negotiate their exclusion?

I reached these final questions through an iterative process, as I developed the research project. Behind each of them stands a theoretical and empirical grounding which I present further below in situating the thesis (Section 3). Here, I summarise this context to present the logic behind my questions.

My starting point is to examine the assumption that service provision is depoliticised (Section 3.1.). I use this term to mean that it is identified as a technical sphere where resistance, and power relationships, might be absent. It is removed from the political sphere, defined as 'a space of contestation and agonistic engagement' (Swyngedouw & Wilson, 2014, p. 6). However, concepts of fluid power and non-apparent resistance suggest not only that power relationships are inescapable, but also that they are necessarily characterised by the presence of resistance and that resistance may be strategically non-apparent, ambiguous, and without clear demands, particularly in conditions of power imbalance (Section 3.2.). As I demonstrate, power operates via discursive norms which legitimise and delegitimise certain ways of acting and being. Dominant discourses create misperceptions concerning disability and 'social' organising, where both are misrecognised as non-contentious (Section 3.3.). In the Russian context, social action is contingently legitimised, and actors perceive an incentive to avoid identification as political (Section 4). This creates conditions where, rather than depoliticization, we might expect the presence of infra-political resistance, discussed further below (Section 3.2.).

It is therefore telling to explore how apparently legitimised social actors perceive and navigate their environment (RQ.1). Much research has focused on actors engaged in overtly delegitimised, human rights organising (Salamon, Skokova, & Krasnopolskaya, 2020). This research has also at times used the label of 'rights' in a reductive manner, perpetuating a problematic reduction of human rights action to (delegitimised) civil and political rights and implicitly not considering social action as rights-based. In contrast, exploring how actors dominantly perceived as social in fact understand and navigate their environment draws out potentially political and rights-based aspects of social action. Rather than naturalising the

distinction between delegitimised political action and legitimised social action, I analyse how this division is constructed. I do so by interrogating the naturalisation of disability organising as depoliticised (RQ.2). I also show how resistance continues without disturbing apparent legitimacy, expanding our recognition of resistance based on actors' intention, meaning-making, and its relationship to dominant discourses of disability (RQ.3). I suggest that actors instrumentalise the dominant depoliticization of disability organising to continue to resist. However, ambiguous action may struggle to challenge existing power relationships (RQ.4). Furthermore, apparent compliance also creates certain exclusions and limitations, particularly where actors wish to maintain relationships with public, state institutions and bodies. By looking at the experience of LGBTQ+ actors in disability organising, I explore one of these identity-based exclusions (RQ.5). I thus create a picture of the operation, experiences, and challenges of infra-political resistance.

3. Situating the Thesis: Key Theoretical Aspects

3.1. Social Services and Depoliticization

> '…most disability activists and NGO leaders in CEE [Central and Eastern Europe] are currently focused more on service provision than advocacy or implementation of disability rights' (Holland, 2008, p. 544).

> 'Neoliberal restructuring has resulted in […] [the] depoliticization of disability organizations by restricting their activities to service provision' (Mladenov, 2016, p. 104).

> 'Nevertheless, the party-state discourages civil society from participating in contention, in part by regulating and channelling organizations into social services delivery' (Fu, 2017, p. 501).

The above citations from Holland, Mladenov, and Fu describe the problem from which I began. I found service provision either opposed to or contrasted with advocacy or rights implementation (Holland, 2008) or equated with depoliticization and compliance (Fu, 2017; Mladenov, 2016). Incentivising participation in social service delivery is a technique to control civil society and legitimise the state (Fröhlich & Skokova, 2020). However, social service delivery can also be a channel for advocacy and rights implementation. Furthermore, social service delivery is not necessarily depoliticised and non-contentious.

Some of my interview participants described developing programmes with the aim that they would be taken on by the state and absorbed into its budget. Service provision becomes a way of advocating for a mode of working which might better respect rights. Others related how they understood and intended volunteering in art and activity groups as an ideological, political, or otherwise resistant act. A minority of actors discussed moving into apparently social action as a way of either politicising their practice or continuing to engage in political resistance in an environment where that resistance is strongly disincentivised. The state disincentivises overtly contentious, political action and attempts to depoliticise actors by encouraging them into social service delivery. This may have the unintended paradoxical effect of in fact further politicising aspects of social service delivery. Where actors perceive social action as relatively legitimised and political action as delegitimised, people who might otherwise be engaged in more directly contentious action may seek the outlet of apparently social action. Attempting to depoliticise actors through engaging them in social service delivery means that more investigation is needed of experiences, understandings, and intentions of actors whose work is dominantly perceived as social.

The need to investigate non-apparent, ambiguous aspects of actions under conditions of imbalanced power has been recognised by the concept of infra-politics. Infra-political action is the less apparent action which 'continuously press[es] against the limit of what is permitted onstage' (Scott, 1990, p. 196). It is one form of action which may shift perceptions of the self and propose 'an alternative framework of sense' (Melucci, 1988, p. 249). It seeks change by shifting meanings in everyday life (Polletta, 1997, p. 431). In the next section, I further explain the concept. I show why it is useful here to explore action which has been dominantly legitimised as social, without assuming depoliticization and an absence of resistance. First, however, I pause to explain how I use the category of 'social' in this thesis.

As I will demonstrate empirically (Chapters 5 and 6), I understand the social as a discourse legitimising civil society action. As discourse is 'a terrain of conflict' (Steinburg, 1998, p. 853), various actors shift its exact content or referent as they mobilise the social. However, as concerns civil society action, the social is dominantly associated with social rights and opposed to the political. It is associated with service provision in areas in which the state encourages CSOs to act (Fröhlich & Skokova, 2020), such as housing, healthcare, and social security (Bindman, 2015, p. 345). Political activities have been defined as not including 'health

care and healthy ways of life, maternity assistance and child care, social support of the disabled, and charity' (Kulmala, 2016, p. 207). Given the exclusive ways in which the two are defined, the social then may refer to these areas. Here we also see another facet of the label of 'social', which may be associated with charity and lose its association with rights (Revillard, 2018). In my use of the social, I interested in the functions of the label, how it is often exclusively opposed to the political, and what that does.

3.2. Infra-Politics and Ambiguity

Marche (2012, p. 7, italics in original) argues that infra-political actions matter politically as they 'not only exact a cost on the dominant, but they represent a threat if they are not held under check—and they *cannot* be held under check for lack of being noticed'. Similarly, Staeheli, Ehrkamp, Leitner and Nagel (2012, p. 630) suggest that these non-obtrusive actions 'hold the potential to nudge established patterns of control and authority'. They do so while and by evading control because they are 'beyond the perceptual field of the dominator' (Lugones, 2000, p. 177). Movement beyond perception does not only mean hidden action, but action and discourse which takes place openly but whose meanings are not necessarily legible in the same way to everyone (Scott, 1990). Fröhlich and Jacobsson (2019) have also suggested that liminality and ambiguity are a key property of infra-politics occurring in Russian urban spaces.

Here, strategic liminality is my focus, rather than any potential outcome or clear effect of the pressure which infra-politics may create. As suggested above, this characteristic allows infra-politics to evade control by avoiding identification. Actors may choose such action to be able to continue to organise in restrictive circumstances or otherwise out of a preference to minimise how apparent they become. However, chosen avoidance of identification vis-à-vis a wider audience, including the state, should not necessarily be replicated by research. Rather, research should aim to recognise this resistance. Scott comments: 'So long as we confine our conception of the political to activity that is openly declared, we are driven to conclude that subordinate groups essentially lack a political life or that what political life they do have is restricted to those exceptional moments of popular explosion' (1990, p. 199). Rather than participating in erasing resistance, Scott's conclusions encourage us to look for discourses and moments which might not be made visible to the dominator and may yet

undermine the norm. As I discuss in my methodology chapter (Chapter 2), I seek not to replicate the view of the dominator, but to propose another perspective.

Given that strategies controlling civil society legitimise depoliticised, social partnership with state, participation in social action may be perceived as dominantly legitimised. This is particularly the case around disability, which is associated with discourses which construct the disabled person 'as beyond the realm of politics' (Kafer, 2013, p. 97). While disabled people may be constituted as a threat to the norm in discourses of infection and pollution (Kondakov, 2018), they are not dominantly constituted as a political threat. However, given the possible infra-political life of apparently compliant, social action, it is important to look at the perceptions and experiences of those who are dominantly constituted as involved in such social action. It is also important to question their understandings of their actions.

So far, I have suggested both that social action is often assumed to be depoliticised (Section 3.1.) and that infra-politics suggests that non-apparent resistance may continue in these spaces (Section 3.2.). Grounds for assumed depoliticization is formed by dominant discourses, reflected in both the quotations from which I begun (Section 3.1.) and how the state attempts to channel civil society. These discourses play a role in constructing certain norms and logics of appropriateness for different spheres. In the following section, I peel back a further layer to present what I mean by legitimised and delegitimised, and how this relates to both disability and civil society in Russia.

3.3. Dominant Discourses and Power

On a Foucauldian analysis of power, disciplinary power operates via discursive norms. Norms are constructed by discourses, which are a form of social action that draws upon 'conventions that naturalize particular forms of knowledge and ideologies' (Jones & Norris, 2005, p. 8) in order to structure the field of action (Foucault & Rabinow, 2010; Rile Hayward, 1998). In other words, discourses legitimise certain expressions and actions, while delegitimising others. Under disciplinary power, those who do not fit with a discursive norm are labelled as abnormal. Lilja and Vinthagen summarise Foucault's telling of disciplinary power (1991, pp. 177–184): 'to be different is to be inferior' (2014, p. 109). It is, therefore, to be subject to various interventions to 'reform, fix, or rehabilitate' (Lilja & Vinthagen, 2014, p. 109, cf. Lilja, 2008; Johnston, 1991), as disabled people's experiences amply demonstrate (Chapter 3).

Power and resistance are mutually constitutive (Lilja, 2008; Lilja & Vinthagen, 2014; Sharp, Routledge, Philo, & Paddison, 2000). Therefore, where subject to techniques to integrate a norm, we can conclude that people may comply with, resist, subvert, and instrumentalise those attempts. Resonant discourses are instrumentalised in both 'strategies of domination as well as those of resistance' (Diamond & Quigley, 1988, p. 185). As disciplinary power acts on the individual, we might expect resistance to disciplinary power also to be individualised, non-obtrusive, and have qualities in common with infra-politics. Lija and Vinthagen make a similar argument, suggesting that in response to disciplinary power, 'we find other types of more "everyday resistance" and discursive forms of challenges, which might be hidden or disguised and are not typically open' (2014, p. 114).

Therefore, if action which is perceived as social is discursively naturalised as apolitical and compliant, it in fact calls for research to investigate how this is instrumentalised and resisted, including in non-apparent ways. Similarly, if disabled people are subjected to naturalised misrecognition as apolitical and non-threatening and targeted by interventions which aim to rehabilitate them to a norm, we might expect responses to include resistance to interventions and instrumentalization and subversion of misrecognition. Dominant discourses around disability and civil society create a field of action which naturalises certain representations, actions, and modes of being. This, however, does not imply a relationship of domination, but one of agency and resistance as those naturalised actions and identities are contested.

We must question as an operation of power relationships why certain spheres of action, and certain actors, are considered threatening and others are naturalised as removed from threat. Here we turn to discourses concerning disability and their relationship to the depoliticization of social service provision. To apply the argument made above about disciplinary power and its relationship to discursive norms: to be disabled is to be different, and to be different is to be necessarily perceived as inferior and requiring rehabilitation to meet a norm. Indeed, disability has been dominantly misunderstood as an individualised medical issue and personal tragedy (Cameron, 2014b, 2014a), evoking responses of pity and charity (Revillard, 2018). Reflecting the 'myth of global incapacitation' (Wendell, 2016, p. 17; see also Amundson, 1992), disabled people have been infantilised and thought of as inherently vulnerable and needing protection (Satz, 2014). Tied to these ideas of pity, charity, and paternalism are

discourses of passivity and a lack of agency. Crucially, where social welfare is misperceived as charity, it is then associated with disability.

There are multiple misperceptions here. The first collapses the distinction between social welfare and charity. The second understands disability as medical tragedy or burden. It thus associates disability both with welfare, and therefore charity (Revillard, 2018), and with medicine, and therefore a depoliticised field adjudicated by external technical experts (Zola, 1972). Therefore, while disabled people are indeed often perceived as deviating from and threatening the norm, this threat is perceived as depoliticised. These discourses misunderstand disability and social service provision. Without questioning them, actors cannot perceive certain meanings and knowledge. This creates space propitious for infra-political action, which is based on precisely that ambiguity and non-apparency to the perception of the dominator.

This raises questions about how misperceptions can be used to gain power, particularly in conditions where actors perceive a strong imbalance of power and aim to avoid external identification of resistance. This has been suggested by literature on the use of vulnerability as a strategy of power (Butler, Gambetti, & Sabsay, 2016). Here, I contribute an empirical investigation of the experiences and resistance of actors who organise in a field which is assumed to be social and depoliticised. I also raise questions about some of the limitations of strategies which depend on maintaining ambiguity and not disrupting the assumptions of disabled people's vulnerability upon which the characterisations of social, depoliticised action are contingent. Before outlining my contributions around these questions, I present some further contextual factors in situating the analysis of my thesis not only in relationship to Russia, but also power relationships which, in varying forms, go beyond Russia.

4. Why Russia?

Using resonant norms to exert power is not unique to Russia. It is also not unique to Russia to use civil society in regime legitimation strategies. Equally, in many places, civil society seeks out, instrumentalises, and resists the state's efforts to use it as a source of legitimacy. This occurs in regime types across a spectrum from more authoritarian to more democratic. While I explore my questions in close relationship to a particular context in present-day Russia, instances and explanations I identify occur and hold to differing degrees and forms elsewhere.

A parallel argument from Sperling (2014) about the mobilisations of legitimacy demonstrates another effort to offer deeply rooted cases, while recognising wider explanations. It also again makes clear the nuance which my research seeks to add to arguments around power, resistance, and vulnerability.

Sperling (2014) explores how discourses of femininity, masculinity, homophobia, and heteronormativity are used to channel power in Russia. She notes: 'a larger part of the explanation goes beyond the Russian case and is rooted in a widespread, if not universal, phenomenon: *the cultural framing of masculinity under patriarchy makes the assertion of masculinity a vehicle for power'* (ibid., p.4, italics in original). I differentiate my argument: as suggested above, I propose that it is not only the assertion of a powerful norm (i.e., hegemonic masculinity) which is a vehicle for power, but also identities which are assumed to be vulnerable and apolitical. However, similarly to Sperling, part of my explanation clearly goes beyond Russia. As with patriarchy, ableism is not unique to Russia.

Ableism asserts 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)' and the other (Campbell, 2015, p. 12). The ableism identified in dominant discourses concerning disability may be expressed differently in different places, as the category of disabled is fluid and contextual. However, ableism is hardly unique to Russia. Moreover, certain abstracted forms of oppression appear widespread (Linton, 1998, p. 37): exclusion, segregation, medicalisation, mistrust around malingering and 'faking disability', pathologizing dependency, the Supercrip and inspiration porn, and discourses of infantilisation and disability as burden and tragedy (Dorfman, 2019; Hartblay, 2014a; Martin, 2017; Rasell & Iarskaia-Smirnova, 2014; Revillard, 2018; Schalk, 2016; Zola, 1972). These understandings, in other contexts too, may construct disabled people as vulnerable and disability as apolitical.

Still, I am exploring disability more specifically as a category motivating civil society organising. Ableism structures the use of assumed vulnerability and depoliticization as a source of power. However, this also depends upon alignment with an environment where civil society is legitimised as depoliticised and responding to social welfare needs. Again, beyond Russia we have also seen attempts to channel civil society into responding to social welfare needs as a partner of state. Looking to the UK only, for example, we also see the development of civil

society as a partner of state tendering for government grants and resolving welfare gaps ("Civil Society Strategy: building a future that works for everyone," 2018; "Creating effective partnerships with civil society," 2013; Harris, 2017). In Russia too, certain mechanisms incentivise specific behaviours as legitimised and compliant. For example, funding mechanisms and legal forms for CSOs encourage social action (Fröhlich & Skokova, 2020).

However, the Russian context also sets further contours to legitimacy. The Foreign Agents Law (2012)[4] clearly signals the need to avoid 'political action' (*politicheskaia deiatel'nost'*). There is legislation prohibiting sharing information about LGBTQ+ relationships with people under 18,[5] one consequence of which is the dominant perception of LGBTQ+ organising as political (Mason, 2016; Soboleva & Bakhmetjev, 2015; Stella, 2013; Wilkinson, 2014). Finally, the Soviet Union attempted to 'inflect the agenda away from civil and political freedoms' and towards 'state-organised economic and social guarantees' (H. Dean, 2008, p. 2). Post-Soviet Russians are presently characterised as using 'diverse political strategies that draw on multiple discursive patterns [and] moving deftly between logics of social rights, civil rights, and neoliberal selfhood' (Hartblay, 2019, p. 547; cf. Hemment, 2007; S. Phillips, 2010; Shevchenko, 2009). However, legacies of legitimacy surrounding economic and social guarantees in the post-Soviet space, and the politicisation and shifting meanings of rights in the present day, provide resonant discourses potentially legitimising social action for civil society.

Depoliticizing discourses about disability and civil society may not be sufficient to produce infra-political action and strategic compliance, whether through alignment with discourses of vulnerability or otherwise. Rather, the dynamic is clearer where there is a strong incentive to align with discursive norms. In Russia, civil society action is also shaped by actors' awareness of power imbalances and wariness over potential sanction around action (Clément, 2008, 2015; Greene, 2014). '[F]ormal rules, institutions, and rights' are often viewed by civil society actors as poorly institutionalised 'arbitrary tools' (Clément, 2008, p. 72). These perceptions

[4]This commonly used name references the Federal Law No.121-FZ of 20 July 2012 'On Introducing Amendments to Legislative Acts of the Russian Federation regarding the Regulation of the Activities of Non-Commercial Organisations Performing the Functions of a Foreign Agent'). I discuss the law in more detail in Chapter 4.

[5]I refer to the Federal Law No.135-FZ 'For the Purpose of Protecting Children from Information Advocating for a Denial of Traditional Family Values', or the so-called 'gay propaganda law', which was passed in 2013.

may push towards infra-political action and everyday resistance, and also indicate the need to explore them.

In Russia, legislation, policy, and actors' awareness of power dynamics, sanction, and threat makes the operation of certain power relationships more starkly expressed, while similar dynamics may still occur to differing degrees elsewhere. My analysis builds on certain wider discourses, such the misperception of disability under ableism, as they are present in a particular context. This context structures these discourses in a particular way and ties them to legislative and administrative measures which highlight existing power relationships. Russian disability organising provides a telling context to investigate questions of resistance and infra-political action, providing insights which may be relevant for analysing civil society organising more widely.

5. Contributions

Thus far, I have suggested that service provision is often perceived as non-contentious and depoliticised. We see this both in the civil society literature and in the strategies of the Russian state and other dominant actors. Channelling CSOs into social action is therefore equated with its depoliticization. However, in conditions of imbalanced power and strong discursive norms around legitimacy, this equation in fact opens space for ambiguous, infra-political resistance. Instrumentalising assumed vulnerability and depoliticization may thus become a resistant strategy, as well as one which shapes and perpetuates certain exclusions. Thus, resistance may perpetuate the misrecognition of disability in what is simultaneously agentic strategy and limiting factor. My recognition of resistance not only nuances the misrecognition of disability organising as depoliticised, but also outlines why actors perceive this as strategically necessary and considers how it limits challenges to existing power relationships. This argument contributes to knowledge on the operation of constructions of depoliticization, disability, and resistance in Russian civil society organising.

I demonstrate that apparently social actors nonetheless perceive themselves as potentially subject to restriction and sanction. Research on CSOs in Russia has tended to focus on CSOs involved in human rights organising, where this identification is restricted to CSOs working for civil and political rights (Salamon et al., 2020). Actors perceived as social are less investigated. My analysis therefore starts from investigating actors' perceptions of their own

environment. I find that these actors strategically adjust their operations, relationships, and discursive framings to remain seen as depoliticised, social actors. I show that actors may identify their apparent compliance as a strategic choice to maintain possibilities of action. I thus challenge assumed depoliticization by demonstrating actors' agency vis-à-vis their environment.

I further suggest that the misrecognition of assumed depoliticization in fact creates space for resistance to evade perception. This operates both by misrecognising resistance and disability. The former operates through the tendency to give precedence to extraordinary moments of public, and publicly claimed, activism and to elide or minimise forms of resistance which are ambiguous, everyday, or occur outside the public sphere (Chebankova, 2015; Véron, 2016). The latter is seen in how disability is dominantly associated with the private sphere, infancy, pity, victimhood, and inherent vulnerability. This misrecognition positions disabled people as legitimate recipients for legitimised social or charitable civil society action. I demonstrate that assumptions of depoliticization may be strategically instrumentalised by actors to continue resistance. Thus, assumed vulnerability becomes a source of power.

To recognise how and where resistance continues, I propose the need to recognise a wider range of resistance. I operationalise this through examining actors' intent and meaning-making, rather than the form of their action. The meaning of action may be deliberately externally ambiguous. However, I argue that this is an agentic choice as actors strategically draw resistance beyond dominant perceptions. Their dissimulation of resistance should not result in its erasure by research. Rather, research should seek to go behind dominant perceptions to identify infra-political action. I propose that doing so nuances understandings of organising spaces and investigates the value and meaning of actions to their actors. Particularly where operating in a hostile environment, inward-turning, ambiguous resistance can be protective and transformative for that in-group.

However, I argue that the limits of misrecognition also constrain resistance. It is both a source of power and a limiting factor, particularly for organising which seeks to evade the risk of sanction. The need to remain ambiguous around crossing the limits of legitimacy operates unequally, reinforcing exclusions of those who are delegitimised. I demonstrate this through the erasure of LGBTQ+ people from formal disability organising spaces. Their normatively politicised identity exceeds the bounds of normatively depoliticised disability identities.

Consequently, their experiences demonstrate how exceeding the bounds of misrecognition simultaneously delegitimises action.

6. Thesis Outline

The thesis continues with my methodology chapter (Chapter 2), in which I outline how I conducted the empirical, qualitative research. I consider questions around ethically researching and representing disability and civil society, their meanings, and my positionality vis-à-vis this project. I thus aim to provide information necessary for the reader to become an active, critical participant in receiving the thesis.

I then move to the theoretical framework (Chapter 3). I introduce power and resistance as two foundational concepts which allow analysis of both civil society organising and disability. I define civil society and the different (non-)organisational forms and modes of organising included in the research. These range from government-organised non-governmental organisations (GONGOs) to social movements, communities, and nonmovements. I consider a wide range of forms of action, relationships to the state, and fluid modes of participation in multiple spaces. This lays the groundwork for considering resistance and infra-politics through a focus on the individual and their agency in navigating these different spaces. I then consider how I use concepts of resistance and infra-politics, as well as the critique that the resistance paradigm is too all-inclusive to be analytically useful. I answer by proposing a situated use of resistance which considers both discursive and concretised legislative and administrative tools of control. I highlight criteria of actors' intent and meaning-making, and their relationship to dominant power relationships, as central to identifying resistance. I then outline the definition of disability and how it is constructed and controlled. I suggest that disability has been misidentified as extra-political and propose the possibility that removal from the political sphere may become a tool which actors instrumentalise to continue resistance.

Next, I present the Russian context (Chapter 4). I demonstrate why this context supports consideration of my research questions. First, I briefly present the development of civil society from the end of the Soviet Union to the present day. The state currently promotes a binary division of Russian civil society into legitimised and delegitimised actors. The division is fluid and itself a tool of control. However, how this state-led distinction is experienced by civil

society actors themselves remains under-researched. This is particularly the case for action considered to be on the legitimised side of the binary. I argue that disability organising has been considered as legitimised. Investigating it therefore stands to nuance our understandings of how that binary distinction plays out from the bottom up. I support this argument by presenting some dominant discourses and constructions of disability in Russia, which are associated with charitable, welfare-driven responses.

I then begin my four empirical chapters. With existing literature identifying a top-down, state-led binary between legitimised and delegitimised civil society actors, the first empirical chapter (Chapter 5) examines how the environment is understood from the bottom up. I demonstrate that actors organising around disability perceive risk and act strategically to minimise it. While their environment is perceived as unpredictable and rules as often poorly institutionalised, actors have nonetheless distilled certain rules. Key among them is being identified as social, non-political actors. I show how they enact compliance in discursive, relational, and operational strategies.

In my second empirical chapter (Chapter 6), I analyse why this enactment of compliance works in relationship to disability. I demonstrate that disability is linked to depoliticising discourses. I argue that disability organising is legitimised through the overlap in these discourses and those characterising legitimised, social civil society action. Civil society organising against negative stereotypes surrounding disability, such as those of perpetual infancy and victimhood, itself demonstrates the resonance of those discourses. Some actors in fact instrumentalise this positioning of disability to continue ambiguous resistance from a space assumed to be non-contentious. Their action benefits from dominant discourses of passivity and vulnerability to evade recognition as resistance. The disability sphere is seen as relatively less subject to sanction than others; this space is identified by actors who moved from overt protest which is dominantly identified as political into disability organising with the aim of continuing resistance. Beyond demonstrating an undocumented path of the diffusion of knowledge and practices, I thus offer an empirical demonstration of the instrumentalization of the assumed vulnerability of disability as a strategy of resistance.

In the third empirical chapter (Chapter 7), I ask what forms this resistance takes while not disturbing apparent compliance. I show how resistance continues in repressive environments where overtly rights-based framings are delegitimised and may attract sanction. I argue that

actors respond to an unpredictable, ambiguous, threatening environment with action which is itself ambiguous and multiply legible. A tourist excursion is seen as a protest march by one of its participants, while an unannounced lecture looks to outsiders like a gathering among friends. Through the accounts of research participants, I outline how actors dissimulate how they work for rights, give new meanings to everyday actions, and turn inwards and manage which audiences access different parts of an action's meanings. Recognising these incidence of infra-political action challenges assumptions of depoliticization. Rather than perpetuating actors' own strategic dissimulation of resistance, I use meaning-making and intent to look beyond what is apparent.

In the final empirical chapter (Chapter 8), I look at how the discursive and legal environment which incentivises apparent depoliticization structures the unequal misrecognition of disabled people. I use one example to do so: the interaction of LGBTQ+ identities with disability organising. While the former is highly politicised, the latter is normatively depoliticised. This makes problematic the recognition of LGBTQ+ disabled people and LGBTQ+ people in general who are active within disability organising. I find that LGBTQ+ people may exit from or self-erase within disability spaces. They build their own spaces and communities and engage in hidden collaborations with formal disability CSOs, as well as differentiating their expectations for LGBTQ+ and disability organising spaces. While resistance remains founded on not overtly challenging the dominant misrecognition of disabled people as vulnerable, passive, and pitiable, claims around sexual identity, particularly those seen as threatening (Kondakov, 2014, 2018), are elided. In a context where disability CSOs are performing useful functions, this means that LGBTQ+ people are at a greater risk of unmet need. Furthermore, this example is where I rest my argument on the importance of recognising liminal, ambiguous, often inward-turning resistance. If we limit ourselves to discussion of any tangible, large-scale, policy-based outcomes of civil society organising, we minimise or miss the importance of inward-focused resistance as in fact transformative for an individual and building important resources for communities unwelcome elsewhere.

In the conclusion (Chapter 9), I review the main contributions of the empirical chapters and the arguments of the thesis as a whole. Finally, I present some further questions my research has raised, some of its untold stories, and directions for future research.

Chapter Two

Methodology: Researching Civil Society and Disability

1. Introduction

An interview at one participant's flat began in the kitchen. He introduced me to another person who was living there, and we talked about how the binbags they had bought that month were far too small for their bin. He put the kettle on. This participant himself was a student and asked me about my research, what I was reading, what my methodology was. I explained that right now I was basically just drinking a lot of tea and listening to people. He looked up from chopping ginger for our tea: '*kukhonnoe u tebia issledovanie.*' 'You're doing "kitchen research".'

It's an interesting characterisation. 'Kitchen research' reflects the concept of a kitchen as the place for private, honest, open conversation among people you can trust. It raises questions about my place in the research and my relationship with participants. It shows how disability inflects the locations of my research. It also immediately demonstrates the rooted nature of my research, and the necessity and complexities of translating it; the kitchen holds shades of meaning in Russian which are not necessarily understood in English without further explanation. Both Ries (1997) and Hartblay (2020) describe the intimacy of Russian kitchens. In *Second-Hand Time*, one speaker evokes the meaning of the kitchen (Alexievich, 2016, pp. 38–39):

> For us, the kitchen is not just where we cook, it's a dining room, a guest room, an office, a soapbox. A space for group therapy sessions. […] Thanks, Khrushchev! He's the one who led us out of the communal apartments; under his rule, we got our own private kitchens where we could criticize the government and, more importantly, not be afraid, because in the kitchen you were always among friends. […] We talked about everything: how shitty things were, the meaning of life, whether everyone could all be happy. […] A tiny handful of people resisted openly, but many more of us were "kitchen dissidents."

Beyond a certain friendship and trust, the kitchen also suggests a position of criticism and even dissidence. The late-Soviet period saw a 'culture of kitchen discussions' which 'substituted public debate' (Bodrunova & Litvinenko, 2014, p. 121). Conditions for public debate may have shifted, but the sense of the kitchen, and indeed many of the Khrushchev-

era apartments with their small kitchens, has persisted. Discussing present-day grassroot activism in Russia and the United States, Clément and Eliasoph cite Havel's 'kitchen table talk' in a list of terms valuing the 'hidden political face of this local, experiential level of engagement', alongside Bayat's 'social nonmovements' and Scotts' 'infra-politics' (2019, p. 252).

My research is built on kitchen table talk, my own and participants'. This connotes an engaged stance, building on the work of disability scholars who advocate for empathy and solidarity in research (Gibson, 2019). It recognises that I arrived at this research through experience and engagement, rather than any 'deductive selection of a case chosen for theoretical reasons' (Cornish, 2020, p. 80). Finally, as much as it denotes entering a space of trust away from a greater public sphere, it also denotes the blurring of public and private in researching disability. In a context where much material public sphere is not easily accessible, meeting for interviews at times meant an invitation into the home (cf. Hartblay, 2020). This research, both physically and in terms of its talk, often entered the personal space of participants. With that in mind, I present how I go about this project and reach this text.

I begin by presenting my position vis-à-vis my research and its epistemology as the lens through which the chapter, and indeed the research as a whole, should be read. I make my subjectivity clear in outlining a reflexivity of discomfort (Pillow, 2003) which recognises the contingencies of the text. Secondly, I engage with how my research represents disability, as well as how experience of disability is linked to my positionality and others' perceptions of me. Thirdly, I explain how I recognise and operationalise this in my practices of interviewing, both through sample building and conducting interviews. Finally, before concluding, I consider questions of interpretation and translation as I lay out my practices of analysis and writing up. Throughout the construction of this research, I seek to avoid replicating a relationship of dominance. As infra-political resistance is not apparent to the eye of the dominator (Chapter 3), exploring this resistance necessitates a research relationship of solidarity and trust. In this chapter, I outline how I aim to build such a relationship.

2. Contingency and an Epistemology of *Différance*

Explorations of discomfort in research recognise the contingency of any apparently final text (Pillow, 2003). Disability as methodology takes this optic further; Price and Kershbaum argue

that researching disability means questioning and transforming the 'assumptions and outcomes that ordinarily characterise – or assumed to characterise – research situations' (2016, p. 18). Price and Kershbaum (2016) speak of 'cripping research', where to 'crip' is to transform typical representations and practices 'to reveal able-bodied assumptions and exclusionary effects' (Sandahl, 2003, p. 37). Disability research as methodology is, then, deeply engaged with questioning power relationships and practices to 'expose the arbitrary delineation between normal and defective' (ibid., p.37). Questioning typical standards of 'good' research and embracing messiness and discomfort are part of this endeavour.

However, any messiness is often then tidied away and hidden in the process' product, with the position of author demanding the clarity of a neat, final document. Here I argue that my research should be understood as a (co-)construction which cannot be final; while interpretation and translation are a necessity in research, they are also tempered by the discomfort and *différance* which ground my authorial position. Through this chapter, I make visible the research process and analytical and representational choices. Here and in my concluding chapter, I reflect on the presence of untold stories, silenced by my focus on other questions. Rather than a cathartic telling of discomfort, these move this document away from a 'comfortable, transcendent end-point' (Pillow, 2003, p. 193) and any single 'easy story' (ibid., p.189). To think about research, authorship and authority, and the contingencies of representations, I mobilise the concept of translation. I argue that a constant awareness of my research's translations can motivate a standpoint of discomfort and emphasise the constructed nature of its knowledge.

All research inhabits many languages and is subject to multiple translations. Translation occurs not just from one language into another, but also within languages – moving up and down registers and from everyday language to that of different disciplines. Translation occurs where participants formulate, by whatever means, their answers to questions during an interview. This translation is not just transformation into language. It is also a negotiated process, where a participant considers what aspects to share with, or translate to, the researcher. Translation occurs again in the researcher's understanding and analysis of what the participant has said. Translation occurs in writing, as the researcher frames a final story and what will be made visible to a reader. It occurs again in reading or listening to a text.

Certain aspects of the forms translation listed above are commonly discussed, although in other terms; the researcher's positionality, for example, or participants moving between public or private accounts. However, translation itself is an under-used concept in social science research. Not discussed either directly or critically, translation is often at best presented as a 'fundamentally technical operation' acknowledged in a footnote (Pereira, Scharff, & Marhia, 2009, p. 2). Agar criticises researchers for remaining 'eerily quiet' about the experience of translating (1996, p. 140). Poblete speaks of research conducted across languages which is presented '"as if" our informants spoke the same language as our readers' (Poblete, 2009, p. 632).

I respond to this 'eerie quiet' by offering translation as a powerful concept to motivate the presentation and critical analysis of my methodology. Translation is sometimes presented in terms of what is lost (Pereira et al., 2009). However, it is also important to consider its constructive potential as a revealing frame of analysis. What does the consideration of translation make visible? Firstly, discussion of translation has been often linked with that of betrayal (Danto, 1997). While the characterisation is itself questionable, drawing on this link questions the relationship between participants and researchers, and the researcher's fidelity to participants. Secondly, the concept of translation reveals the power relations linked to who holds the ability to name, to define, and thus to create knowledge. It motivates discussion of authorship and the construction of texts, as well as the construction of the project of research which has gone before. These questions are themselves linked to disability organising, where various actors discussed working to produce knowledge which goes against dominant views. Thirdly, it asks how I translate myself into my research contexts and the ways in which I am both an outsider and an insider; how I am perceived by others; and how I, in turn, translate them through steps of whom I have interviewed, how I have understood them, and whom I cite and how. This forms another parallel with disability defined as a negotiated power relationship (Chapter Three); identification as disabled is both something a person adopts, and an identity which others assign to them. Equally, I both translate myself and am translated by participants, and they both translate themselves and are translated by me. All these questions relate to making visible the messiness of research. They are therefore productive in contributing to an uncomfortable reflexivity (Pillow, 2003).

Reflexivity has been criticised as centring the author (Brueggemann, 1996) and as an egotistical enterprise which in fact undermines the emancipatory potential of research (Kemmis, 1995; Patai, 1994). In response, emphasising the contingencies of translation suggests rather the death of the author and the birth of the reader (Barthes, 1967). The reader is shown the seams of the research-construction and given the tools to pick apart its messiness. Revealing the struggles of translation is thus a reflexivity of discomfort, which should 'challenge the reader – pushing the reader to analyze, question, and re-question her/his own knowledges and assumptions brought to the reading' (Pillow, 2003, p. 189). This is in turn consonant with Garland-Thomson's presentation of a feminist disability studies methodology which 'asks difficult questions but accepts provisional answers' (Garland-Thomson, 2011a, p. 40) and privileges 'the partial, the provisional, the particular' (ibid., p.42), as well as Kafer's argument for a methodology of questioning which is 'resolutely a work in progress, open-ended, aiming for but never reaching the horizon' (Kafer, 2013, p. 18). Translations are always provisional, presented by Derrida through the concept of *différance* which refers to both to difference and to deferring meaning, getting rid of an 'end point' (Derrida, 1982, p. 8). It speaks 'not to what is there (language), but what is not there' (Gentzler, 1993, pp. 158–159). The information provided in this chapter should situate the reader in an optic of *différance*, where they are given the information to engage with the difference and dislocations of the research's many translations, its deferral of a stable end point, and have a heightened awareness of constructions of meanings (Kruger, 2004) and the discomforts in that. In the concluding chapter, I return to this point to reflect on the stories which I have not told.

3. Communicating and Representing Disability

I begin by discussing some issues with the isolation of disability as a static object of the research process, given an understanding of disability as a negotiated power relationship (Chapter 3) and the contention critical disability studies mounts that it is itself a methodology (Minich, 2016). I make visible different modes of naming disability in English and Russian as a tool to allow the reader to criticise and draw more information from participant citations. This is based on the contention that a reader's lack of knowledge of the initial language is 'the most significant factor responsible for their uncritical acceptance of what is presented to

them as translation' (Sun, 2018, p. 23). Finally, I discuss how my relationship with disability influenced the research and the question of who has the right to represent disability.

3.1. The problem with 'Disability or'

For much of this project, I have been followed by one question: 'Are you doing a civil society PhD or a disability PhD?' I believe that the root of the question reflects a problematic understanding of what disability is and does, in life and in research. One debate around the language of disability gives an entry to the issue: person-first language (PFL) Vs identity-first language (IDL).

As the name suggests, the person-first side of the debate advocates for language which places the person first. For example, a woman with a mobility impairment, a man who is d/Deaf,[6] or, at its most generic, a person with disability/disabilities, etc. Those on this side of the debate suggest that this emphasises the common humanity of the people and its importance above and before any disability or impairment. PFL has gained wide usage; its traction is reflected by its use in the United Nations' Convention on the Rights of Persons with Disabilities (UN CRPD, 2008).

However, the other side of the debate argues that PFL compartmentalises disability (Aubrecht, 2012; Lester & Nusbaum, 2018). PFL suggests that disability is not an integral part of a person's identity, but rather an attribute which can be isolated and boxed off. Some further argue that by dividing the disability from the person, PFL inherently constructs disability as something negative and to be distanced from the person. They also criticise PFL for suggesting that disability is something static which someone 'has', rather than something which is constantly contextually negotiated and which, at the same time, may also be imposed upon a person. In contrast, people who prefer IDL argue that disability is a fundamental part of a person's identity, though expressed contextually and occupying different places and significations at and in different spaces and times. They prefer language such as 'a d/Deaf

[6]The capitalisation of 'Deaf' is used by some d/Deaf people to suggest association with wider Deaf culture(s) and identities. By contrast, 'deaf' without capitalisation would typically be used to refer to the state of being with some degree of hearing loss, without wider associations with Deaf cultures. Regardless of a strong Deaf culture in Russia, the same distinction between the capitalisation or not of the Russian word for 'deaf' (*glukhoi*) and related difference in meanings does not appear to be made.

person' or 'an autistic person'. At its most generic, IDL would use 'disabled person' rather than 'person with disabilities'.

Also held within the language of 'disabled person' is the idea that disability is something which is enacted upon a person. In this sense, a person is disabled by their environment and according to others' perceptions of them, and how they are categorised and related to as a result. The passive participle 'disabled' here is used in much the same way as 'vulnerabilised' or 'racialised' to suggest the identification and positioning of a person operated upon them by wider society. Thus, the person is 'disabled' by their environment and change therefore needed from the environment, not the individual. This reading of 'disabled' stands on the concept of the social model of disability,[7] which stems from a document published in the United Kingdom by the Union of the Physically Impaired Against Segregation (UPIAS, 1976) and was initially more fully developed by Oliver (1983). Its use here does not indicate my complete agreement with the social model of disability, which I discuss in more depth in presenting how I conceptualise disability in this thesis (Chapter 3). Here, I intend only to emphasise the socially constructed nature of disability.

To bring it back to my approach to this research: the question, 'disability or?' is then closer to the criticised aspects of person-first understanding. It construes disability as something compartmentalised and static, a potential individual focus of my research. However, my understanding of disability situates it as something negotiated, contextual, and part of a person's identity in ways which are complex, multiple, and fluid. Disability is a way of being and an identity inhabited and negotiated by the disabled person themselves, as well as simultaneously enacted upon them. Disability is therefore a negotiated power relationship (Tremain, 2005).

As I present in my theoretical framework (Chapter 3), my research brings together concerns of power negotiation which are common to both disability and civil society studies. In this thesis, I explore how the category and identity of disability operates through and is shaped

[7]The disability studies literature commonly uses the word 'model' to refer to an approach to understanding disability. Writing on the medical model of disability, Cameron defines a model in this sense as 'a framework of ideas used to make sense of phenomena and experience in the social worlds we inhabit. A model represents a particular way of ordering and structuring knowledge and, indeed, shapes what can be known' (2014a, p. 99). In the subsequent chapter, I present more fully the theoretical identification of disability used in this thesis, including more in-depth discussion of certain common 'models' of disability.

by civil society organising. As such, here there is no choice to be made between civil society or disability; one illuminates the other. Disability is not a detachable item, but rather runs throughout the chapter's standpoint emphasising contingencies, discomforts, and translations.

3.2. Naming Disability in English and Russian

Thus far, I have used the difference between person-first and identity-first language to distinguish two broadly different approaches to disability, and to argue for disability not as a detachable item, but as a construction, concept, identity, and methodology (cf. Minich, 2016; Sandahl, 2003). Here I discuss the directly negotiated naming of disability in my research and its translations. For many participants, naming is a central exercise in meaning-making around disability and claiming different modes of visibility. Conversely, other participants move between multiple modes of naming within one interview (e.g., PFL and IDL), confounding any categorical divisions between modes of naming and understanding disability. Providing information about the language is therefore not necessarily a shortcut to defining the participant's attitude to or understanding of disability. However, it does suggest some nuance in potential meaning and clarifies the links and divergences between naming disability in the Russian and English languages.

In English, the debate largely centres around that already outlined above: PFL Vs IDL. These modes of naming have different meanings for their different supporters and detractors, particularly within certain disability communities (e.g., the Deaf community, who both claim and capitalise Deaf to refer to a wider Deaf cultural and identity, as noted in Footnote 6). In addition to what has been outlined above, there are some criticisms of English-language IDL which say that its foregrounding of pride around identity makes it either taboo or simply more difficult to discuss the lived reality of certain impairments and traps people within positive discourses, which are also reductive.

In Russian, the currently most common word for 'a disabled person' is '*invalid*'. Historical terms of diagnosis and reference to disabled people previously used by the medical profession are no longer officially used in that setting. These words, such as 'idiot' (*idiot*), 'cretin' (*kretin*), and 'fool' (*durak*), currently exist largely as insults. Disability is translated as '*invalidnost'*'. The word '*invalid*' is grammatically masculine; it can be used without change to

refer to both men and women. Disabled children are typically referred to by adding the word 'children' before the word '*invalid*', as in: '*deti-invalidy*'. It is also possible to modify '*invalid*' by adding before it the word for young girl (*devochka*), girl/woman (*devushka*), boy (*mal'chik*).

Aside from the further modifications mentioned with young girl, boy, etc., this vocabulary is consonant with that of Russian legislation around disability. The legislation defines four overarching categories, literally: (1) '*invalid*' of the first group (*invalid pervoi gruppy*); (2) '*invalid*' of the second group (*invalid vtoroi gruppy*); (3) '*invalid*' of the third group (*invalid tret'ei gruppy*); and (4) child-'*invalid*' (*deti-invalidy*). Groups one to three are defined according to judged severity of impairment and consequent need for support, from most to least. '*Deti-invalidy*' are defined as being disabled minors, without any further division according to social care needs within that category. I discuss Russian policy around disability in more depth in Chapter 4.

I have suggested '*invalid*' as the most common translation for 'disabled person' in Russian. However, here already there is a key difference. 'Disabled person' is still explicitly followed by 'person'. Despite the anglophone debate between PFL and IDL, 'person' still features in both 'disabled person' and 'person with disabilities'. In Russian, '*invalid*' already implicitly suggests a person, without the grammatical need for a further word. Other words are added only as compound constructions (e.g., *deti-invalidy*, etc.). Some people use this word without issue, some use it in a conscious attempt to reclaim it, others argue for PFL in Russian too. In Russian, 'a person with disabilities' has been translated as '*chelovek s invalidnost'iu*'. Unlike the English plural (disabilit*ies*), the Russian remains singular (person with disabilit*y*); the expression reaches towards the concept of disability as something abstract and unquantifiable. While participants largely used one of these two modes, broadly following the divide between PFL and IDL, some participants moved between the two modes.

In contrast to the anglophone criticisms of PFL, in Russia, PFL is largely thought of as more critical and reflexive in counterbalance to the state language of '*invalid*' which categorises disabled people and thus determines to some degree their support entitlements. While '*invalid*' is not necessarily derogatory (Wiedlack & Neufeld, 2016, p. 222), there appears to be some generational shift away from its use, at least among activists. This may also be influenced by the language of the UN CRPD and the World Health Organisation (WHO) (Iarskaia-Smirnova, 2001). However, this use remains fairly emergent. While in the UK, PFL is

more institutionalised, in Russia is appears to be less so. PFL is, perhaps on this basis, more welcome and used among social movements and associated communities as more radically alternative language to that used by the state.

The question of naming also influenced my research practice. Where I initially contacted a potential participant in writing, I presented the research using the abstract noun '*invalidnost*" (disability). Where first contact was oral, either in person or on the phone, I listened to them and adapted how I referred to disabled people to reflect their speech. During interviews, I also adapted how I referred to disabled people to reflect the participant's speech and modes of (self-)identifying. By matching my speech to theirs, I aimed to respect participants' preferred form of (self-)identification, maintain mutual intelligibility, and build rapport. However, I also avoided using modes of naming which I found inherently negative and limiting, for example: *liudi s ogranichennymi vozmozhnostiami zdorov'ia* (lit.: people with limited health possibilities), *liudi s otkloneniiami ot normy* (lit.: people with deviations from the norm). This trade-off is part of remaining close to my own ethics in conducting research, as I did not feel comfortable with perpetuating the use of expressions which I find stigmatising. In these cases, I typically returned to the more neutral Russian of '*invalid*'. Here too, I felt somewhat uncomfortable, although in English I typically use and am comfortable with 'disabled person.' Despite efforts to reclaim it, it remains a totalising word often associated with state policy. Although this is not necessarily felt as an absence by native Russian speakers,[8] I miss the word 'person' which is common in English to IDL and PFL.

My positionality vis-à-vis language use and power in the interview process will be discussed more below (Section 4). In this section, I rather make different modes of naming disability visible for those who do not speak Russian with the aim of deepening their understanding of quotations in this research; the different expressions in Russian do not have the same

[8]UK, and perhaps also US, English speakers have moved towards adding the word 'person' to identifying descriptors such as 'an Italian' and expressions such as 'Spaniard' and 'Frenchman' have largely fallen out of use in favour of 'Spanish person' and 'French person.' In contrast, Russian comfortably uses nouns which imply 'person' for many identifiers, not only disability. For example: *ispanets* (a Spanish man), *frantsuzhenka* (a French woman), *invalid* (a disabled person). The difference between nationality-based examples and disability examples is that nationality identifiers have male and female version, while the female version of '*invalid*' (i.e., '*invalidka*') is not so widely used. *Invalidka* is now being claimed by feminist disability groups, along with a wider movement to use 'feminitives', or female-identified noun forms.

implications as in English. I discuss this further in presenting how I create voice in translation in the process of writing up (Section 5).

3.3. Disability and Reflexivity: Чужая-родная/*Chuzhaia-rodnaia*

Ozhegov's Dictionary gives three main definitions of the adjective '*chuzhoi*' (TextoLogia, n.d.-a). Firstly, the word describes something which is not your own or belongs to others. Secondly, it describes something or someone which is not '*rodnoi*', not from your family, foreign to you. Thirdly, it describes someone or something distant in views from you. The same dictionary defines '*rodnoi*' in three main ways (TextoLogia, n.d.-b). Firstly, as describing a relative or someone in a direct, blood relationship. Secondly, as describing something or someone which is close to you by birth or by a closeness of habits or point of view. Thirdly, as a way of addressing a person as 'dear' (*dorogoi*) or 'sweet' (*milyi*). It gives the example of a '*rodnaia dusha*': a person (literally a 'soul') who is close to you in all ways and understands you. In Russian, '*rodnoi*' suggests a complicity and closeness with a warmth which is not necessarily suggested by the term 'insider'. '*Chuzhoi*' suggests foreignness, distance, and lack of understanding.

Given the warmth of '*rodnoi*', I prefer to use *rodnaia-chuzhaia* (respectively '*rodnoi*' and '*chuzhoi*' in feminine forms) as closer to my experience in research than the typical spectrum of 'insider-outsider' positions.[9] Throughout the research, I moved between the two points in different manners and due to various linguistic and personal traits, affecting the interview process. Remarking on my spoken Russian, participants simultaneously highlighted both my foreignness and my belonging. The former as speaking Russian is only remarkable if I am perceived as not Russian. The latter as speaking Russian was read as a token of my commitment to and understanding of Russia. Both are productive in different ways discussed below. The step to the warmth of '*rodnaia*' typically seemed to function by the disclosure of personal experience, again with various consequences which are discussed below.

The reading of me as foreign legitimised questions which, from a Russian person, would have implied at best naivety and at worst ignorance. As I inhabited the role of a foreigner, and therefore someone a priori ignorant of the situation in Russia, participants seemed not to find potentially naïve questions jarring and responded well to my requests for further explanations

[9]For one overview of the shifting and fluid spectrum of insider-outsider positionalities, see Kwak (2019).

or clarifications. Furthermore, participants' reading of me as foreign did appear to lead many to make comparisons (both positive and negative) between Russia and the UK, even without my having asked the question in that frame. Goode refers to a similar experience in Russia, as his presence elicited international points of comparison (2016, p. 438). Participants' perception thus seemed to lead them to make wider comparisons and considerations of the situation for civil society in Russia, in fact supporting my research.

At the same time, I was also not foreign in ways which were also productive. Where comparisons with the UK were mainly to defend Russia from the stereotypical understandings of the country which participants felt that foreigners held, my experience in Russia and how I speak Russia were mobilised by participants as articles of good faith which distinguish me from 'other foreigners'. Their remarks suggested that they perceived how I spoke Russian as marking a deeper understanding of Russia. This and my prior experience living and working in Russia may have built participants' confidence and trust in me.

Participants' perceptions of my use of the Russian language, my commitment to and knowledge of Russia, and any ability to obey certain interactional codes are ways in which they translated me. Their reactions to these perceptions are doubtless part of the interviews' co-construction. In the ways I have outlined above, I saw myself as instrumentalising these perceptions in order to be productively both *chuzhaia* and *rodnaia*. However, it was close personal experiences of disabilities which made me truly *rodnaia*. This disclosure felt again to shift the dynamic of the conversation, bringing it in some way closer to respecting reciprocity in disability methodologies (Price & Kerschbaum, 2016), but also raising questions about the nature of relationship between researcher and participant and the potential for emotional manipulation and faking intimacy.

Criticism of 'faking friendship' (Duncombe & Jessop, 2002; Finch, 1984; Miller & Bell, 2002; Mirza, 1995) argue that, in working to build rapport and create an environment where participants feel free to tell stories, the researcher applies emotional pressure which in fact 'induces the respondents to provide their stories, perspectives or narratives' (Tyldum, 2012, p. 204). Tyldum argues that 'breaking out of the interview or refusing to disclose particular information' is made more difficult if the participant perceives friendship between themselves and the interviewer (ibid., p.204; see also Duncombe & Jessop, 2002). I will outline my response to this further below in my emphasis on using a conversational approach,

open-ended, narrative questions, not using an interview schedule, emphasising the participant's ownership over both the audio and the transcript, and remaining in contact to various degrees where the participant wishes (Section 4.2.). I also did not meet with participants repeatedly over a long period of time, aware that this can lead to further difficulties in managing the friendship/researcher relationship (Tyldum, 2012). My second response consists in interrogating the stance that friendship is necessarily false or 'a threat' to the research process. Friendship with participants is often referred to in terms of negative risk. In one example, Dickson-Swift et al. observe that qualitative research by its nature leaves researchers 'ultimately more *vulnerable* to crossing the boundaries from research into friendship' (Dickson-Swift, James, Kippen, & Liamputtong, 2007, emphasis added).

However, as Dickson-Swift et al. also recognise, a form of friendship in research can also be a strength. As Tillman-Healy observes, 'We never ask more of participants than we are willing to give. Friendship as method demands radical reciprocity, a move from studying "them" to studying us' (2003, p. 732). Although I was deliberately not embedded in each individual participant's life for as long as Tillman-Healy proposes, I adopted a stance of friendship in a mode of engaged, reciprocal sharing and openness, without pressure. This stance again recognises my presence and the 'us' of some shared experiences which I interrogate in my research. The naming of certain personal experience is consonant with how disability research has advocated rapport based on shared vulnerability (Gibson, 2019). For Gibson (ibid.), shared vulnerability transforms into solidarity. This also reflects my experience, as participants and I often discussed questions of injustice which required my solidarity as they implied both identifying a problem and recognising the need for change. This suggests a common viewpoint and goal, blurring the distinction between researcher and researched.

My disclosure of personal experience often responded to participant questions about why I was doing this research. Mann observes that, 'we should expect our colleagues and our respondents to question us about our motives, not just our methods' (1996, p. 70). Hertz too finds it 'important to admit that we study things that trouble or intrigue us, beginning from our own subjective standpoints' (1997, p. xvi). When participants asked about me and why I am doing this research, the questions were of course legitimate. Given that I had contacted them, often out of nowhere, to request their time and energy for this project, responding to these questions seemed a normal part of both developing trust and rapport. More

importantly, responding openly to such questions cast the interview as a conversational exchange of experiences, rather than a purely one-sided interview where only I am entitled to ask questions. The interaction thus resembles more closely a typical meeting between people who have not previously met and aims to better respect the principle of reciprocity in research (Price & Kerschbaum, 2016).

However, people did not ask why I was studying civil society. Rather, people almost uniformly questioned why I would study disability. The answer which appeared to entirely satisfy these questions was my disclosure of family relationships with disabled people. Other answers (e.g., that I was drawn into the subject by my own long experience with another disability CSO in Russia) led to further questions around why I had chosen to volunteer precisely there. Although I could have answered that it had happened by chance, the principle of reciprocity again suggested to me that I mirror the honest disclosure for which I was also in effect asking them. Two factors are important in participants asking and accepting my answers to 'why disability'. In some ways, the recognition of my disclosure of personal relationships as a satisfactory root cause which put an end to participants' questions was unsettling. It appeared to be well-received because of a dominant narrative that disability is not inherently worthy of attention or study; only a personal connection could motivate my engagement with the topic. Kafer has identified the tendency to 'relegate' questions of disability 'to those with a personal relationship to disability' (2013, p. 2). When disability is seen as only an issue for those with a personal relationship to it, we have a problem: ableism and discrimination on the grounds of disability is a problem for everyone (cf. Dorfman, 2019, p. 1083).

However, the recognition of my disclosure as satisfying also appeared to speak to another issue in disability research: who has the right to represent disability? There have long been calls to centre the experience of the disabled person (Fine, 2019) and criticism of research which rather objectifies, misrepresents, and profits from disabled people (Schalk, 2017). As Minich writes, 'there is an immense body of scholarship about disabled people that few in the field recognize as disability studies: work that objectifies disability; places it under the medical gaze; pathologizes it; deploys it as a device of characterization; or uncritically treats it as a metaphor for decay, decline, or failure' (2016, para. 5). O'Toole (2013) explicitly invites disability scholars to disclose their relationship to disability in their work. Furthermore, given the aggression and lack of comprehension which participants often described experiencing

on the basis on disability, their checks of my background and relationship to disability made sense. The disclosure appeared to build trust and indeed solidarity, as Gibson (2019) suggests. Participants would speak about how I must understand and empathise with certain situations or observe that it was good that one 'of our people' ('*iz nashikh'*) was doing this research. Others would speak of their lack of trust of 'outsiders' ('*chuzhie liudi'*) who were working around disability and question their motives and understandings. One participant described disability as something higher than national boundaries; far from being 'foreign' or an 'outsider' (both in Russian can be translated as '*chuzhaia*'), it was this disclosure than made me truly '*rodnaia*', with all the closeness and emotional rapport that the Russian suggests.

I only disclosed any such information in response to participants' questions, given both reciprocity and participants' grounds for concern around others' understanding and representations of disability. These disclosures also opened conversation about what people thought was missing from representations of disability and disabled people. For example, participants often welcomed my research as a project seeking a non-medical, non-pathologizing picture. As I describe further in Section 4.2., this was an accessible manner of including participants directly in conversation about the direction of the research and the representation of disability.

However, issues around trust and performative aspects of 'doing rapport' (Tyldum, 2012, p. 204) meant I did not deliberately create the opportunity for such disclosure. Rather, I only spoke about this in response to participants' questions and where they found important to discuss the issue; I felt it cynical to disclose any relationship otherwise, as though doing so would be instrumentalising personal experience to hack closeness and emotional rapport. For it is precisely this closeness and rapport that the disclosure seemed, almost inevitably, to elicit. People would refer to how I understood them, their situation, or the situation of their families. Some people would express how glad they were that someone 'who knew from experience' was doing this research, that they could not trust those who worked in disability 'for no reason', without immediate personal lived experience of disability motivating them.

4. Practices of Interviewing

4.1. Sample Building

In total, I interviewed 61 people to investigate how discourses of disability interact with discourses about civil society in Russia. Interviews were conducted from 2017-2018, with a few further interviews conducted in 2020. Sample building was one of the first steps in the research's construction. It passed through four major stages: identifying disability, selecting research sites, identifying disability organisations and movements and, finally, identifying and building contacts with relevant individuals. Here I present these stages.

4.1.1. Identifying disability

Behind sample building stands my conception of disability organising and, therefore, of disability. Given that I set out to look at a range of discourses around both disability and civil society, I cast the net deliberately wide. Disability research has been criticised where it objectifies, pathologizes, or 'deploys [disability] as a device of characterisation' (Minich, 2016, para. 5). Minich's characterisation may also be true of some CSO organising. However, this was not here a reason to exclude such organising from study, given that I am interested in investigating a diversity of discourse. I therefore deliberately included CSOs from government-organised non-governmental organisations (GONGOs) to grassroots groups and social movement communities working around disability as they defined it. This identification with and of disability was based also on their own representation and use of disability, not necessarily aligned with any one diagnosis or impairment. In the words of participants, this included self-identification with and work around physical disabilities, psycho-social disability, mental and/or intellectual disabilities, sensory disabilities, non-neurotypical people, people with psychiatric diagnoses and/or experience of psychiatric hospitalisation, depression, and other identities, experiences, and diagnoses. In this manner, disability was defined in various, fluid manners by different participants without me setting limits or boundaries on that definition. This is also reflected in where and how I identify people as disabled as I cite them. In some cases, people commented that they could technically register as disabled or that they technically were disabled. However, in the first case, they did not register as disabled because this would mean forfeiting the carer's allowance they received or, in the second, they did not identify as such because, in comparison to a family member, they felt that their impairment had a lesser effect on their daily life. The category of 'disabled' was relational and ambiguous, and not everyone identified as such. This aligns with the understanding of 'the state of affairs called "disability"' (Tremain, 2005, p. 1) that I use here (Chapter 3). As such, disability is a fluid

and contextualised category which I explore through the social reality of its use by civil society actors. This loose approach resulted in few concerns around boundary cases. In particular, it led to the inclusion of some organising around impairment acquired in later age and palliative care; these movements often cooperated with wider disability civil society, particularly around deinstitutionalisation, and identified themselves as working on disability. These boundary cases were included based on the primacy of actors' own self-presentation and identification in driving my selection and inclusion criteria. It is consistent with my aim of exploring how the category of disabled is used by civil society actors.

4.1.2. Research locations

I restricted the locations of my research to three large cities and their surroundings: Moscow, Saint Petersburg, and Nizhny Novgorod. In choosing these cities, I replicate an imbalance in research by focusing on larger urban centres in Western Russian. However, my choice of these cities is motivated by the objective of exploring diverse forms of organising: Moscow, Saint Petersburg, and Nizhny Novgorod have a large volume of organising of different forms. Looking at urban centres particularly facilitates the inclusion of social movements (de Moor, 2020, pp. 124–125) and a diverse range of views. I do not aim to make comparison between views in different cities. In fact, the range of views uncovered in each urban location overlaps; I do not use the research location as a motivating factor in any analysis of difference. Moreover, the fact that certain CSOs have their seats in one city, such as Moscow, does not restrict them to working solely in that location; many of the CSOs included in the research also work in other regions across the country in both urban and rural settings. The location of and good transport links with and between all three cities was also a factor in their choice as it safeguarded the logistical feasibility of completing the research to schedule. Finally, the choice of urban locations allowed me to enter discussion with existing research on both disability organising and infra-politics, which has often been conducted in urban settings (e.g., Fröhlich, 2019; Christian Fröhlich & Jacobsson, 2019; Toepler & Fröhlich, 2020). As I aimed to bring these bodies of work together and to think about how disability shapes resistance, I here maintained a largely urban focus so as not to add further complexity at this point.

While interviews were conducted with participants based in one of those three cities or their surroundings, I continued to read social and other media articles and posts which discuss or are by CSOs in other locations. Although these did not enter my analysis directly, this

information remained part of my picture of organisation more generally. Additionally, I previously participated directly for many years, and remain punctually involved, in a city-based CSO which also organises in the countryside. Experience with this CSO in various locations and with other CSOs associated with it also forms a background to the research.

4.1.3. Identifying and contacting CSOs and people

I define civil society as 'the arena of uncoerced collective action around shared interests, purposes and values' (CCS, 2005, p. 1), without taking a normative position on values or intentions. How I define CSOs is dealt with in more detail in the literature review (Chapter 3); these criteria were also used to identify and include CSOs in the sample. The research includes CSOs of four main types, namely:

a. Government-organised NGOs (GONGOs);
b. CSOs with recognised, registered legal form (i.e., funds, socially oriented non-commercial organisations (SONKOs), etc.);
c. Unregistered grassroots groups; and
d. Social movements, (associated) communities, and nonmovements.

I thus seek to explore a wide range of organising and the interplay between different spaces, going beyond an emphasis on registered, long-standing, or more formalised organisational forms.

In the three research locations, I identified CSOs positioning themselves as organising around disability by several routes. These included via direct online publications *by* CSOs on various platforms, indirect publications *about* a CSO on various platforms, recommendations of friends from my own involvement in the field, recommendations of journalists with whom I met to discuss the sector in general, recommendations from participants at interview (who recommended both speaking to people with whom they agreed and did not agree), and my own participation in various offline meet-ups, events, and conferences. Recommendations from participants for other people to contact allowed them also to participate in the construction of the research. Meet-ups and events, as well as meeting through recommendations and by chance, allow me to identify and include individuals who participate in both social movement communities and formal, registered CSOs. In these cases, I often met people as participants at events of social movements and associated communities and

then found out that they are also involved in other forms of organising. By using these different routes, I aimed to identify a diverse range of CSOs and not to exclude organisations without an online presence, thus responding to the danger of engaging uniquely with the 'most accessible' people (M. N. Marshall, 1996, p. 525).

Finally, 38 of the 61 people interviewed identified as women, 21 as men, and two as Trans or non-binary. The relatively greater number of women compared to men reflects some gender imbalance in disability civil society,[10] as well as in Russian civil society in general, towards women (Salmenniemi, 2005). 20 people identified as disabled, using various terms (Section 3.2.), and 41 did not. Among those 41 people, most are family members of disabled people. Some mentioned that 'technically' they could register as disabled, however, as primary carers to people already registered as disabled, they avoided doing so to continue receiving a carer's allowance. The organisation of entitlements creates a binary opposition between those may receive a carer's allowance and those who need care. This is example of how '[p]olitical discourse and policy create categories' which 'separate groups of people', although these categories do 'not necessarily reflect a similar separation of those groups in social life' (Bonjour & de Hart, 2021, pp. 2–3). It also cautions against any overly binary, quantified distinction between participants who do and do not identify as disabled in the sample.

Still, disabled people remain a minority within the sample. This reflects a sphere which, although it has seen an increase in CSOs founded by disabled people in recent years (Battalova, 2019, pp. 909–910), still sees 'the relatively low involvement of people with disabilities in non-profit organizations' (ibid., p. 911). Across the sphere, people who do not identify as disabled are often in positions of responsibility. This is particularly the case in formal, registered CSOs. Still, aware of this imbalance, I have taken care around how I have

[10]There is little specific exploration of the disproportionate representation of women in disability organising in research literature. However, women seem to be over-represented, particularly in parent-led organising. Reflected by my sample and discussed by some participants was that divorce or separation of parents appears to disproportionately affect families with disabled children. As I discuss in Chapter 6, many women begin organising following their child or children's diagnosis. While civil society is not the direct topic of the paper, a telling slippage occurs in Iarskaia-Smirnova, Romanov, and Yarskaya's investigation of parenting disabled children (2015). The article's title refers to 'parenting' and uses both 'parents' and 'mothers' in its text. However, the paper only appears to discuss the experiences of mothers, rather than those of fathers. Without necessarily itself problematising or reflecting more on the gendered division of labour and the presence of (female) single-parent families, the article reflects the overwhelmingly female nature of care labour, perhaps exacerbated in the case of disabled children and disproportionate family separation.

listened to and was guided by interviews. Of the 34 interviews cited directly, I quote 11 people who identify as disabled and 23 who do not. Thus, disabled people move from one third of those interviewed to around half of those quoted. Their voices particularly guide reflection on identity, assumed vulnerability, and resistance in the latter empirical chapters. The initial empirical chapters, which look at how actors in the sphere identify and navigate legitimised action, draw from the interviews more broadly.

I stopped interviewing at the point where I had explored the avenues opened to me through interviews to the point where I was hearing the same opinions and instances repeated, without identifying new avenues for exploration; I reached an uneasy theoretical saturation where I was no longer 'develop[ing] properties of the category' (Glaser & Strauss, 1967, p. 61). I followed Glaser and Strauss in sampling purposively to 'look for groups that stretch diversity of data as far as possible', aiming for research which 'is based on the widest possible range of data on the category' (ibid., p.61). This meant that reflection and analysis were ongoing and cyclical as I looked for and contacted participants, rather than confined to later stages of the research.

However, limitations in my sample nonetheless undercut any claim of comprehensive exploration of areas of investigation. For example, given the relatively small number of GONGOs and social movements identified or even actually existing as compared to registered CSOs, I interviewed relatively fewer participants involved in these organisational spaces. In the case of GONGOs, there are only three main organisations; I therefore ensured that I interviewed at least one person at each GONGO and, where possible, built a sample of multiple people involved at different levels (regional, national, etc.) of the same GONGO. However, questions remain about whether I was able to access the fullness of different theoretical perspectives based on my sampling and inclusion in the research. In Appendix 2, I provide an anonymised overview of participants showing their involvement in CSO(s), gender identity, age bracket, and disability status. Further information is not given in this overview as a risk to confidentiality. For example, I do not connect information in the overview to specific pseudonyms used in the research or to location. To safeguard anonymity, information about location is detached from the overview of participant characteristics (Appendix 2).

When I did not initially meet someone in person at another event, I typically made first contact with them by a personal social media page, e-mail, or phone number. In some cases,

I used the official CSO contact address. However, I only did this when I found no alternative. This is because I did not want to approach the person as a CSO representative, but rather in a more personal capacity. From the outset, I wanted to suggest that I was approaching them not to reproduce any CSO line, but to share with me their personal experiences and opinions.

When initially contacting potential participants, I provided broad information about the research project and the nature and conditions of their participation in an interview, including anonymity and confidentiality of their participation, the information shared, and their name and that of the CSO(s) with which they are involved. I explained how the interview would be used and how they could withdraw or modify consent for the interview to be used at any point. I also stated and explained why I often use audio recording at interviews. I said that I would discuss this and ask them for their permission to do so at any interview. I generally provided the information in a brief form in my initial contact, so that it could be read and responded to quickly. I offered in the initial email to provide more detailed information and to respond to any questions, by email, telephone, or video-call, if they were interested. This more detailed information was then further discussed at the beginning of the interview, as I outline in the next section.

4.2. Conducting Interviews

Here I present the setting and modality of the interviews, consent negotiations, and inclusion of participants in the research project. The apparent conventionality of interview methods does not preclude 'challeng[ing], revers[ing] or otherwise subvert[ing] the hierarchises of power and knowledge that characterize standard academic and policy research' (Cornwall & Sardenberg, 2014, p. 79); here I outline both how I disrupt a hierarchical power dynamic through my interview practices and how this dynamic is inherently troubled as I conduct interviews in a non-native language. I also recognise the limits of any challenge to a hierarchy of power in my methods.

4.2.1. Interview settings and modalities

The participants decided themselves where and when they preferred to meet. This was often at cafés, but also at people's homes. More rarely still, a few interviews were conducted at CSO working spaces. I left it to participants to name the time and place where they felt comfortable meeting. Participants were also able to suggest a different modality for the

interview. In cases where the participant was neither comfortable leaving their home nor having me at their home, interviews were conducted by video calling. Kondakov also uses this method to widen participation while interviewing disabled people (2018, p. 78). One participant preferred to type answers, rather than speak. Therefore, we corresponded over a few weeks. Otherwise, interviews were oral. I responded to the limitation of the immediacy of this mode through using pauses and interview breaks, as well as open-ended questions which do not seek a final, single answer (Section 4.2.4.). I also revisited certain points either later within the same interview or in another mode (e.g., via messenger or e-mail). This depended on the participants' involvement and is discussed further below (Section 4.2.2.).

Most interviews were conducted on a one-to-one basis; a few interviews also had another person present in line with the initial participant's stated preference. Where a second person was present, they were either someone who also participated in the CSO or someone with whom the initial participant had a personal relationship. Often the second person had both statuses simultaneously. Interviews lasted from one hour to three hours; they rarely took under one hour 30 minutes. In a few cases, participants spent longer than three hours with me, for example showing me certain spaces they felt were important.

Some of these shifts in modality reflect how disability research shifts expectations typical in conducting qualitative research. Lefkowich reflects on how researchers are typically not encouraged to meet research participants in their homes (2019). This is based on the identification of homes as part of the private sphere and interviewing in others' homes as increasing risk to researchers. Without dismissing this concern, disability research shifts these expectations in two ways. Firstly, access to the material public sphere may not be easy, comfortable, or indeed possible for some disabled participants. It may therefore not be an option to conduct interviews in person outside the home. Secondly, disability often blurs the boundaries between public and private space. Disabled people's homes may not be particularly private; many disabled people shared their homes with care assistants, family members, care assistants, or otherwise live in close proximity to others. Using typed interviews and long pauses in interviewing also allowed for 'crip time', or 'the elongated temporal frame in the performance of disability' (Hartblay, 2019, p. 559). Rather than prizing immediacy, these formats allow time for reflection and composition.

4.2.2. Informing for inclusion, participation, and consent

Informing and consent were approached as a linked process understood as 'informing-for-consent' (Cutliffe & Ramcharan, 2002; Tymchuk, 1997). Informing the participant about the interview process is also one way of increasing their power or ability to change its course. This mode does not insist on potentially demanding participation or overly draw on the participant's resources. Rather, it makes explicit certain choices in the interview set-up and allows the participant to question, challenge, accept, or disagree with them. The issues which caused the greatest amount of debate and challenge were anonymity and confidentiality. This raised questions which go beyond interview processes and practices, also speaking to interpretation, writing, and power dynamics in research. I therefore address them in Section 5.

In practice, at the interview, I ran again through the information which had been provided before meeting (Section 4.1.3.). This was done in the form of a discussion, which allowed me to answer any questions and hear some of their initial thoughts about the research project more generally, thus including them in discussion of its development. I also explained why I often use audio recording and asked for their permission to do so. This is one example of bringing participants into the construction of the research and inviting challenges and questions. It gives entry into the co-construction of our 'rules for recording'. For example, I suggested that the recording could be paused at any time, if they wanted. I showed participants how to stop and start recording and invited them to control the Dictaphone and stop or pause it at any point. The Dictaphone was also always positioned closer to the participant than to me to facilitate this. Some participants were more comfortable with the Dictaphone's use and did not enter into this conversation as much as others, simply agreeing to audio-recording with few or no further questions. In that case, I outlined my own practices more directly. However, in both scenarios, I shared information about recording and sought consent.

I also offered participants a copy of the audio and of the transcript. Not every participant wanted this; the few who did were sent a copy of both. In some cases, this led to further conversation about what they had said at interview and reflection outside of the immediacy of an oral interview. However, this was fairly rare. I did not insist on participants reengaging with the transcripts as I did not want to place too many demands on their time and resources, agreeing with Brueggemann's assertion that it is not 'entirely ethical that we unequivocally

assume that [research participants] want to be involved, to collaborate, to respond, to co-construct representations with us' (1996, p. 33). Less demanding forms of participation thus included coming back to issues raised in the interview at later points within the same meeting, as well as discussing the nature and direction of the project as a whole with participants. This was important to negotiating the representation of disability, discussed in Section 3.

Discussion of consent was constant throughout providing information about the research project. I used oral consent, given that participants themselves said that they preferred this to signing forms. The lack of forms also contributed to a more relaxed, less formal atmosphere for the interview, something which both I and participants observed. When I did experiment with forms, I used them at the end of the interview, taking it as another opportunity to run over questions of consent and permissions. However, I found that people did not read or engage with the form properly; they would just instantly agree and ask me where they should tick boxes and sign. Therefore, I retired the form and instead orally ran again through questions of consent and permissions at the end of the interview.

4.2.3. Interview language

Interviews mainly took place using spoken Russian. In some cases, written Russian was used for further reflection and correspondence after the initial interview. In very few cases, the interview was typed only. Russian was a first language for almost all participants, although in a few cases participants were bilingual in Russian Sign Language (RSL) and Russian. The use of spoken Russian was not a condition for participation in the research. For example, I prepared to use sign language interpreters. However, civil society actors identified as organising around disability rights did use spoken Russian. One Deaf participant described the fact that they used spoken Russian as well as RSL as the reason why they were able to participate so strongly in civil society organising; using both languages allowed them to communicate between Deaf and hearing communities. Civil society organising's emphasis on language, and even orality, was therefore perhaps reflected in the fact that my participants all used spoken language.

I speak Russian fluently and could always understand my participants' responses. However, unlike participants, I am not a native speaker. In both English and Russian, you can speak of your control over the language as a kind of mastery. In English, you 'master' a language. In Russian, the verb is '*vladet*" and can be translated variously as to master, own, manage,

command, or govern, amongst other possibilities. Put simply, I do not master Russian to the same level as my participants. Therefore, the interview-conversation was not a conversation between equals. The fact of conducting the interview in Russian immediately placed them above me on the hierarchy of freedom of expression, fluidity, and richness of language. After checking with participants a final time if I had their permission to record at the start of an interview, I noticed myself sometimes repeating a joke about how I would find it more painful than them; I would have to listen back to any moments where I had struggled to convey my precise meaning. Participants were immediately and inherently positioned as experts regardless of the subject of the conversation.

Specifically concerning language referring to disability, I chose to privilege the participant's choice of expression and reflect it both in the moment of interview and in writing this text. The practicalities of negotiating and operationalising this choice are presented in the section on communicating disability (Section 3). Here, I conclude only that the fact of conducting interviews in a language with which participants were more comfortable than me and my deliberate choice to accept and reflect participants' use of language both shift the power dynamic of the conversation. Discussions of power relationships in research often identify power as the researcher's, shared only at their own choice and instigation (Pillow, 2003) and always given by the researcher, rather than beginning as the participant's. However, in my case, the realities of interviewing in the Russian language destabilised this construction of power from the start.

4.2.4. Interview questions

I prepared an interview schedule including specific questions divided by topic area (see Appendix 3). Finally, writing this document served more as preparation for the interviews, rather than as a tool used in the interviews themselves. In practice, I had the interview schedule by me for the first two interviews and referred to it towards the end of the conversation to ensure I had covered all the topic areas. After that, I had the interview schedule with me, but never took it out of my bag. Rather than using the interview schedule exactly, I preferred an informal, conversational mode of working drawing on both the initial schedule's topic areas, which I had broadly memorised, and notes I made following each interview. These fieldnotes both provided on-the-spot reflections of what I perceived as key areas, facilitating reflexivity (Hockley, Dewar, & Watson, 2005). They summarised how the

participant had reflected on my research's direction and the representation of disability more generally. They also highlighted an evolving set of topics which I wanted to explore further in subsequent interviews, thus supporting the development of interview questions and the research more generally.

Not using an interview schedule was also motivated by considerations of the interview's power dynamic. An element of the interviewer's power is that they present questions which they have previously prepared to an interviewee who must respond on the spot; the interviewer has greater knowledge of the contents and more control of the direction of the interaction. Interviewing without a schedule removed the possibility of having pre-prepared questions before me, supporting me in conducting the interview both linguistically (especially given the linguistic imbalance between myself and participants, Section 4.2.3.) and offering formal structure as a sign visible to most participants. Working without pre-prepared questions emphasised listening directly to participant and responding to what they were telling me at that moment. Furthermore, it removed the physical sign of a list of questions dividing researcher from participant. This suggested a more natural conversation and connection.

This mode of interviewing emphasised open-ended, narrative questions which allow participants to respond as they wished and respected their silences (Garland-Thomson, 2011a; Tonkin, 1992). For example, I often began by asking people how they ended up doing what they do, whether that question referred to some form of grassroots activism or running a formally registered CSO. This elicited a long, narrative response and gave me a framework within which to anchor further questions. It also produced long, rich, and wide-ranging interviews, leading to further complexities in analysis, interpretation, and writing up (Section 5.1.2.) as I dealt with framing and focusing the work.

5. Interpretations and Translations: Creating and Silencing Voices

Above, I reflect on how I translate myself and perform my roles. I discuss how I perceive these roles as understood by participants as, in short, *chuzhaia-rodnaia* and how this affects the research process at interview. In this section, I move on to how I interpret the stories and experiences entrusted to me. I look at how I negotiate my interpretative power as author, how I translate and dislocate, and how I both silence, transfer, and create voice in these

processes. Through analysis, interpretation, and writing, I become the sole named author of this document, despite the multitude of voices which stand behind the research. Furthermore, given that 'practices of doctoral writing simultaneously produce not only a dissertation but also a doctoral scholar' (Kamler & Thomson, 2008, p. 508), this authorial position is far more transformative for me than for any participant. In this section, I discuss the tensions between the necessities of interpretation and authorship and any emancipatory project of the research.

5.1. Analysis and Interpretation

5.1.1. Transcription

The translation of sound recording into text (Slembrouck, 2007; ten Have, 2007) is necessarily selective and demands interpretative and representational choices (G. Cook, 1990; Duranti, 1997). Rather than naturalising this interpretive process as an objective, technical matter, I present my choices below. I do not use transcription as itself analytic tool, analytic procedure, or a form of analysis (Davidson, 2009, p. 39). In this research, the main work of analysis begins largely after the development of a transcript. I have therefore developed a hybrid approach to transcription. The aim in striking this balance in a pragmatic verbatim transcription is to produce text which remains accessible to readers who may find denaturalised transcription (Bucholtz, 2000, described below) harder to read (Davidson, 2009) and supports my own understanding for analysis, as well as that of any subsequent reader of quotations taken from transcripts. Furthermore, this mode of transcription aligned with my research objectives and analytical perspective.

Ochs argues that 'a more useful transcript is a more selective one' (1979, p. 44) as 'extraneous information makes a transcript difficult to read and might obscure the research purpose' (Davidson, 2009, p. 38). Oliver, Serovich, and Mason (2005) have argued that questions of epistemology drive different approaches to transcription. Practices which seek to provide 'as much detail as possible' (D. G. Oliver et al., 2005, p. 1273) are associated with a view that language can 'represent the real world' (ibid., p.1274). Opposing this, those which remove 'idiosyncratic elements of speech' (ibid., p.1273) are associated with the standpoint that 'within speech are meanings and perceptions that construct our reality' (ibid., p. 1274). This latter standpoint is closer to my analytical approach and research questions, as they revolve

around investigating participants' meaning-making and understandings. This standpoint is therefore also closer to my approach to transcription. However, I also understand the associations argued for by Oliver et al. (2005) precisely as tendencies, rather than absolutes. I therefore did maintain certain elements of oral language and added further notes where I perceive them as conveying meaning.

I transcribed over half of the interviews myself; the remaining transcription was outsourced with confidentiality agreements made with the transcribers. More concretely, we struck a balance on a continuum between naturalised and denaturalised transcription, as per Bucholtz's conceptual framework (2000). Naturalised transcription prioritises written features of language over oral features to incorporate, as we did, punctuation. Denaturalised transcription rather retains oral features, such as the discourse markers (e.g., so, well, I mean, etc.) and filler words (e.g., er, um, ok, etc.) which we included in our transcriptions. We also included basic notes marking laughter, tone, or non-verbal gesture where these were judged relevant to maintaining meaning and understanding. For example, adding a note to clarify that the speaker was being ironic supports understanding for the reader of a transcribed text. Non-verbal gestures conveying meaning included gestures like silently pointing upwards to refer to government. These gestures were captured in my fieldnotes and then integrated into transcriptions to ensure understanding. As fieldnotes were not shared with transcribers, I added notes concerning non-verbal gestures myself as I checked the transcripts against the audio recording.

5.1.2. Analysis and memo writing

As I revised the outsourced work and reread my own transcriptions, I first made mapping categorisations identifying actors, goals, and actions. I then grouped these actions by four broad functions: direct help, information and empowerment, and government-centred advocacy and oversight. Rereading the transcriptions again, I then began to write analytic memos (Glaser & Holton, 2004) drawing out broader themes from the interviews. I integrated these notes into the typed-up fieldnotes I had initially made after each interview. Subsequently, I grouped interview extracts by the corresponding issues and themes identified by the analytic memos. These issues and themes are themselves responded to in different ways by various participants; different views are thus included in response to a single issue or theme. These notes were largely made in English, while the transcriptions remained

untranslated in Russian at this point. Checking accuracy of the outsourced interviews and adding non-verbal gesture notes myself, as described above (Section 5.1.1.), also supported active revision of the interviews. This rebalanced the tendency I otherwise had to overuse those interviews I had transcribed myself, given that the transcription process had developed a more detailed knowledge of them.

The practice of writing more detailed memos attempted to guard against Packer's warning that 'a theme never simply "emerges"; it is the product of interpretation. […] [T]hemes that "stand out" tell us more about the researcher than the interviewee' (2011, p. 70). By writing more nuanced memos, I explain my identification and understandings of issues and themes I had heard in interviews and read in transcriptions (Saldaña, 2016). However, given the richness and diversity of these conversations, as well as the breadth of my inclusion frame, the process of focusing into one piece of work was not straightforward. I strongly identified with Acker, Barry, and Esseveld's assessment that a feminist commitment to research has 'led [them] to collect data that were difficult to analyse' (1991, p. 143). After interviews, I had a huge volume of long and wide-ranging conversations which were difficult to categorise. The interview conversations could have been used in many ways. In distilling the research to the few areas which make up this document, there was ultimately of course a narrowing and discarding, at least from direct use, of aspects of the interview conversations. In identification of the research areas and of the themes subsequently identified, I am led by my own standpoint (Hertz, 1997); the work presented here is one possibility among many potential others.

The themes I followed further and include here both speak about me and about my response to the state to the relevant research literature. I do not spend great amounts of time on topics which have already been largely explored. In this way, I attempt to enter a conversation and answer both implicit and explicit questions and absences which I have identified in my reading of the literature (cf. Cornish, 2020). However, I also try not to silence the stories, opinions, and experiences which participants shared with me. I do this in two main ways.

Firstly, I involved participants in the discussion of my research and its direction as part of the interview. I attempt to respond to their views on representation of disability in my work, for example a common insistence that work on disability was dominantly medical and elided social questions. More specifically, I also try to amplify voices and identities which participants

emphasised that they found not to be represented elsewhere. For example, this includes the experiences of disabled feminist and LGBTQ+ activists. In doing this, I take the position that reflexive thematic analysis 'does not equate frequency with importance' (Braun & Clarke, 2021, p. 18): 'a small number [of people] may say or write things that are crucial' (ibid., p.18). The importance of these few people is linked to the theoretical and empirical conversations upon which I am building, and the gaps in the current literature which I address.

Secondly, I question the idea that the only full or valid use of an interview is represented by the inclusion of quotations from that interview in the written piece. Participants informed me and inflected the direction of my research even where they are not cited. Given both my interview practice based on a conversational, non-directive style and the evolving nature of my research precisely based on participants' directions, interviews were often lengthy (from one and a half to three hours) and included material which was not finally of immediate relevance to the research as written up. This is sometimes presented as an ethical issue; researchers are exhorted not to misuse participants' time by seeking information which they will not then take up. However, this mode was simultaneously necessarily to ensure both the evolving, exploratory approach described and the use of open-ended questions which neither pressure participants nor assume final answers (Section 4.2.4).

5.2. Translating Voice

The transcribed interviews remained in Russian for the analysis portion of the research. However, I translated quotations which I include in this text into English. In translating, I create the voice of participants in a very direct way which cannot remain neutral (Temple & Young, 2004). This process raises questions about whether and how I allow the voices of my participants to come through to the reader. Translation not only disrupts 'etymological resonance' (Gentzler, 1993, p. 160), but also cultural resonance. How can I translate how participants refer to disability? How can I best preserve expressions in Russian which may suggest their age, background, or character? How can I approach how they might sound in Russian to Russian speakers, without presenting their language as irrelevant (Temple & Young, 2004) or suggesting that they initially 'spoke the same language as our readers' (Poblete, 2009, p. 632)? These questions are further complicated by their interaction with the dislocations necessary to maintain anonymity and confidentiality (Section 5.3.).

My discussion of naming disability in English and Russian (Section 3.2.) presents the first step of my response to the initial question. There, I present how disability is spoken about in English and Russian and make comparisons between the two. I lay out the different feelings and uses of these various expressions with the aim of allowing non-Russian speakers to draw greater meaning from the translated quotations they will then encounter in the text. Furthermore, even within the English translation of any quotation, I also preserve such key words in transliterated Russian (i.e., Russian written using the Latin, rather than Cyrillic, alphabet). For example, a quotation would read, 'a person with disabilities (*chelovek s invalidnost'iu*).' This will allow me to maintain participants' references particularly where a Russian mode of naming disability does not have an entirely equivalent English expression, such as with the Russian '*inva-dvizhenie*'. This expression reclaims the word '*invalid*' while distancing it from the language of state policy and legislation by contracting it to '*inva*'. Some participants used this word to denote disability as a proud identity. '*Inva*' is then used as a prefix to modify words like '*dvizhenie*' (movement), '*soobshchestvo*' (community), and '*NKO*' (non-profit organisation, lit.: non-commercial organisation). Preserving these expressions in the English translation allows me to make visible the exact word choice of a participant. It also clarifies where they may have in fact chosen an English word, which would have otherwise been made invisible by translation into English. For example, some participants use the word '*kom'iuniti*' (community), choosing the loanword over the Russian word which is often translated as community ('*soobshchestvo'*).

As well as translating disability, translation of interviews raises wider questions about voice. Interviews carried out in Russian and written up in English currently appear to fall into one of two camps. In the first, the Russian becomes invisible; participants appear to have spoken with the researcher directly in native, 'standard' English. In the second, the Russian is translated into English more literally; the resulting sometimes unusual language suggests something about the participant which may not be true of their expression in Russian. The reader's perception of the person is altered. Paradoxically, it is this second camp that might offer more help to speakers of Russian reading translated quotes. Overly literally translated language gives a Russian speaker more clues to intuit what the participant originally said. However, not everyone can operate a dual reading which both sees the English language on the page and reconstructs the shadow Russian behind it. Furthermore, the advantage given

to the Russian speaker in reading literal translations simultaneously creates a disadvantage for a non-Russian by altering their perceptions and understandings. At the same time, translation into 'standard' English reflecting voice does not address the Russian speaker's frustrated question: what did the participant actually say?

I address the dilemma of participant voice versus visibility of Russian by aiming to translate the Russian into an English which reflects the participant's voice, not the Russian language itself. While the cultural resonance of exact expressions will be lost, the character of the person's speech should not. I try to translate using idiomatic and 'natural' English, to the extent that the speaker used Russian in that way. I also provide the original language of each quotation in Appendix 4. This makes visible participants' original words and expressions, also allowing Russian speakers to interrogate the choices I have made in my translation. This dual approach makes visible my role as author and translator, while also decentring myself, preserving participants' words, and opening the possibility of criticism of my translation choices. Through it, I attempt to hold onto the importance of language in constructing meaning (Barrett, 1992; Bradby, 2002; Duranti, 2003) and to disrupt the power dynamic of the researcher-translator's silencing of original language.

5.3. Ethics of Voice and Anonymity

Above, I considered the preservation of voice in translation. This section questions anonymisation as potentially a further dislocation, alongside and complicating translation, which problematises the preservation of voice. Finally, it explains the messiness of why I nonetheless seek to maintain confidentiality and anonymity and how I do this. I define confidentiality as referring to keeping information about the participant, including the fact of their participation, private beyond the primary research team (here beyond myself only including transcribers for the outsourced work) (Saunders, Kitzinger, & Kitzinger, 2015, p. 617). I define anonymity as one part of confidentiality, namely that of keeping participants' identities secret (ibid., p. 617).

At the time I completed ethical review, LSE's research ethics approval procedure sets anonymity and confidentiality as the assumed standard to be observed. The section on confidentiality (LSE, 2016, p. 3) asks, 'what arrangements have been made to preserve confidentiality and anonymity for the participants or those potentially affected?' It further

asks about compliance with data protection laws and my consideration of 'the limits to confidentiality', which it associates only with the researcher receiving information that the participant or 'someone else may be at significant risk of harm' (ibid., p.3). The research ethics review form's other section on confidentiality asks whether the research will use 'visual/vocal methods that potentially pose an issue regarding confidentiality and anonymity' (ibid., p.6). Observing confidentiality and anonymity is presented as the correct way to do research. The form only questions how we might preserve them, rather than asking about if and why the researcher judges them necessary at all.

I passed this procedure with assurances that my research would respect participants' right to anonymity and confidentiality. Then and now, I do find convincing arguments around anonymity as promoting frankness (Farrimond, 2013, p. 131) and empowering people to speak openly without concern about negative consequences (Guenther, 2009), especially where discussing potentially sensitive or personal topics (Elam & Fenton, 2003). Anonymity is argued for as protecting individuals from harm and even potentially encouraging solidarity and amplifying little-heard voices from a position of safety (Gordon, 2019). I consciously try to engage with this position by amplifying voices and experiences which participants identify as unheard or unseen (Section 5.1.2.). In previous research of my own, participants confirmed the need for anonymity and confidentiality by checking with me that what they told me would not be related to them in any publication.

However, where preserving anonymity and confidentiality is presented as a blanket rule, the idea of protection sits uneasily close to assumed vulnerability and a repeated silencing of participants' voices. Its imposition has been criticised as disempowering (Lahman et al., 2015; Mukungu, 2017) and reducing pride in participation (Yanar, Fazli, Rahman, & Farthing, 2016), not challenging underlying power structures and therefore minimising the transformative potential of research (Baez, 2002), and a form of erasure and distancing, which 'separates participants from researchers and the audiences for whom they write' (Smart, Hockey, & Janes, 2014, p. 11; see also Mukungu, 2017). Anonymisation 'naturalises the decoupling of events from historically and geographically specific locations' (Nespor, 2000, p. 549), just as translation may do the same. Moore further argues that anonymity in fact 'creat[es] vulnerability through rendering people nameless' (Moore, 2012, p. 332). While this thesis is under my name and a vital part of my becoming a doctoral scholar (Kamler & Thomson, 2008),

other participants are separated from authorship and related claims to authority. Assuming a default position of anonymity is criticised by those who claim participant identification as empowering (Giordano, 2007; Gordon, 2019; Grinyer, 2002).

These concerns are pressing in relationship to research with disabled people given their repeated discreditation, infantilization, and exclusion from positions of power. Participants' work often focuses on promoting the voice, visibility, and representation of disabled people. Creating new knowledge and awareness around disability is too a key part of the work of many people. The emphasis on anonymity therefore felt counter-intuitive, a disjuncture which has been previously discussed in relationship to researching with activists (Mukungu, 2017), although not, to my knowledge, in particular vis-à-vis disability activism. The idea that anonymity prevents harm and provides protection was not at the forefront of many participants' minds. In line with the assertion that anonymity creates vulnerability (Moore, 2012), many rather felt that a lack of visibility was at the root of vulnerabilities created for them. At interviews, when I discussed anonymity, some participants responded by asking why or saying that they had nothing to hide. I responded by assuring them that it was so they could speak entirely freely and empathising that of course they had nothing to hide. I also offered the justification that it was a requirement of the university, the same for all researchers and research participants. Participants typically responded that of course it was fine for the interview to be anonymous. However, I remained aware of their first question and more aware still of the fact that I had used the expert weight of 'the university's guidelines' to justify myself, potentially quite directly disempowering the participant and reinforcing a knowledge hierarchy where 'the university' may decide how research is to be done. Nonetheless, I was indeed called to abide by anonymity and confidentiality in order to be passed to conduct research by LSE's Ethics Committee. I also attempted to rebalance power inequalities, including the erasure of voice, in other ways throughout my research process, as this chapter describes.

This resolution to the situation was also in part because these conversations arose relatively infrequently, as well as coming up for the first time some months into my period of carrying out interviews (although more people may have had questions around the issue, but felt uncomfortable questioning this apparent convention). In my previous research, participants had almost uniformly actively welcomed anonymity. In preparing for this research, I had both

questioned and had reinforced to me the university's blanket application of confidentiality and anonymity. On the spot when these questions reoccurred, I did not have a satisfactory response. I myself still had the same questions as participants. Some way into the research process and after some interviews had already been conducted under the condition of anonymity, when the issue was brought up, I was concerned about directly attributing citations to a minority of participants while the others, as agreed, went unidentified. How consent to anonymity played out illustrates broader questions around consent in research, where unequal power relationships in the interview may undercut the participant's ability to give consent.

Finally, I do seek to maintain anonymity for participants. This is in part due to the messiness of the research process described above, but also due to the fact that many participants still wanted their identity to be concealed (Corden & Sainsbury, 2006; Kelly, 2009). As I will discuss in my empirical chapters, participants' perceptions of their environment for organising suggested a need for compliance and fear of sanction; anonymity thus potentially allowed more freedom to speak without concern about sanction. Furthermore, the impossibility of providing entirely precise information at the point of interview of how exactly the interview conversation would be used and represented is another argument for anonymisation (Saunders et al., 2015). This is given that I myself do not know before I have received and analysed the information not only from any given interview, but from the interviews in general (Sin, 2005). The potential for future harm is also hard to predict should anything change in the research context (Wiles, Coffey, Robinson, & Heath, 2012). Thus, without wanting to contribute to an exaggeration of potential harm (Moore, 2012), I finally remain with the principle of anonymity.

However, anonymity is itself difficult to ensure; its complete guarantee has even been characterised as impossible (Van Den Hoonaard, 2003). This is particularly the case where potential readers are closely involved with the research setting or milieu and may therefore be able to recognise participants (Nespor, 2000; Scheper-Hughes, 2000). As with the 'small population' problem (Van Den Hoonaard, 2003; Walford, 2005) also arising with a 'geographically dispersed population with unusual characteristics' (Saunders et al., 2015, p. 619), my research includes participants, and could be read by researchers, who move within the same circles. As participants themselves at times commented, they are part of the same

'*tusovka'* (social circle, company, party). The use of some snowball sampling increases this risk, as does the use of 'geographically convenient locations' which 'makes research sites more easily traceable' (Saunders et al., 2015, p. 618; see also Walford, 2005).

In practice, I followed Saunders et al. in considering six areas which could lead to identification (2015, p. 620). These are:

1. Names (in my research: of person *or* CSO)
2. Places
3. Religious or cultural background
4. Occupation
5. Family relationships
6. Other potentially identifying information

I used pseudonyms for participants. I largely chose either Slavic, Russian or more widely used names which would have some resonance for participants and reflected their actual names (Grinyer, 2002, p. 3; see also fuller discussion on the complexities of pseudonyms in Lahman et al., 2015). However, I did not necessarily use names which could be associated with a religious or cultural background beyond this. Given the small population issue, this would have posed an identification risk (Saunders et al., 2015). I did not name CSOs directly. Rather, I used generalised descriptions based on the CSO types I present both here (Section 4.1.3.) and more fully in my literature review (Chapter 3). For example, I could speak of a participant in 'a formally-registered CSO'. The issue was greater in referring to GONGOs because they are relatively far fewer in number. Moreover, the largest ones are broadly divided by impairment (i.e., VOG, VOS, VOI, the All-Russian Societies for, respectively, Deaf People, Blind People, and Disabled People, see Chapter 4). If I described a participant as involved in an GONGO and, in the citation, also somehow included that the participant is Deaf, the reader could logically deduce that the GONGO in question is VOG. To avoid 'deductive disclosure' (Kaiser, 2009, p. 1632), I redacted citations.

Secondly, while I do disclose the locations of my research here, I do not associate locations with quotations. The relative homogeneity in my choice of urban location and the range of views which are identified across locations means that location is not a motivating analytical factor; I am therefore able not to disclose it. Other factors, from religious or cultural

background to occupation, family relationships, and other information, were dealt with on a case-by-case basis for each quote. Where I was concerned about identification, I substituted general terms. For example, in a story including references to a person's relationship with their disabled son and how this motivated a certain action, I would change 'son' to 'child'. This approach required a balancing act between preserving data integrity and limiting it in order to avoid identification. There is clear scope for the criticism that anonymisation results in decontextualization (Baez, 2002; Nespor, 2000) and removes some of the richness of the interview (Parry & Mauthner, 2004). In this research, the compromises were necessary to ensure anonymity. Given this dislocation and distancing, the importance of maintaining the voiced quality of the translations so as not to only centre the named author also returns to the fore.

6. Conclusion

In this chapter, I have presented my research approach and practices of sample building, interviewing, analysing interviews, translating, and writing up the thesis. In doing so, I reflect on the ethics and power dynamics of my research and my position as named researcher, translator, and author of a document built from the voices of many people. This is no doubt a position of privilege and power. Here, I describe aspects of the research that try to decentralise that position of power and the problems of doing so.

I recognise how I have potentially used or reinforced power inequalities, for example in the intertwined risks and strengths of 'doing rapport' or in my observation of anonymity. This latter's equation with ethical research is problematised in two main ways: firstly, by how it positions me as the sole author of, and authority on, this text and, secondly, by its potential to be motivated by assumptions of vulnerability which repeat the model of the empowered researcher opposed to disempowered research subjects. This is complicated by researching disability, where people often spoke of feeling unseen and voiceless and working precisely against this.

In presenting these complexities, amongst others, and the ways in which I have responded to them, I am interested in a more open-ended reflexivity of discomfort (Pillow, 2003). My responses should not be understood as resolutions, but as contextual decisions which have contributed to creating the version of the project presented here. Discussion of

representational choices in the project attempt to make present the need to read this text from the standpoint of translation, which is inherently contingent and suggests the deferral of meaning, rather than its finality (Kruger, 2004). Finally, making the work's translations and interpretations visible to the reader operates a shift of authority towards them. Thus, rather than (mis)using reflexivity to centre the author, I aim to support the birth of the reader (Barthes, 1967) by supporting them to challenge not only the text with which they are presented, but also the knowledge they themselves bring to it and the position from which they read (Pillow, 2003, p. 189).

In this chapter, I have also presented how I have operationalised two key concepts: disability and civil society. I discussed their operationalisation particularly in building a sample and considering inclusion criteria, in the language I use at interviews, and in signposting or referring to disability in the final thesis. In the following theoretical chapter, I link this operationalisation to an extended conceptualisation in dialogue with civil society and disability literatures. Here, I proposed the following: firstly, to understand civil society as a space of uncoerced action, without normatively-defined values or intentions, and without necessarily an organised base or structure. I include a diverse range of organisations, communities, and nonmovements to reflect this. Secondly, to understand disability as a fluid and relational category. In practice, this means that I follow participants' identifications of and with disability in including them in the sample, reflecting the language they use, and signposting whether they identify as disabled. Bringing both civil society and disability together, this also means that I am led by participants identification of disability CSOs, as I discuss in reference to border cases (Section 4.1.1.). This reflects my intention to explore how and to what ends actors use categories of 'disabled' and 'disability organising.' In the following chapter, I provide the full theoretical underpinning for these operationalisations.

Chapter Three

Power and Resistance in Civil Society Organising around Disability: Theoretical Framework

1. Introduction

> Critical disability studies start with disability but never end with it: disability is *the* space from which to think through a host of political, theoretical, and practical issues that are relevant to all. (Goodley, 2017, p. 82, emphasis in original)

In later work, Goodley et al. nuance the above statement: 'While [the] expansive purpose [of critical disability studies] is to be celebrated, we also need to acknowledge that some critics might wonder whether this decentres or sidelines disability. […] We want to keep this question alive; to consider the impact of an intersectional approach that magnifies our politics and extends our engagements' (2019, p. 977). I began to address this in my research methodology (Chapter 2, Section 3), as I positioned disability as a category which shapes and is shaped by civil society, rather than a separate, static object of research. The tension between 'decentring' and 'thinking with' is equally central to developing a theoretical framework capable of recognising and analysing both civil society and disability. In this chapter, I aim to present a theoretical framework which grapples with and is motivated by this tension. In doing so, I follow Goodley et al. (2019) to offer one response: I seek to centre disability experiences while demonstrating both their relationships to other fields and what those relationships can do.

I therefore begin this chapter by stepping back to present its unifying concept: a theory of power as decentred, productive, and defined by the presence of resistance. This concept lays the groundwork to explore multiple actors, non-apparent, or infra-political, forms of contention, and disability as a locus of agentic resistance. Secondly, I define civil society as a space for collective, non-coerced action around shared interests, purposes and values, without normative definition of its nature or its relationship to the state. I include various forms of (non-)organisation space, including social movements and associated communities and nonmovements. This gives entry to less visible forms of action and widened understandings of resistance. Finally, I present the literature defining disability as itself

produced by power relationships. These relationships often marginalise and exclude. Experiences of disability clearly cannot and should not be essentialised to exclusion; disabled people have reclaimed ability and potentiality (Goodley et al., 2019) and agency and art (Kuppers & Marcus, 2009; see also Marcus in O'Toole, 2013, n.p.). However, dominant misunderstandings of disability have naturalised both paternalistic responses and the misrecognition of disability as an extra-political, medicalised phenomenon.

The constructed exclusion of disabled people and the misunderstanding of disability throws light on both theoretical weaknesses in the literature on civil society and social movements, as well as the empirical implications of dominant understandings of legitimised and delegitimised organising. While there has been a clear movement towards studying everyday events and actions, literature on social movements has broadly tended to focus on moments of extraordinary events and evident actions in alternative spaces, often in the public sphere. Véron summarises the treatment of everyday actions as peripheral as demonstrating three biases: temporal singularity bias (i.e., focus on 'extraordinary moments'), spatial singularity bias (i.e., focus on 'extraordinary places'), and case singularity bias (i.e., finding micro-political activities to be peripheral) (2016, pp. 758–759). These biases mean that a range of action and resistance has gone unrecognised or misidentified. Disability organising calls attention to this weakness. A highly simplified example illustrates one form of the connection I make here: the inaccessible material environment makes it harder for some disabled people to access the public square. Their resistance may therefore take place in private spaces. The private sphere has been misrecognised as extra-political and disabled people and their actions have, therefore, also been construed as extra-political. Some forms of disabled resistance therefore go unrecognised. Therefore, recognising them calls attention to the ways in which theoretical understandings of resistance can be extended.

We cannot assume that, for example, the private sphere is apolitical, that actors do not see social care as politicised, or that disability is objectively apolitical. Furthermore, in a context where CSO actors perceive a benefit to being seen as apolitical, dominant assumptions of apoliticism, vulnerability, and passivity may in fact support continued action. In some cases, these assumptions may even be deliberately instrumentalised by actors to continue action which they themselves identify as political. I argue that engagement with the resistance paradigm and constructed vulnerability as power in fact offers a path to centring disabled

people and disability resistance as agentic. This harnesses the potential of disability to transform assumptions (McRuer, 2006; Sandahl, 2003) and to question and extend the boundaries of contention, particularly where claims of intersectional identity, complex embodiment, and 'unhealthy disability' are taken seriously (Siebers, 2013; Wendell, 2016). Furthermore, analysis of the intersectional construction of exclusions and vulnerabilities demonstrates that the resistance paradigm, criticised as weakly recognising the thicker, weightier power of state (Bayat, 2013, p. 44), may in fact remain engaged with this power (Cho, Crenshaw, & McCall, 2013).

Power is productive and resistance is paradoxically enabled, if not produced, by the power relations against which it fights (Butler, 1990; Munro, 2003). Greene makes a similar argument about Russian civil society organising to suggest that an acute awareness of power relationships results in '[o]pposition [which] reflects the power structure that provokes it: individualised, ad hoc, opportunistic, and unstructured' (2014, p. 221). Recognising infra-political action is necessary to make legible much of Russian organising. I discuss the empirical resonance of this theoretical framework in the Russian context in the following chapter. Here, I make the argument that analysis of disability organising both demonstrates the relevance and strength of the resistance paradigm, including infra-political action, and challenges and further transforms definitions of forms of resistance. In doing so, I aim to use disability to 'to think through […] issues that are relevant to all' (Goodley, 2017, p. 82).

2. Power and Resistance

Power is multi-faceted, diffuse, and negotiated. It is constituted by accepted knowledge and embodied in regimes of truth (Foucault & Rabinow, 2010) which structure the field of action and actors' logics of appropriateness, forming boundaries which both enable and constrain action (Rile Hayward, 1998). Borrowing pragmatically from discussions of governmentality, I understand power as shaping conduct through a heterogenous, decentred assemblage which draws together 'forms of practical knowledge with modes of perception, practices of calculation, vocabularies, types of authority, forms of judgement, architectural forms, human capacities, non-human objects and devices, inscriptions, techniques and so forth' (Rose, 1999, p. 52; see also Foucault, 1980, p. 194). This includes discourses, which I define as a form of social action which draws upon 'conventions that naturalize [or, in the terms I will argue in

here, legitimise] particular forms of knowledge and ideologies' (Jones & Norris, 2005, p. 8; see also: Chouliaraki & Fairclough, 1999; Shotter, 1993; Weedon, 1987). Discourse can be the location of both 'strategies of domination as well as those of resistance' (Diamond & Quigley, 1988, p. 185).

This conceptualisation offers three interlinked elements which are useful here. Firstly, it recognises 'the range of parties involved in attempts to regulate the conditions under which lives are lived' (Murray Li, 2007, p. 276). This range includes civil society actors; power is not held by a monolithic state alone. Rather, it is diffused throughout society in different ways and to differing degrees. Thus the analytic of governmentality asks, 'how different locales are constituted as authoritative and powerful, how different agents are assembled with specific powers, and how different domains are constituted as governable and administrate' (M. Dean, 2010, p. 40). I connect this to analysis of the regulation of civil society and the (de)legitimisation of certain of its roles in Russia (Chapter 4), using this to unite a diffuse theory of power with recognition of the 'thicker power' of state operating through legislation, policy, and other formalised instruments.

Secondly, the heterogeneity of the assemblage recognises the variety of techniques and practices through which power both operates and is resisted. This identification better represents the variety of resistant action, including discursive work around meaning-making and knowledge creation engaged in by civil society actors organising around disability.[11] It goes beyond the focus of much literature on Russian and other civil societies on 'high-visibility activities with consequences for institutionalised social structures' (Kendall & Knapp, 2000, p. 11). Rather, it opens the door to consideration of less visible, identity-based, or infra-political practices (Scott, 1990). These non-apparent practices respond to 'the values and norms of discipline' (Lilja & Vinthagen, 2014, p. 115); '"everyday resistance" and discursive forms of challenge […] might be hidden or disguised and are not typically open' (ibid., p.114). It is precisely analysis of these forms of disability action that challenges the boundaries of contention and resistance.

[11]For an overview of 'dynamic and contingent [relationship between action and discourse], located at a nexus of social practices, social identities and social goals' (p.9), see Jones and Norris (2005).

Thirdly, 'governmental power is not homogenous and totalising' (Murray Li, 2007, p. 276). Instead, its limits are intrinsic to 'its characterisation as a form of power' (ibid., p.276). This stresses that power acts on actions, in all their different forms: '[power means] that "the other" (the one over whom power is exercised) be thoroughly recognized and maintained to the very end as a person who acts; and that, faced with a relation of power, a whole field of responses, reactions, results, and possible inventions may open up' (Foucault, 1982, p. 220). This definition insists upon the existence of resistance to power as central to the latter's very existence. The concept of power as productive (Munro, 2003) has been identified as serving as 'a key theoretical backing for micropolitics, and thus the "resistance" perspective' (Bayat, 2013, p. 41). This perspective suggests that power and counterpower are not in 'binary opposition', but rather 'a decoupled, complex, ambivalent, and perpetual 'dance of control'' (ibid., p.41; see also Daudi, 1983 for discussion of moving beyond binaries in understanding discourse and power). This fluidity also supports the argument that 'dichotomising resisters and dominators' fails to recognise the 'multiple systems of hierarchy and individuals that can be simultaneously powerful and powerless within different systems' (Lilja & Vinthagen, 2014, p. 112; cf. Hollander & Einwohner, 2004); this supports analysis of disability as a multi-faceted relationship of power, which interacts with other systems of oppression.

Beyond this complex location of resistance, the definition of resistance remains debated (Hollander & Einwohner, 2004). However, Hollander and Einwohner argue that all forms of resistance share two key features: recognition and intent (ibid.). In this chapter, I discuss the criterion of actors' intent further as central to enabling the recognition of resistance in infra-political, potentially less apparent forms. I address recognition in three related ways. Firstly, in relationship to the theoretical framework and, therefore, both to myself and to the reader. By this I mean that I seek to offer a theoretical framework which allows actors' resistance to be recognised according to how they present their understandings, rather than enacting further epistemic oppression by my research (Toole, 2019).[12] Secondly, throughout the thesis, I explore recognition in presenting some implications of how disability has been dominantly

[12]I nuanced this further through discussion of the co-constructed nature of participants' responses during interviews in Chapter 2. However, above all, my approach to participants' accounts is one which 'takes what social actors say seriously […] instead of aiming to show how they are blind to their own reality' (Lamont et al., 2016, p. 6). In identifying resistance, I aim to engage in research which goes beyond the eye of the dominator, to whom, by definition, infra-political action and intent are not apparent (Section 3.3.).

(mis)recognised, including the potential instrumentalization of some forms of (mis)recognition. Thirdly, I recognise both the instrumentalization of (mis)recognition and the avoidance of identification as in fact a strategy of resistance; not all resistance aims for recognition from a wider audience.

Understanding power as tied to resistance has both theoretical strengths and weaknesses. These are analysed below in relationship to civil society and disability as concepts of resistance, marginalisation, and vulnerability are expanded upon or introduced. To initially summarise: the conceptualisation of power as presented thus far opposes the binary opposition of power and lack of power; recognises the potential power of vulnerabilities (Butler et al., 2016) and marginalisation (Bayat, 2013; Perlman, 1976); frames civil society organising as both reinforcing and resisting dominant power relations; and provides a counterweight to literature emphasising large-scale, public action by offering a framework to recognise infra-political and other action through intent.

3. Civil Society

3.1. Defining Civil Society

I define civil society as 'the arena of uncoerced collective action around shared interests, purposes and values' (CCS, 2005, p. 1). This suggests a space within which diverse actors operate. 'Action' is specified only as 'uncoerced' and 'collective'; the definition thus goes beyond high-visibility actions carried out in public space. Furthermore, the definition is not prescriptive about organisational forms. Collective action also includes *fragmented* collective action, as defined by Bayat (2013) and discussed further below (Section 3.3.). This supports my focus on individual actors, as I look at how they negotiate and move between different organising spaces, sometimes also acting in ad hoc, fluid, groups and distanced, sometimes online, loose communities of recognition. Description of action as uncoerced reflects actors' agency and the understanding that power acts on actions (Foucault, 1982); while actions may be moderated by the logic and boundaries implied by certain power relations (Rile Hayward, 1998), they are not entirely coerced. To do so would go beyond a relation of power into one of domination.[13]

[13]Some criticism of Foucault has identified 'domination' and 'power' as synonymous in his work (as discussed in McIntyre, 2016; see also McIntyre 2019). However, Foucault's later works clarify that

Furthermore, this definition of civil society does not set boundaries as to the nature of collective action. It accepts 'a range of diverse values and intentions' (Lewis, 2002, p. 583) without 'preliminary assumptions regarding possible de-radicalizing or co-optation effects' (Revillard, 2013, p. 4). This includes diverse negotiations of power relationships with the possibility that actors' aims may oppose or contradict each other. By refusing initial assumptions concerning (de)radicalisation, I understand, consonant with the diffuse definition of power given above, that what is considered 'radical' is itself contextually negotiated. This approach thus nonetheless coexists with literature that relates professionalisation to a decrease in mobilisation features (Bayat, 2013, p. 35); it merely emphasises the contextual nature of resistance, the need for empirical work rather to ground such findings, and, as I discuss further below, is open to explorations of intent and meaning.

This initial definition suggests civil society as both locus of resistance and channel of control (Howell & Pearce, 2001, p. 3). Again, these aspects are not in binary opposition; as with power, resistance is contextual and operates through and against multiple systems of control. Civil society plays a variety of roles, including empowering marginalised groups, responding to needs neglected by state provision, and improving state services (Evers & Laville, 2004; Nyssens & Defourny, 2006; Phillips, 2009). CSOs advocate for empowerment and 'embed themselves in new social relationships' (Bebbington, Hickey, & Mitlin, 2008, p. 26). Research on the role of civil society around and following the fall of the Soviet Union also examined its potential role in democratisation and regime change (Buttigieg, 1995; Koopmans, 2007; McLaverty, 2002; G. White, 1994; Wnuk-Lipiński, 2007). I discuss this normative position further (Chapter 4) as motivating foreign funding and other involvement in post-Soviet Russia, as well as potential backlash and recontrol of civil society from the state (Howell, Ishkanian, Obadare, Seckinelgin, & Glasius, 2008).

However, any unproblematic link between democratisation and civil society development has been challenged and unpicked, particularly in the case of more authoritarian states (Lewis, 2013). While CSOs may offer a counterweight to the state (Foley & Edwards, 1996) and to aim

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domination is a distinct mode of highly asymmetrical, stagnant power relations, where 'the margin of liberty is extremely limited' (Foucault, 1994, p. 12). Where even this margin is removed, there 'could not be a relation of power' (ibid., p12); this would rather be a relationship of violence over object or objectivised. To summarise, 'if there were no possibility of resistance […] there would be no relation of power' (ibid., 12).

both to balance and teach it (Taylor, 2006), they may also be 'controlled, co-opted or used to legitimize the existing political order' (Lewis, 2013, p. 326) or to '(re)create society in the interests of the government [as] one which is more legible and more easily governable' (Hasmath, Hildebrandt, & Hsu, 2019, p. 271). The broad nature of the initial definition of civil society adopted here avoids normative assumptions about civil society's role and aims. It suggests that 'civil society's role in democratisation needs to be proved, not assumed, and the role of 'uncivil' society and other forms of contention [taken] equally into account' (Cheskin & March, 2015, p. 264).

3.2. (Non-)Organisational Forms and Spaces

Different civil society organisational forms have been associated with varying tendencies in organising and relationships with institutional organs of state power (Andrews, 2014; Banks, Hulme, & Edwards, 2015). I therefore include a deliberately wide range of organising, with a focus on more fluid, non-structured organising and individuals' movement between and co-existence in different organisational spaces. This aims to encompass various forms of action and recognises co-existence in and use of multiple spaces as a strategy of resistance (Glasius & Ishkanian, 2015). It also responds to criticism of sociological studies of social movements as restricted by the model of the social movement organisation proposed by McCathy and Zald (1977), defined as a 'structured and hierarchical entity, including a number of members (as distinct from external supporters), and upholding explicit political goals' (Bereni & Revillard, 2012, pp. 9–10).

Within the space of civil society, I differentiate between four main forms of organising and clearly include non-structured entities. These are: (1) GONGOs; (2) CSOs with recognised, registered legal form (i.e. funds, socially oriented NKOs, etc.); (3) unregistered, grassroots groups; and (4) social movements (Tilly, 2004), (associated) communities (Buechler, 1990; Staggenborg, 1998; Taylor & Whittier, 1992), and social nonmovements (Bayat, 2013). The definition of these organisational forms, processes, or spaces is slippery. Rather than seeking to set hard boundaries between them, I use them to locate the different spaces within and across which actors are active, as well as to ground analysis of different forms of action. In this thesis, differentiating between these forms and spaces lays the groundwork for my empirical focus on the individual and their agency.

GONGOs are defined as non-governmental organisations (NGOs) 'organized at the government's behest' and led 'of the government's choosing' (Hasmath et al., 2019, p. 269). They have little formal independence and often closely mirror government structures in their own organisational structure. They seek to manage opposition, channel discontent, and rally support for the state (L. J. Cook & Vinogradova, 2006; Hemment, 2012). They therefore form part of the state project of managing civil engagement to facilitate its governability (Hasmath et al., 2019; Scott, 1998). Still, as Hemment (2012) has shown and I also suggest (Chapter 7 and 8), individual members maintain agency and may use the organisational form instrumentally for other purposes. Furthermore, the identification of a NGO as a GONGO has become increasing slippery, particularly given that NGOs have been pulled into closer relationships with the state through their role as agents tendering for and delivering social services (Hasmath et al., 2019; Nelson-Nunez & Cartwright, 2018; Rich, 2013) and the penetration of state funding for civil society even reaching grassroots groups in some cases (Martens, 2002). However, in the case of Russia and disability organising, I use the term GONGO pragmatically to identify the relatively clear current cases of the three All-Russia Organisations for Disabled People, Deaf People, and Blind People (respectively: *Vserossiiskoe obshchestvo invalidov* (VOI), *Vserossiiskoe obshchestvo glukhikh* (VOG), *Vserossiiskoe obshchestvo slepykh* (VOS)), discussed in the following chapter.

In Russia, formal CSOs are registered with the government under one of the official legal forms of CSO, such as fund, association, or NGO. Lavinski provides one overview of these different legal forms (2013). Formal CSOs are professionalised to various degrees, ranging from larger CSOs with paid employees, to those which have one full-time paid worker and other ad hoc volunteers, to others which are entirely volunteer run. The structure and division of labour within these organisations also varies from structured teams of employees to ad hoc solutions depending on the time and resources of volunteers. In short, the formal registration of a CSO does not necessarily imply that the organisation has stable or numerous employees; it may have only one leader who, themselves a volunteer, takes on most of the work associated with running the CSO. However, registration does at least formally mandate CSOs to respond to various administrative obligations to the Russian state (Crotty, Hall, & Ljubownikow, 2014). It makes CSOs visible to the state, potentially drawing them closer to its logic as it offers funding and other opportunities (Fröhlich & Skokova, 2020). In contrast,

grassroots groups are not registered and potentially less visible. They are 'localised, segmented and rooted in everyday life' (Clément, 2015, p. 212). While not officially registered, they are generally more structured than social movements and (associated) communities. Some grassroots groups are on the pathway to registration and becoming formal CSOs, while others wish to remain unregistered to circumnavigate administrative obligations to the state.

Finally, I include social movements, (associated) communities, and nonmovements as related, but differentiated, phenomena. Tilly, as paraphrased by Bayat, defined social movements as combining simultaneously 'organised and sustained claim-making on target authorities' (Bayat, 2013, p. 4); 'a repertoire of performances including associations, public meetings, media statements, and street marches' (ibid.); and 'public representation of the cause's worthiness, unity, numbers, and commitment' (Tilly, 2004, p. 7). They have been defined by Diani (1992, 2003) and Diani and Bison (2004) as 'distinct social processes, through which actors engaged in collective action: are involved in conflictual relations with clearly defined opponents; are linked by dense informal networks; [and] share a distinct collective identity' (Della Porta & Diani, 2006, p. 20). Tilly's definition emphasises public meetings and performances, action which is organised and sustained, and directed explicitly towards target authorities. Diani and Bison do not emphasise the public nature of action, however they too suggest a sustained organisation process, however informal.

The bar for identifying a social movement is, then, fairly high. These definitions' emphasis on aspects including public and sustained action, dense networks, and clearly defined opponents exclude much organising in Russia, particularly around disability. Despite the helpful turn of contentious politics frameworks in challenging the boundaries between institutionalised and non-institutionalised politics and emphasising the need to recognise less visible action (McAdam, Tarrow, & Tilly, 2001), less organisationally-driven theorisations arising from the concept of social movements are nonetheless necessary to investigate a wider range of action.

One such development is the concept of social movement communities. Originally proposed to overcome the dominant focus on organisations in research investigating second wave feminism in the United States (Buechler, 1990), it has been further developed by Taylor and Whittier (1992) and Staggenborg (1998). Taylor and Whittier define social movement

communities as ‘a network of individuals and groups loosely linked through an institutional base, multiple goals and actions, and a collective identity that affirms members’ common interests in opposition to dominant groups’ (1992, p. 107). Staggenborg takes the definition further to remove the necessity even of a loose institutional base to include ‘all actors who share and advance the goals of a social movement: movement organisations; individual movement adherents who do not necessarily belong to SMOs [social movement organisations]; institutionalized movement supporters; alternative institutions; and cultural groups’ (1998, p. 182).

Thinking in terms of communities includes ‘a continuum of activities that have a contentious dimension without being based on formal membership to a political [or indeed other] organization’ (Bereni & Revillard, 2012, p. 4) or demanding high-visibility action taking place in a narrowly-defined ‘public’ sphere. The definitions from Taylor and Whittier (1992) and Staggenborg (1998) also productively recognise common interests and shared goals as creating a sense of collectivity, without stipulating either how distinct that collective identity be or its relationship to organisational membership. The concept of social movement communities thus emphasises individuals’ identity and associated claims in opposition to a dominant group, without specifying an institutional opponent as necessarily a direct target. For example, Whittier notes that ‘collective efforts for social change have involved culture, identity, and daily life as much as direct confrontation with the State’ (1995, p. 21). These types of claims tie this work conceptually to research on new social movements, which defines as activism the work of challenging assigned identities and producing new ones, often outside of direct confrontation with state structures (Melucci, Keane, & Mier, 1989).

Finally, Bayat’s discussion of social nonmovements (2013) differentiates itself from new social movements by proposing less overt forms of action, functioning through passive networks. It thus widens the forms of action which are framed in terms of challenge to state power structures. Nonmovements are composed of the ‘fragmented but similar’ actions of noncollective, detached, dispersed actors which may trigger for social change (Bayat, 2013, p. 15), particularly under authoritarian, patriarchal states (ibid., p.17).

I would specify that actions may be similar in *intent*, if not in *form*. To give one example from my research, by everyday, fragmented actions, we might think of a research participant who described dying their hair a bright colour to redirect attention from their cane, and thus

silently claim an identity other than an externally-imposed monolithic label of 'disabled', as they moved through town. The exact act of dying one's hair may not be repeated by a fragmented nonmovement. However, in other forms, people conduct actions with a similar intent: that of (re)claiming identity and self-representation, and problematising dominant associations and images of disability. These quiet actions form 'not a politics of protest, but of practice, of redress through direct and disparate actions' which, in contrast to social movements, do not go beyond 'the ordinary practices of everyday life' (Bayat, 2013, p. 20). As they enter into relationship with how disability, and disabled people, are disciplined, these practices are resistant. They operate through meaning to an individual who exerts agency vis-à-vis a dominant norm and by solidarities formed by tacit recognition in public spaces, potentially extending to the online,[14] which create passive networks.

Fragmented groups which do not have access to a space for mutual recognition to build these passive networks rather operate through distanced networks to build 'imagined solidarities' (ibid., p.23). Imagined solidarities are an important possibility both for disability action and for applying Bayat's concept of the passive network to invisible and passing[15] individuals, or to those identifying with markedly smaller groups than suggested by Bayat's focus on, for example, women or people living in material poverty. The concept aims to explore hitherto 'unnoticed social practices' which may create change and to challenge surveillance and control as claimed justification for inaction and exit (ibid., p.29). Looking at these social practices to recognise dissimulated resistance supports other such challenges in work

[14]Bayat finds online space problematic given lack of access on the part of a wider population, a propensity for organising via this medium to be limited 'largely to young, literate, and well-to-do groups', and the increased danger of its exposure and thus vulnerability to surveillance and control as compared to passive networks (Bayat, 2013, p. 24). Both inequality of access ("Regiony Rossii. Sotsial'no-ekonomicheskie pokazateli - 2019 [Russian Regions. Socio-economic Indicators - 2019]," 2019; Vedomosti, 2020) and vulnerability to punitive control hold in Russia. The latter is amply demonstrated by court cases brought for social media posts under anti-extremism laws (Robinson, 2018), attempts for sovereign RuNet and state control (Asmolov, 2020; Asmolov & Kolozaridi, 2017; Daucé, 2020), and other legislative regulation of internet media (Fröhlich & Jacobsson, 2019, p. 1154). However, online spaces still provide important networks, both passive and active, of recognition; although beyond my scope here, I have explored one case of disability collective identity building online elsewhere (Mullins, 2021).

[15]Passing is a complex performative phenomenon, both proactive and reactive (Renfrow, 2004a), where individuals manage identities which are stigmatised or perceived as threatening (Goffman 1963) by presenting themselves as or being categorised by others as someone other than who they are (Ginsberg, 1996; Renfrow, 2004b). In relationship to disability, passing has been used to refer not only to concealment of disability, but also to exaggerating aspects of its performance to meet external criteria for recognition and access a good of some kind and to the imposition of restrictive disability identities on people (Brune & Wilson, 2013; Siebers, 2004).

critiquing the characterisation of Russian citizens as docile or inactive or Russian civil society as weak (for example: Greene, 2014; Salamon et al., 2020; this is discussed further in the next chapter).

I have introduced a range of fluid (non-)organisational forms and spaces to lay the ground for explorations of a range of actions (Section 3.3.). Focusing on the spectrum of forms and spaces of action problematises the boundaries between, for example, formal NGOs and other less structured forms of organising. Actors involved in NGOs may simultaneously be involved in a variety of other communities and networks, both imagined and active, and move strategically among different spaces to ground and find support for various forms of action. This movement is part of their negotiations of power, often reflecting what they understand as contentious or legitimised in relationship to different audiences. Presenting these fluid forms of (non-)organisational spaces aims to focus consideration on the agency of actors active within them and their action, as they negotiate the constraints of different spaces.

The concepts of nonmovements and social movement communities both include more fluid, unstructured organising and support focus on individual actors and their agency. They also have some common aims. The concept of nonmovements explicitly looks to '[bypass] the rigid dichotomies of "active"/"passive," "individual"/"collective," or "civil"/"political" resistance which have limited our conceptual horizons' (Bayat, 2013, p. 29). Like nonmovements, the concept of social movement communities, originally used vis-à-vis women's movements, also aims to destabilise binaries of participation and non-participation, private and public (and, concomitantly, visible and invisible), and protest and involvement in formalised CSOs. The active, collective, visible, public side of these binaries has been identified as political, while private, individual, apparently passive has been identified as apolitical (Bereni & Revillard, 2012; Viguier, 2013). As I argue, these exclusive oppositions have influenced the characterisation of disability organising (Section 4) and that of Russian civil society more widely (Chapter 4). The concept of infra-politics, which I now introduce, is a tool to destabilise these binaries further by going beyond organisational spaces to reconsider forms of action which are non-apparent, ambiguous, and, yet, resistant.

3.3. Infra-politics and Resistance

CSOs have been criticised for tending to operate superficially, without capacity for creating structural change (Bebbington et al., 2008). However, the conceptualisations of decentred power and various (non-)organisational forms presented above resituates the charge of superficiality. Rather, they give weight to micro-practices in their own right, as well as in reflecting and sometimes challenging structural problems; micro and meso levels are linked by pervasive power relations (Lemke, 2001, p. 203) which are challenged by various forms of infra-politics (Scott, 1990; 2012) and diffuse practices of daily life (Bayat, 2013). This opens the door to examining actors' practices of everyday resistance (Scott, 1985), meaning-making and motivation (Andrew & McClaren, 2014; Melucci et al., 1989; Sawer, 2013; Whittier, 1995), and ordinary, dissimulated, or liminal practices (Fröhlich & Jacobsson, 2019) as actions which 'hold the potential to nudge established patterns of control and authority' (Staeheli et al., 2012, p. 630). These practices are an important mode of continued action, especially in authoritarian settings where actors are formally excluded from institutional forms of power and the balance of power is firmly tilted in toward state government (Bayat, 2013). I discuss this further in relationship to Russia's regulation of both civil society and disability in the next chapter.

In addition to more classical repertoires of contention which go beyond daily life, such as demonstrations, petitions, and meetings, people engage in a wider range of actions resisting power via 'everyday tactics' and 'life experiences' (Reger & Taylor, 2002, p. 100). Concepts of 'quiet encroachment' (Bayat, 2015) and 'insurgent citizenship' (Holston, 1999) see a 'discreet but persistent process of claim making in daily life' with the aim of 'establish[ing] alternative (if extra-legal) norms that often come to be articulated in terms of "rights"' (Bayat, 2015, p. S34). While Bayat figures quiet encroachment as often illegal, I include actions and modes of being which are strongly stigmatised and thus excluded from the realms of the possible even while not formally illegal. As disability 'stands in uneasy relationship to the ideology of ability' (Siebers, 2013, p. 279), to live as a disabled person is to make such stigmatised encroachments (Section 4). Identifying these as resistant builds on Scott's work on everyday forms of struggle and resistance, which highlights 'the ordinary weapons of relatively powerless groups' (Scott, 1985, p. 29). He notes that 'everyday resistance most strikingly departs from other forms of resistance in its implicit disavowal of public and symbolic goals' (ibid., p.33). These concepts are united under that of infra-politics, which describes daily

actions of resistance which are 'beyond the visible end of the spectrum' (Scott, 1990, p. 182). This includes ambiguous, liminal actions which may not be associated with any structured organisational form, as outlined above.

In repressive contexts, dispersed, individual action may be a tactic to evade state control (Bayat, 2013, p. 27). CSOs may also use invisibility strategically (Hildebrandt & Chua, 2017). In boundary-spanning contention 'straddl[ing] the border between transgressive and constrained action' (Fu, 2017, p. 501; cf. O'Brien, 2003), seemingly individual action may be in fact coordinated by organisational structures. Organisations coach individuals to make claims through a hidden pedagogical process, but are not present at the moment of the claim being made. Fu theorises this as blurring the boundaries between 'collective action such as strikes or protests (McAdam et al., 2001; Tarrow, 1998; Tilly, 2006) and individual action such as "everyday resistance" (Scott, 1985)' (Fu, 2017, p. 501). The connection between such coordinated activity driven by organisations and the less structured or unstructured activity of individuals in nonmovements or communities is that both are infra-political in how they go unrecognised by those in power and, although differently, in their work to evade control.

An infra-political resistance paradigm thus recognises the difficulties of apparent mobilisation and the possibilities of ambiguous, liminal, and invisible mobilisation. It encourages examining alternative forms of struggle, such as the instrumentalization of various organisational forms, movement between various spaces, and ambiguous, non-apparent resistance. Where infra-political responses are associated with responses to authoritarian, paternalistic control, they are situated as coming from places of constructed marginalisation and vulnerability. This is a key strength of the resistance paradigm; it recognises agentic responses to power. This re-evaluates vulnerability by challenging the presupposition that 'paternalism is the site of agency, and vulnerability, understood only as victimisation and passivity, invariably the site of inaction' (Butler et al., 2016, p. 1). Rather, where the presence of resistance is a condition of power (Foucault, 1982), vulnerability too can be re-imagined as 'one of the conditions of the very possibility of resistance' (Butler et al., 2016, p. 1). Much as organisations and individuals may instrumentalise invisibility, vulnerability too can be both 'exacerbate[d] […] as a way of achieving power, [and] disavow[ed] […] as a way of achieving power' (ibid., p.4). Similar to Butler et al.'s discussion of vulnerability, Bayat's discussion of marginality situates it as a site of alternative power, which 'subvert[s] mainstream power [by] […] constantly

caus[ing] anxiety by threatening to pollute the mainstream and disrupt its governmentality' (Bayat, 2012, p. 21; see also Douglas, 1966).

The link to disability is clear. Russian policy also deals with disability in terms of contagion and threat to the wider population (Kondakov, 2018), as I discuss further in the following chapter. Bayat identifies Simmel's wandering stranger (Simmel, 1971) as the precursor to his 'marginal man' (Bayat, 2012, p. 16). This same stranger moves from the margins of society to confinement in institutions in Foucault's account of the construction of the concept of madness (Foucault, 1967). The stranger reappears again, without conserving Simmel's itinerant elements, in Hughes' use of Bauman's stranger (Bauman, 1973, 1989), whom 'social and cultural practices produce and invalidate', to explore processes of disablement (Hughes, 2010, p. 573). Where so marginalised and constrained that presence itself is unsettling threat, presence become resistance. Take Bayat's characterisation of the 'art of presence' as 'the story of agency in times of constraints' (2013, p. xi) and Butler et al.'s observations on how, 'under certain conditions, continuing to exist, to move, and to breathe are forms of resistance, which is why we sometimes see placards in Palestine with the slogan "We still exist!"' (2016, p. 26); similar slogans ('we exist!'; 'we are here!') also feature in Russian disability protests. One Russian disability CSO is called 'I exist' ('*ia est*"). Applied to disability, Iarskaia-Smirnova and Verbilovich have observed that in Russia the 'appearance of a "crip" in public provokes and actively works to undo ableism (McRuer, 2006), confronting discrimination and exclusion' (Iarskaia-Smirnova & Verbilovich, 2020, p. 432). While this work names the resistance of disabled people's presence in Russia, still needed is a fuller exploration of the limitations and complexities of such strategies and how assumptions of vulnerability shape disability organising.

3.4. Issues with Resistance

While this widened characterisation of resistance is analytically productive, it introduces a challenge to the resistance paradigm. Namely: where resistance may encompass so many different acts, does it lose analytical strength as a concept? As Bayat asks, '[d]o reciting poetry in private, however subversive-sounding, and engaging in armed struggle have identical value?' (Bayat, 2013, p. 42). If not, why not? And (how) can different forms of resistance be distinguished? Scott (1985) draws a distinction between 'real resistance' which is 'organised, systematic, pre-planned or selfless practices with revolutionary consequences' and 'token

resistance' which is made up of unorganised, small-scale acts which 'are accommodated in the power structure' (Bayat, 2013, p. 43). While Scott insists that these two forms of resistance are equally real, despite the suggestion of the nomenclature used, the opposition between 'real' and 'token' does not necessarily hold in relationship to disability organising. Bringing a further consideration from Scott into dialogue with disability organising may offer one response to this critique of the resistance paradigm.

Scott specifies that resistance is an intentional act (Scott, 1985; see also Bayat, 2013, p. 43). Thus, just as above (Section 2), intent is identified as a condition of identifying resistance. While this leaves out many practices where unintended outcomes do indeed challenge power structures, it remains a productive specification particularly in acknowledging that the weight or cost of undertaking certain actions is not equal for everyone; what is a small-scale action for one person may be a large and important action for another. In one example, disability research's critique of the concept of 'slacktivism' (or 'slack' or 'lazy' forms of activism) is grounded in accepting the inequality of cost of action for different actors (Pal, 2019). Focusing on intentionality and meaning-making (Sawer, 2013) contextualises action to uncover if and in relationship to what norm it is understood by actors as resistant.

This approach identifies resistance based on actors' perception of the relationship of an action or way of being with dominant norms, as well as of the emotional, physical, psychological, or other labour taken in negotiating these norms. This is the case irrespective of the apparent scale of an action, or whether it is planned as resistance in advance. The actors' perception is also important as a single action or project may be endowed with differing meanings by different actors (Chapter 7). People seek to 'escape from discipline' in ways which may be ambiguous, hidden, or turned towards their own inner world (Lilja & Vinthagen, 2014, p. 115). I therefore argue that unorganised, small-scale acts remain important to the individual and may shift dominant patterns of control (Staeheli et al., 2012). Particularly in situations of imbalanced power, engaging in such actions may be a strategic choice which should be recognised as such.

However, this still does not answer Bayat's challenge to differentiate, rather than to flatten difference. I offer one further answer to this, which simultaneously relates to a final criticism of the resistance paradigm. Bayat argues that the paradigm, couched in understandings of diffuse and decentred power, often fails to recognise the 'thicker' power wielded by the state,

thus leaving 'cherished acts of resistance [to] float around aimlessly in an unknown, uncertain, and ambivalent universe of power relations' (2013, p. 44). While I stand by the decentred notion of power as underpinning many of the conditions which disability organising challenges, I would respond that the resistance paradigm does indeed recognise the 'thickness' of state power. This is particularly the case in identifying how CSO actors negotiate state legislation and policies and access to levers of formal, institutionalised control. This simultaneously answers the challenge to differentiate, which can be done through examining actors' relationships to these institutions of thicker power. This approach operates through analysis of structural inequalities, as modelled by works on intersectionality (Chun, Lipsitz, & Shin, 2013; Crenshaw, 1989, 1991). Since its introduction into the social movement field (Cho et al., 2013), this approach has emphasised political and structural inequalities (ibid., p. 797). Furthermore, even where state power is not a chief concern, acts of resistance are far from free-floating in an 'unknown, uncertain […] universe of power relations' (Bayat, 2013, p. 44). Disciplinary power produces clearly situated discursive norms. Resistance is thus also situated in time, space, and relationship to particular dominant discourses.

I discuss this perspective further in relation to the creation and control of disability, below (Section 4) and to Russian civil society (Chapter 4). Here, I propose this perspective as justifying my research's foundation in state legislation, policies, and public rhetoric around both civil society and disability, which participants identify as structuring their fields of action. I thus maintain both the resistance paradigm and a stronger analysis of state power through investigation of the inequalities formed by state policies. Finally, differentiation occurs between resistance as related to two multi-dimensional phenomena: firstly, (de)legitimised performances of disability norms and, secondly, (de)legitimised performances of civil society. Resistance in relationship to one may or may not interact with resistance in relationship to the other. As 'stigma is a multidimensional construct (Link & Phelan, 2001; Pescosolido & Martin, 2015), destigmatizing constructions may reduce stigma on one dimension while leaving other dimensions untouched' (Clair, Daniel, & Lamont, 2016, p. 224). Similarly, as disability and civil society are both multi-dimensional constructs, an actor may perceive an action as challenging norms around legitimised action for civil society, while not stepping beyond dominant understandings of disability. Investigating the implications of the fluid and changing legitimacies of multiple categories reflects the 'analytical sensibility' of

intersectionality (Cho et al., 2013, p. 795), which explicitly calls for 'reshaping modes of resistance beyond allegedly universal, single-axis approaches' (ibid., p.800). Recognising this allows investigation of how dominant discourses around legitimised civil society action and disability interact with each other. In the empirical part of the thesis, I argue that the control of disability legitimises it as a depoliticised sphere of civil society, which also shapes how disability is made apparent and recognised in civil society organising.

4. Disability

4.1. Defining Disability

Disability is itself a matrix of power relations producing and produced by tools of control and sites of resistances (Tremain, 2005, 2017). This theorisation recognises that disability interacts with multiple other identities and forms of oppression, going beyond an approach by 'models of disability' (Hartblay, 2020). It thus equally exceeds a 'single-axis' approach (Cho et al., 2013, p. 800). Here I explore some of the principal theoretical conceptions of disability and argue for why disability might be identified as a matrix of power. I show how this theorisation of disability as apparatus of power usefully aligns with analysis of civil society and resistance and is therefore productive in terms of my questions here. I present how disability has broadly been associated with and created by exclusion from power, infantilization, and vulnerability. Such connections motivate restricted understandings of disability as extra-political, individualised, and medical. The resistance paradigm is therefore an important counterweight to go beyond these categorisations, recognise agency, and reframe vulnerability as in itself a potential source and form of power.

The social model of disability (UPIAS 1976; Oliver 1983) provided a revolutionary theoretical structure to move action and analysis away from charitable or medical frameworks of disability (Garland-Thomson, 2011b). The latter frameworks situate disability as an individualised, medical, and fixed problem which necessitates charitable, often pity-driven responses. In contrast, the social model sees disability as a social justice issue located outside the individual and addressed by right-based claims.[16] This operates by drawing a distinction

[16]The social model as described here has been referred to more precisely as 'the UK social model'. However, I characterise it deliberately at a certain degree of abstraction in order to include the North American social model, if not the Nordic social model. Owens presents an overview of key features of and differences between these approaches in her exploration of the critiques of the social model (2015).

between impairment and disability, somewhat similar to earlier feminist distinctions between sex and gender (Garland-Thomson, 2011b), where impairment is a physical condition and disability is created by a social process which 'gives meaning and consequences to those impairments in the world' (ibid., p.591). In the social model's first formulation by the Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom, disability was defined as 'something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (1976, p. 14). Thus, the individual disabled person does not need to change, but society does. The activist roots of the social model and disability studies are clear (Anastasiou & Keller, 2011; M. Oliver, 2009; Owens, 2015; Thomas, 2004), alongside their implications for the nature of disability studies as an engaged discipline (Minich, 2016; Price & Kerschbaum, 2016; Sandahl, 2003). The social model is foundational for much of disability studies, both in the revolutionary nature of the distinction it proposes and in its continued presence, even where that presence is a generative rejection.

A central critique of the social model has revolved around its binary division between impairment and disability, as well as the concern that it has not adequately reckoned with embodied aspects of disability. The social model's suggestion of impairment as pre-social fact has been criticised for relinquishing impairment and the body as proper to medical study (Anders, 2013; Hughes, 2002; Hughes & Paterson, 1997). In response, scholars developed Foucauldian analyses of disability (Shildrick & Price, 1996; Tremain, 2001, 2005). Further theoretical work sought to bring back impairment and physical experience, largely while retaining disability as a social phenomenon (Clare, 1999; Feely, 2016; Schweik, 2009; Scully, 2008; Siebers, 2008; Snyder & Mitchell, 2006). I examine embodied and socially constructed aspects of disability in relationship to disability organising below (Sections 4.2. and 4.3.). First, I clarify the Foucauldian lens taken in defining disability as:

> a historically specific aggregate that comprises, constitutes, and is constituted by and through a complex and complicated set of discourses, technologies, identities, and practices that emerge from medical and scientific research, government policies and administrative decisions, academic initiatives, activism, art and literature, mainstream popular culture, and so on (Tremain, 2017, p. 22).

Tremain's definition notably does away with any distinction between impairment and disability; both are constructed by 'a far-reaching and systematic matrix of power' and a

'contingent network of force relations' (2017, p. 22) which makes these categorisations salient as tools of control. Lilja and Vinthagen summarise: 'In Foucault's analysis of power, the production of a discursive norm is central' (2014, p. 109). In disciplinary power, 'those deviating from the norm are defined as abnormal' (ibid., p.109). Thus, to deviate is to be inferior and consequently subject to various interventions and pressure to integrate the norm. These categorisations control disability and understand disability as abnormal and subject to correction. According to this definition and unlike the social model, disability and impairment are not two separate categories. This has some commonality with Abberley's theory of disability as oppression in the latter's insistence upon both the need for a social theory of impairment (Abberley, 1987, p. 9) and 'the body as a site of oppression' (ibid., p.10).

This connection begins to respond to criticism of Tremain as excluding the reality of embodied experience; my use of Tremain's definition does not seek to minimise or deny such experience. In that sense, I adhere clearly to accounts which give space to 'messy, fleshy, nuanced texture of disabled people's lives' (Reinke & Todd, 2016, p. 170; see also: Kafer, 2013; Linton, 1998; Mairian, 2001). However, I argue that Tremain's definition nonetheless holds space for these embodied aspects and has the strength of emphasising power relations in their control. Thus, disability as apparatus usefully places weight on the 'constructed perceptions and interpretations of (inter alia) bodily structure, appearance, style and pace of motility, mode of communication, emotional expression, mode of food intake, and cognitive character' (Tremain, 2017, p. 23); constructed perceptions and interpretations form how disability, now including impairment, is made legible and salient as a category. They are 'outcomes of contextually specific and performative relations of power' (ibid., p.23).

Disability is thus a negotiated, contextual matrix of power relations which operates 'within a framework of multi-layered and complex patterns of inequality and identities' marked by stigmatisation, itself a tool of control (Sherry, 2008, p. 76). This conceptualisation explicitly identifies: disability as the construction of diffuse power relations created and upheld by multiple factors and actors; the responses of civil society actors as negotiating and resisting multiple fields of power (Foucault, 1982); and disability as one of multiple other intersecting identities. It thus dialogues with Crip theory, which builds in part on Foucault's conceptualisations of power (McRuer, 2006; McRuer, 2016). Among other concerns, Crip theory expands disability studies through its departure from 'the social model's assumption

that ‘disabled’ and ‘non-disabled’ are discrete, self-evident categories’ to instead explore ‘the creation of such categories and the moments in which they ‘fail to hold’ (Kafer, 2013, p. 10)’ (Schalk, 2013, n.p.); the creation and limits of categories as a feature of the power relations are key concerns of Crip theory in general (Reinke & Todd, 2016) and Tremain’s definition in particular.

4.2. Control of Disability

I define disability above as a complexly embodied, socially produced phenomenon. Here I clarify the associations and attributes of disability as so produced. I suggest that these negative associations represent discursive norms, and thus tools of control (cf. Collins, 1986). Negative definitions of disability neither suggest such characterisation as inherent, nor deny the existence of alternative views. Rather, they suggest the consequences of dominant ideology of ability in an ableist society which devalues disability, forming ‘legitimising myths’ which ‘attempt to naturalize social hierarchies by treating [them] as naturally mandated’ (Toole, 2019, p. 612; see also: Pratto, Sidanius, Stallworth, & Malle, 1994; Sidanius & Pratto, 1999). Thinking about these aspects of the construction of disability and other categories ‘does not necessitate a total rejection of the social reality of categorisation’ (McCall, 2005, p. 1779); naturalised negative characterisations are one part of disability’s social reality. Examining disability means questioning dominant understandings of social categories and their construction and operation in the world in order to analyse the selective imposition of vulnerability on certain bodies (Cho et al., 2013; Spade, 2013). This allows the categories of dominantly legitimised expressions of disability to be subsequently explored in terms of their effect on perceptions and opportunities for disability organising.

Charitable and medical approaches remain prominent, identifying disability as individual deficiency. Stigma, otherness, and lack of ability are common in defining and creating disability; disabled people ‘misfit’ (Garland-Thomson, 2011b) and fail to match up to an ideology of ability which smooths movement through the world (Goodley et al., 2019; Siebers, 2008). Disability may also be externally identified as an unsettling threat to the norm (Hughes, 2010; Kafer, 2013) and to government of the majority (Kondakov, 2018). These and other discourses which construct disability as deficit have been theorised as expressions of ableism, which proposes 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)' and the other (Campbell, 2015, p. 12).

A series of external expectations govern what disability is recognised as and how disabled people may present themselves without becoming suspect or confusing to a majority, non-disabled audience (Kuppers & Marcus, 2009; Siebers, 2004). People 'expect the cripple to be crippled; to be disabled and helpless: to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations' (Goffman, 1963, p. 110). Others' gaze becomes an evaluation, as people watch 'to see how well I do this thing called human' (Marcus, 1988; cited in Kuppers & Marcus, 2009, p. 144). Misrecognition and invisibility become forms of oppression (Siebers, 2004) which 'includes the denial of common humanity or citizenship' and 'equal worth' (James, 2015, p. 99; see also: Fraser, 2007). Thus, for example, disabled people may be represented as themselves social problems or medical issues (Verbilovich, 2013). They may be identified with, and uniquely as, 'the [well-known] tools we use' (e.g., wheelchairs, canes, or hearing aids) or made invisible (Montgomery, 2001; cited in Siebers, 2004, p. 12). Fluid, non-static use of these tools can also cause suspicion of malingering or exaggeration (Zola, 1982, p. 209); disabled people attract far greater pressure to confirm to the norm of compulsory able-bodiedness (McRuer, 2016) than non-disabled people, who 'have the right to choose when to be able-bodied' (Siebers, 2013, p. 280).

Siebers (2004) draws some parallel with the work of Williams (1991, pp. 213–236) who theorises staring through the difference between visibility and recognition to observe that 'the heightened visibility of her blackness produces her social invisibility' (Siebers, 2004). While recognising the agency of the 'staree' in responding to stares (Garland-Thomson, 2009; see also Renwick, Yoshida, Eacrett, & Rose, 2016), Garland-Thomson also comments on this dichotomy through disabled people's 'history of being on display, of being visually conspicuous while being politically and socially erased' (Garland-Thomson, 2005, n.p.).

Non-apparent aspects of disability may be punished not only through lack of adjustment, understanding, and increased burden on the disabled person to adjust and perform, either to fit in or to clarify their status as disabled (Grigely, 2000). Apparent disability[17] may elicit

[17]In using 'apparent disability' and 'non-apparent disability' as an alternative to 'visible disability' and 'invisible disability', I follow Hartblay (2020). Hartblay proposes the expression as alternative to mean 'those disabilities that are observable to others' which is not ocular-centric and 'dovetails with

misrecognition as unique identity, 'silenc[ing] other experiences' (Hill, 2017, p. 115) and other intersections of identity (Stienstra, 2015). This occurs not only in disabled people's relationship to other individuals, but also in their relationships with state institutions (Iarskaia-Smirnova, 2011) and CSOs (Chapter 8); both state institutions and CSOs demand certain specific performances of disability. This misrecognition may be structurally enacted by certain state policies, as I discuss in reference to Russia in the following chapter. Discursive norms around disability also restrict its expression. For example, disabled people's sexualities have been denied via infantilization (Iarskaia-Smirnova & Verbilovich, 2020) or exoticized as 'inherently kinky [and] bizarre' (Kafer, 2003, p. 85). Disabled people's identity management may include self-censorship and denial of aspects of their identity, particularly those which are stigmatised or delegitimised by the ideology of ability, to fit legitimised social norms (Chapter 8).

However, disability is not a 'trump card' (Stienstra, 2015) which erases other aspects of identity. (Self-)identity is multiple and reciprocally constructed (Collins, 2003) and the identities imposed by others neither entirely nor consistently look beyond certain other aspects of identity, particularly where these aspects also attract stigma. The assertion that they do so seems to align with criticism of disability studies' whiteness (Bell, 2006; see also: Annamma, Connor, & Ferri, 2013; Conor, Ferri, & Annamma, 2016), tokenistic engagement with questions of racialisation in particular (Schalk, 2013),[18] and weaknesses in exploring intersectionality. Characterising others as reducing a person uniquely to a perceived impairment does not engage with how that is moderated by the individual's experiences and others' perceptions of gender, ethnicity, sexuality, and other characteristics.

The complexity of identity is underpinned by external misrecognition of intersecting and fluid identities. Exclusive categorisations produce dichotomous thinking which controls how disability is produced, recognised by others, and may be legitimately performed within a discursive norm. Tilly discusses the role of such categorical identities in preserving inequalities

theorizations of disability appearance in relational interactions' (ibid., S32). I also build on Dorfman, who notes that, 'The line between visible and invisible disabilities is not clear-cut, because the concept of visibility can be considered subjective and change over time' (2019, p. 1067).

[18]This thesis perhaps replicates this weakness, as interview participants were largely white, Western Russians. Looking at experiences of disability in other regions of Russia and engaging with religious, ethnic, and other forms of diversity in that experience remains a neessary area for future study.

through his theory of durable inequalities (1998). However, as Verloo (2013) points out, similar theorisations have also been offered earlier, particularly in gender studies (Brouns, Gruenell, & Verloo, 1995; Butler, 1988). Collins also recognised this in writing that, 'Afro-American women have been assigned the inferior half of several dualities, and this placement has been central to their continued domination' (1986, p. S20). Disability too is a signifier and identity which has been assigned to that 'inferior half.' This assignation is 'yet another dimension of the power that dichotomous oppositional constructs have in maintaining systems of domination' (Collins, 1986, p. S21). Black feminist knowledge production has challenged 'dichotomous oppositional thinking [as] natural and norm' (Collins, 1986, p. S27); breaking down control of disability requires the same.

I presented above (Section 3.2.) some dichotomies which theories of social movements and nonmovements challenge: active and passive, collective and individual, political and civil, public and private. Each of these binaries have previously guarded recognition and characterisation of resistance. Their construction and that of disability has also, in each case, worked so that disability is assigned to the less valued side. Disability has been associated with passivity and lack of agency. Equally, definitions of action do not recognise the implications of the embodiment of disability, which may make engaging in recognised action more difficult. Recognised action is also militated against by the production of disability through fragmentation, separation, and control of disabled people (Mingus, 2010; Price & Kerschbaum, 2016), which intersects with failure to meet the criterion of collectivity and defining resistance. In a further intersection, disability has located been within the private sphere, not considering its production through exclusion from and marginalisation within what has been typically understood as public sphere. This also fails to recognise the extent to which disability blurs any normative definition between the two: where the public sphere is inaccessible to disabled people, the private sphere also is made more public to varying degrees through, for example, institutionalisation and the use of personal assistants within the home. Disability has also been associated with vulnerability, pity, charity, and medicalisation, rather than rights (Revillard, 2018; Satz, 2008, 2014); this is part of a matrix, explored further below (Section 4.3.), which frames disability as extra-political.

Fully recognising disability demands going beyond dichotomous thinking to analyse how disability is produced and controlled. Further, I explore some of the implications of

misrecognising disability as an extra-political medical or welfare issue. These characterisations are mutually constructed by some of the misrecognitions explored above; I focus on them here to recentre disability by presenting the theoretical possibility that the exclusion of being assumed to be both vulnerable and extra-political may also be a source of power.

4.3. Disability as Extra-political

Murray Li notes that 'authoritarian forms of government are often reserved for sections of a population deemed especially deficient and unable to exercise the responsibility of freedom' (2005, p. 387). While she does not write about disability in particular, the observation has resonance for the construction and control of disability. Figuring disabled people as vulnerable (Satz, 2014) has naturalised responses including imposed limits to self-determination, infantilization, and authoritarian or paternalistic control (Revillard, 2018). It is against this background that an important body of literature uses concepts of unequal citizenship to explore disablement[19] and, more specifically, to analyse disability rights activism as struggle for citizenship (Barton, 1993; Carey, 2009; Prince, 2009; Sépulchre, 2018). Siebers, for example, argues that 'political membership relies on the ideology of ability' (Siebers, 2008, p. 179) from which disabled people are excluded (Garland-Thomson, 2011b, p. 601). Here, I present how framings of disability situate it as extra-political, or beyond the realm of the political. Reframing understandings of vulnerability from those classically associated with disability, seen as necessitating control and paternalism, to those produced socially and culturally and seen as a place of agency (Butler et al., 2016), then supports analysis of resistance in disability organising.

The portrayal of disabled people suggests the impossibility of their exercising self-determination. 'Queer theorists Lauren Berlant and Lee Edelman suggest that the figure of the child is used to render certain positions *as extra-political, as beyond the realm of politics*, and I suggest that the disabled body performs a similar function' (Kafer, 2013, pp. 96–97,

[19]Sépulchre provides a useful scoping review, which notes also dramatic growth in the quantity of articles about disability and, largely state, citizenship in more recent years (Sépulchre, 2017). Key works in this vein include Beckett (2006), Bezmez and Yardımcı (2010), Carey (2003), Meekosha and Dowse (1997), Rioux and Valentine (Rioux & Valentine, 2006), and Walmsley (1991). In the post-Soviet context, Phillips has written about 'mobile citizenship' in Ukraine (2010) and Romanov and Iarskaia-Smirnova have about Russia (2006). This literature provides a foundation for exploring the thicker power of the state in creating exclusion, marginalisation, and vulnerability; here I largely focus on these latter concepts for their implications for disability organising.

emphasis added). Kafer's argument builds on the portrayal of disability on advertising billboards in the United States of America. However, extra-political, infantilising tropes associated with disability are more widespread. More broadly, assumed and compulsory able-bodiedness often makes disability either invisible and incomprehensible (McRuer, 2016), or narrowly comprehensible only through a limited number of discursive tropes, such as overcoming personal tragedy, or medicalisation (Cameron, 2007, 2014b; Kafer, 2013). 'Overcoming' suggests disability as a deficit, or indeed 'tragedy', to be normalised, suggesting an understanding of disability as eliciting pity and charity. Medicalisation is also one way of rendering disability as extra-political and a matter of pre-existent, individualised fact (Zola, 1972). This operates through the dominant role of 'experts' in adjudicating on courses of medical and other bodily interventions, often with the goal of 'normalisation' (Abberley, 1987), and controlling access to goods and services (Mladenov, 2015; Rose, 1996; Roulstone & Prideaux, 2012). This in turn relates to the thick power of state policy and institutions. To access entitlements as a disabled person in Russia, and more broadly in the modern welfare state, one must submit to a commission which evaluates and categorises functioning. Rose observes that 'the very powers that the technologies of welfare accorded to experts enabled them to establish enclosures within which their authority could not be challenged' (1996, p. 54).

The imposed characterisation of disability as extra-political is not only incorrect according to the theories of power and resistance presented in this chapter. It also highlights the problems of the uncritical equation of disability CSOs' social service provision with apolitical activity. This equation has at its root a descriptive and normatively problematic opposition drawn between 'the notion of "rights" (reduced to civil rights) and that of "welfare" viewed as synonymous to charity' (Revillard, 2018, p. 3). Revillard links this to the roots of the social welfare model in the medical model of disability (ibid., see also Heyer, 2005). However, 'welfare is not necessarily synonymous with charity and paternalism' (Revillard, 2018, p. 3). This problematic binary opposition occurs also beyond disability, with social service provision often linked to a lack of contention. For example, in reference to China, Fu writes: 'Nevertheless, the party-state discourages civil society from participating in contention, in part by regulating and channelling organizations into social services delivery' (2017, p. 501). Such provision is often seen as encouraged by states which need CSOs to fill welfare gaps,

again as a form of regime legitimation. The literature on civil society in Russia too, including that on disability, is no exception in drawing this distinction. As I discuss in the next chapter, disability largely falls into the 'welfare' category which is characterised as extra-political and opposed to rights-based organising. The need for service provision in Russia has even been taken to suggest the continued relevance of the medical model of disability (Thomson, 2006).

However, as both social rights models and Foucauldian theories of power and resistance suggest, the need for social service provision can be recognised equally as both a right-based and political claim. Furthermore, as refiguring vulnerability suggests, recognising the need for social service provision does not mean ceding disability to the field of medical authority and does not automatically necessitate paternalistic response. Accepting the opposite is problematic for three main reasons here. Firstly, it perpetuates assumptions of lack of agency and (self-)determination. Secondly, it removes the possibility of investigating the meaning of social service provision to actors. Finally, it does not permit analysis of actors' instrumental use of a space which is legitimised precisely through apparent depoliticization to continue contentious action in a restrictive context (Chapter 6). It does not examine the opportunity and power of being assumed extra-political, vulnerable, and pitiable.

The fact that this opportunity operates in part through presumed lack of ability and infantilization has parallels with work around vulnerability and marginalisation. Marginalisation may work through discourses of contagion, pollution, and threat to the mainstream (Bayat, 2012, p. 21); disability is dealt with through similar discourses (Kondakov, 2018). Initially introduced above (Section 3.3.), Bayat (2012) and Butler et al.'s (2016) conceptualisations of marginalisation and vulnerability, however, resituate them as a source of power where instrumentalised to resist. This challenges the assumption that 'vulnerability […] cannot be conceived as part of [the] practice [of resistance' (Butler et al., 2016, p. 1). I explore the conditions, understandings, and limitations of vulnerability, both when chosen and imposed, as practice of resistance are explored in Chapters 6 and 7.

Firstly, however, the risk of claiming vulnerability in reference to certain groups must be addressed. This renewed concept of vulnerability must be clearly differentiated from that associated with disabled people as 'classical figures of vulnerability' (Satz, 2014; cited in Revillard, 2018, p. 1) and used to characterise a 'traditional form of intervention towards disabled people, marked by paternalism and pity' (Revillard, 2018, p. 1). Butler et al.'s

reconceptualization of vulnerability specifically has the goal of challenging the idea that vulnerability must be responded to by paternalism and protection (Butler et al., 2016, p. 1).[20] However, Butler et al. themselves recognise the risk of discourses of vulnerability, particularly where mobilised to support 'objectionable ontological claims about […] constitutive vulnerability' (Butler et al., 2016, p. 2) of certain groups as inherent fact. The definition of disability as constructed through power relationships clearly stands against this argument; both vulnerability and disability are 'produced and distributed' (ibid. p.2) and selectively imposed (Cho et al., 2013; Spade, 2013). Experiences of disability cannot be essentialised to those of vulnerability, even where emphasis is on the structural production of this vulnerability.

The danger of misinterpretation and essentialisation in discussing vulnerability in relationship to disability is echoed by the perceived risk of recognising disabled embodiment. Accounts which emphasise the embodiment of disability often argue that this aspect has been elided precisely because of the perceived threat of engaging with impairment (Crow, 1996; Snyder & Mitchell, 2001; Wade, 1994). Wendell comments that acknowledging the experience of 'unhealthy disabled'[21] people presents a danger in 'provid[ing] support for those who prefer the individualized, medicalized picture of disability' (2016, p. 18). She therefore argues that it has been 'safer and more comfortable for disability activism to focus on people who are healthy disabled' (ibid., p.19). This has stressed a normative message of '[r]emove the barriers that have been erected arbitrarily against our participation, and we will perform as well as anyone else' (ibid., p.27). Wendell sees this as in fact disempowering, as it removes the possibility of positive engagement with the power of disability to transform (cf. McRuer, 2006; Price & Kerschbaum, 2016).[22] Just as claiming vulnerability has been subject to the risk of

[20]This has also been approached by reframing vulnerability as universal and constant, a human condition rather than that proper to any group (Fineman, 2008); this argument has also been applied to disability (Satz, 2008). Here I prefer Butler et al.'s approach because it builds on Foucauldian approaches to directly relate the production of vulnerability to analysis of activism and organising. As discussed below, this also enables aspects of embodiment to be brought into analysis of the nature of resistance.

[21]In her work, Wendell differentiates between 'healthy' and 'unhealthy' disabled, where both are themselves fluctuating and unstable categories. 'Healthy disabled' refers to 'people whose physical conditions and functional limitations are *relatively* stable and predictable for the foreseeable future' (Wendell, 2016, p. 19, emphasis added). 'Unhealthy disabled' is not defined so succinctly; rather the experience of this condition is the focus of the article as a whole. However, it can be broadly understood here as implying experience of disability either through or complicated by chronic illness.

[22]A similar argument is used by some scholars against the use of person first language (e.g. person with a disability), suggesting that this language suggests a ''normative' resemblance that we can attain if we

naturalising 'constitutive vulnerability' (Butler et al., 2016, p. 2), so acknowledging disabled embodiment been seen as allowing others to essentialise disability as a medical issue. However, vulnerability as source of agency rejects this essentialisation to stress strategic transformations of resistance. If we look at the depoliticization of medicalisation and imputed vulnerability, among other misrecognitions of disability, as strategic opportunity, how do they shape civil society action around disability in a context where depoliticization is incentivised?

4.4. Refiguring Resistance

Constructions and experiences of disability draw together questions of vulnerability, intent, embodiment, and thick state power, including both formalised instruments and discursive norm-building, to create a different picture of resistance. Disabled resistance, and resistance in authoritarian contexts more generally, may not obey rules of 'organised, systematic, pre-planned,' public, and 'revolutionary' action (Scott, 1985, p. 292). Where disciplinary, sovereign, and biopower seek to normalise and control disability, everyday life may also become resistant (B. Anderson, 2012; Lilja & Vinthagen, 2014). Disability thus demands that the criteria for recognising resistance evolve (Hedva, 2016; Pal, 2019).

Shifting how we consider vulnerability is part of this. Recognising vulnerability's social and political construction, its interaction with embodiment, and its agentic power as forming sources of resistance develops the concept of resistance itself. This is again linked to the importance of actors' intent and meaning-making (Section 3.3.). Butler et al. define vulnerability as 'deliberate exposure to power' (2016, p. 22); I take 'deliberate' here as synonymous with 'intended'. Where exposure to power is not deliberate, something other than vulnerability is at stake. Intent is also, then, what makes vulnerability resistant. Butler et al. argue that vulnerability 'is part of the very meaning of political resistance as an embodied enactment' (ibid., p.22).

Disability studies too have argued for embodiment as resistance. Siebers, for example, argues that, because disabled 'bodies are excluded by dominant social ideologies,' they 'display the

achieve the status of being deemed 'people first' (with the emphasis on independence and extreme liberal individualism) in the eyes of an ableist society' (Overboe, 1999, p. 24; see also Todd, 2016). Both Wendell and Overboe's critiques draw attention to how the insistence on performing to the normative expectations of an ableist society can be exhausting and lead to the erasure of the complexities of lived experience of disability.

workings of ideology and expose it to critique and the demand for political change' (Siebers, 2013, p. 295); '[i]dentities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism' (ibid., p.283; see also: Siebers 2004, p.8). The workings of ableism are also experienced where they are not displayed, as in the case of disability which is not necessarily apparent or observable to others. The discomfort which may be experienced by disabled people who are not apparently disabled also produces friction as they exist in a space which was not imagined or designed with them in mind. Disabled people thus 'misfit' as they pass through space (Garland-Thomson, 2011b). The challenge that their presence therefore creates evoke Bayat's 'art of presence' as a form of resistance (2013, p. xi).

Disruptive presence and other forms of resistance are therefore better recognised in terms of intent and meaning to the actor involved. To clarify by one example, people may wish to pass unnoticed and without necessarily creating challenge by their presence in whatever space, physical or virtual. This itself may have different valences; they may wish to pass unnoticed as within a norm, or they may wish to shift focus something other than disability, in a way which disassociates from the negative perceptions which they may identify others as having about disability and, therefore, about them. They may not intend their body to be used to create meaning as 'demand[ing] […] political change' (Siebers, 2013, p. 295). Equally, people may also understand and experience their presence as deliberately resistant. Furthermore, multiple meanings and modes of presence may be identified by different actors participating within a single action, often connected with the relationship of power which they address as most salient to them (Chapter 7). As shown by investigations of silence (Gest, 2017), invisibility (Fu, 2017; Hildebrandt & Chua, 2017), passing (Brune & Wilson, 2013; Siebers, 2004), and (mis)recognition (Williams, 1991), presence has different meanings, uses, and consequences. While visibility is often identified as a goal of disability action in the face of exclusion and erasure (Snyder & Mitchell, 2006), this goal is perhaps more accurately phrased as recognition on the terms intended by the actor, collective or otherwise. Moreover, invisibility may also be sought as its own source of power, as theories of infra-political resistance suggest.

Recognising the implications of disability as an embodied power relationship challenges the taboo of engaging with embodiment and 'unhealthy disability' (Wendell, 2016), as well as the idea that to do so is to revert to an extra-political, medical understanding of disability associated with paternalistic and authoritarian control. Refiguring the constructed vulnerability of disability as itself a source of agency and power allows the naturalised responses of paternalism and control to be questioned. Embodied disability demands widening the boundaries of resistance. Bereni and Revillard (2012, p. 3) argue that 'beyond its empirical contribution, research on women's movements invites us to rethink the very definition and the borders of social movements and contentious politics'. I argue that disability organising plays a similar, and comparatively neglected, role in questioning the spectra of public and private action, contentious action, and visible, invisible, ambivalent, multiply legible action.

Finally, widening concepts of resistance does not untie it from analysis of the production of vulnerabilities linked to thick state power. Theories of infra-politics (Section 3.3.) and diffuse power argue for recognising 'subversive, infiltrating form[s] of resistance' (Munro, 2003, p. 91). Analysis of disability organising in fact demonstrates the relationship between state power, the control of discursive norms, and resistance to that control. Furthermore, as I argue in reference particularly to Russian state policy, legislation, and rhetorical moves in the next chapter, state authoritarianisms importantly structure the field of action for disability organising by reinforcing a differentiation between social and political CSOs, and by legitimised (extra-political) and delegitimised (politicised) identities. Problematised above, this distinction tends to equate social welfare with extra-political activity and, through a medical and paternalistic model, situate disability as extra-political. This creates its own opportunities for resistant responses. Resistance is about 'a taking up of the tools where they lie, when the very "taking up" is enabled by the tools lying there' (Butler, 1990, p. 145). This is the paradox of power, which in turn is the paradox of vulnerability as power: '[resistance] is in itself enabled, if not produced, by the very power relations against which it struggles' (Munro, 2003, p. 92; see Butler, 1990, p. 15).

5. Conclusion

In this chapter, I brought together theories of decentred, fluid power and resistance to ground discussion of civil society and disability. Both civil society and disability are arenas of control and contestation. Recognising them as such allows exploration of the agency of CSOs actors as they both challenge and reinscribe power relationships through their intent, meaning-making, and action. It also allows the identification of a fuller range of action as resistant. Non-apparent practices may respond to 'the values and norms of discipline' (Lilja & Vinthagen, 2014, p. 115), which construct and delimit the roles legitimised for civil society and disabled people. This resistance paradigm argues for such everyday action as in fact capable of challenging power relationships by nudging established patterns of control (Staeheli et al., 2012) and seeking change 'in culture and consciousness, in collective self-definitions, and in the meanings that shape everyday life' (Polletta, 1997, p. 431).

Recognising these practices as resistance blurs dichotomies of active and passive, individual and collective, civil and political, and private and public. These dichotomies have previously been used to identify resistance and political engagement, resulting in the erasure or minimisation of action which does not meet their criteria. I concur with this use of such controlling dichotomies, but would further question the binaries themselves: where Bayat (2013) opposes civil and political in listing binaries which characterise identification of resistance, 'social' is absent entirely. Yet, identification as 'social', just as identification as 'passive', 'individual', and 'private' has been more used to remove an action or individual from identification as resistant. As I will discuss throughout my empirical chapters, as well as in presenting the Russian context (Chapter 4), the characterisations of CSOs as engaged in civil and political rights action are both delegitimising, while characterisation as social is typically legitimising and associated with the absence of resistance.

First, to summarise the problem: 'So long as we confine our conception of the political to activity that is openly declared, we are driven to conclude that subordinate groups essentially lack a political life' (Scott, 1990, p. 199). The framework I presented in this chapter raises some theoretical possibilities for analysis of disability organising to address this epistemological erasure and extend thinking about resistance. I close this chapter by summarising these possibilities, prior to presenting why Russia is a good environment to test them (Chapter 4) and exploring them empirically (Chapters 5-8).

Firstly, the production of disability challenges the dichotomies mentioned above (i.e., active vs passive, individual vs collective, civil vs political, and private vs public). For example, what we may consider public and private space is transformed by the production of disability. What is classically understood as public space is often neither imagined and nor accessible for disabled people (Garland-Thomson, 2011; McRuer, 2016; Siebers, 2016). Similarly, private space may become public both through institutionalisation or the presence of personal assistants or others within the home. The binary of individual and collective action is troubled by the difficulties of physically uniting in a single place and time, while disabled people's use on online communities and exchange (Hartblay, 2019) is often unrecognised as resistant due to an emphasis on collective, in-person action at a particular time and place (Véron, 2016). Boundaries between active and passive are troubled by complex embodiment and impairment, which can increase the cost of action and problematise planning and extended commitment (Crow, 1996; Pal, 2019; Wade, 1994; Wendell, 2016). Exploring the production of disability, as it is responded to by civil society, may therefore demonstrate how these binaries exert epistemic violence by justifying the lack of recognition of certain forms of resistance.

Secondly, in order to uncover dissimulated resistance and look behind apparent passivity, analysis of disability organising also argues for using intent and meaning-making to define resistance without replicating the perception of the dominator. Holding to criteria of intent and meaning-making answers the criticism of the resistance paradigm as too wide to be analytically useful. It bridges between different forms of actions and re-centres forms of action which have been dismissed as small, meaningless, and peripheral. Furthermore, consideration of the production of disability maintains the resistance paradigm alongside structural analysis which takes seriously state power in setting the field of action. Ambiguously legible, everyday actions also challenge and shift those norms.

Finally, disability organising also offers the opportunity to explore the lack of recognition of resistance as a source of power and agency. Figuring disability as extra-political may create a safer space from which actors resist. In my empirical chapters, I both identify that this occurs and analyse why and how it works (Chapter 6). I also question the limitations of such strategies, as they are dependent on remaining non-apparent (Chapters 7 and 8).

Using disability to develop theory around civil society attempts to respond to the challenge with which this chapter begun. My aim is to think through the lens of disability to investigate resistance, without decentring disability a result. Exploring disability's production through marginalisation is a way to turn that marginalisation inside out (Linton, 1998), reframing it productively not only as its own source of power, but also as powerful in challenging the boundaries of how resistance is identified more widely. Thus the margins not only define the centre, but transform it (hooks, 2000).

Chapter Four

Power and Resistance in Civil Society Organising around Disability: Russian Context

1. Introduction

In the previous chapter, I argue both for greater recognition of resistance based on actors' intent and the potential power of categorisation as vulnerable or extra-political. In this chapter, I present the Russian context as one which provides ground to test these theoretical possibilities. To do so, I outline the control and (de)legitimisations of both civil society and disability.

Firstly, I present the development of civil society in Russia from the late Soviet period to the present day. While the pre-Soviet, Imperial period has some continuities with the post-Soviet period in terms of civil society organising (Bradley, 2002, 2017), these are not my focus here. Rather, I focus particularly on the development and regulation of post-Soviet civil society up to the present day, as well as trends in its research. Prior research has focused unequally on different aspects of civil society organising. In particular, dominant approaches emphasising democratization have upheld the problematic distinction between organising identified as rights-based and politicised, and other organising identified as depoliticised and related to social services. The state may indeed regulate for and otherwise discursively promote a binary differentiation between, on one hand, delegitimised political organising and, on the other, legitimised social organising (Fröhlich & Skokova, 2020). However, the empirical experience of civil society actors apparently operating within the social sphere, as per this binary division, remains comparatively underexplored.

Secondly, I outline broader responses to and policies around disability in Russia. Disability is generally stigmatised and its performance legitimised within the bounds of restrictive discursive tropes. I argue that these legitimised expressions of disability are largely connected to medical and charitable discourses, in an apparent overlap with legitimised, social, and depoliticised areas of civil society organising. Under the resistance paradigm and rethinking of vulnerability presented in the previous chapter, this imputed vulnerability may be used agentically to contest within the limits of a restrictive environment which rewards social,

apparently non-contentious organising. I thus identify the construction of vulnerability around disability to demonstrate how Russian disability organising space allows us to investigate how civil society actors understand, respond to, and instrumentalise the limits and contours of disability's (de)legitimisations. This demonstrates the importance of intent over form of action, uncovering forms of resistance which have been erased under other analytical frameworks.

2. Civil Society

Three broad periods have been identified in the development of Russian civil society from the late Soviet period until the 1990s and early 2000s. Firstly, the state-controlled Soviet period with some dissident movements, latent to differing degrees, and some organisation growth with *perestroika*; secondly, the import-dependent 1990s which saw foreign donor involvement and the development of the new organisational form of the NGO; and, thirdly, the development of a rooted, Russian civil society less led by foreign donor involvement. This third period stretches to the present day and includes key developments in state legal regulation and rhetoric around civil society. Here, I focus on these developments to outline the period since President Vladimir Putin first came to power in 2000, particularly looking at changes immediately prior to and since he regained the presidency for a third term in 2012.[23] I thus describe the current context in which civil society operates, presenting civil society regulation through top-down, state mechanisms including legal, policy, and discursive methods and empirical work on bottom-up civil society experiences, responses, and resistance to this regulation. This forms the broader background against and with which the interviews with participants are critically situated in subsequent empirical chapters.

2.1. Development from the Soviet Period

In the Soviet Union, formal associational life was largely state-controlled sphere which obliged citizens to participate (Evans, 2006; Ljubownikow, Crotty, & Rodgers, 2013; Rose, 1995). State government managed 'public' or 'societal' organisations (*obshchestvennye organizatsii*), greatly restricting their capacity to articulate critical public interests (Evans,

[23]Putin's presidential terms are as follows: first term 2000-2004, second term 2004-2008, third term 2012-2018, fourth term 2018-present. Between his second and third presidential terms, Putin was officially Prime Minister (2008-2012).

2006). While some ad hoc organisations did grow up, those which were non-oppositional were often then centralised and organised by the state; the Timurite movement (*timurovskoe dvizhenie*) is one example (Balakirev, 2015; Kadykało, 2011). Official organisations, including trade unions, the Komsomol, and the All-Russian Societies of Deaf People (VOG), Blind People (VOS), and, eventually and despite its original genesis (Section 4), Disabled People (VOI), were subordinate to the state (Evans, 2006). There were dissident movements which acted independently and in opposition to the state. However, these movements were relatively isolated from mainstream society and faced harsh repression (Evans, 2006; Pape, 2014; Phillips, 2009b). With perestroika, new opportunities arose for informal groups, which were founded in different regions of the Soviet Union (Berezovskii & Krotov, 1990) backed by Gorbachev's socialist pluralism (Henderson, 2003). However, many of these informal groups stopped functioning with the end of the Soviet Union, given that their existence was largely motivated by protest against the regime.

Although collective organising, latent to different degrees, took place over the Soviet period, the collapse of the Soviet Union saw a rapid growth of a 'new institutional form': the NGO (Ishkanian, 2008, p. 34). Non-coercive associative life in different forms, as well as and beyond NGOs, also developed at this time. However, NGOs were the main organisational form targeted by donors who sought to develop civil society apparently in opposition to the Soviet 'radical "flattening" of society [...] in which diversity of opinions and expression of interests were circumscribed' (McIntosh Sundstrom, 2005, p. 3). Foreign involvement in the 1990s was often driven by donors' association of the development of a diverse civil society and strong civic participation with a successful transition to a functioning democracy (Linz & Stepan, 1996).

This link has been problematised and unpicked in practice (Babajanian, Freizer, & Stevens, 2005; Lewis, 2008; Ziegler, 2010); civil society may also be co-opted by the state to legitimise authoritarianisms (Giersdorf & Croissant, 2011; Lorch & Bunk, 2017). Spires suggests that it cannot be assumed 'that NGOs in an authoritarian state, even independent grassroots organisations, are working towards democratic purposes' (2011, p. 35). Nevertheless, it was often on this basis that foreign donors were involved with developing civil society. This donor framing holds the seeds of the discursive link now used by the state to delegitimise civil society organising with foreign involvement as political; I discuss this further below.

Despite their claimed goal of opposing the flattening of dissenting opinion during the Soviet period, foreign funders have been criticised for also flattening of civil society. Their funding has been characterised as creating a 'supply-driven' civil society orientated towards themselves (Henderson, 2003; Pape, 2014), seeking to impose irrelevant, external programmes and modes of action, and favouring the construction of vertical links between funder and supported organisations which did not extend into the wider population (Jakobson & Sanovich, 2010, p. 286; Ljubownikow et al., 2013, p. 158). NGOs of this period have been characterised as top-down and donor-driven (Ishkanian, 2008), in competition for funding and therefore isolated (Crotty, 2006), distant from the needs of Russian society (Henderson, 2002; Klose, 2000; McIntosh Sundstrom, 2005), lacking in contextualisation (Crotty, 2003), dominated by elites (Henry, 2006; Ishkanian, 2008; Ljubownikow et al., 2013), and increasing the divide between activists and society at large (Henderson, 2002). Even as they 'may have had the ability to act as a counter-weight to the state (Taylor 2006), [...] they did not facilitate bridging activity between the individual and the state (Richter 2002)' (Crotty et al., 2014). Their externally-imposed nature meant that NGO programmes were often of limited relevance to citizens' needs and experiences and, failing to map onto the realities of local situations, did not form new social actors (Leve in Bernal & Grewal, 2014).

However, even given this criticism, the lasting influence of the latent growth phase at the end of the Soviet period (Jakobson & Sanovich, 2010), and the proportionally limited interaction of foreign donors with the sector as a whole (Alekseeva, 2010), foreign donors and foreign-supported NGOs nonetheless remained important minority actors. As such, they contributed to setting vectors and modes of action which influenced 'self-consciousness and positioning, language, and models of interaction with the state, donors, recipients, and broader society' (Jakobson & Sanovich, 2010, pp. 234–235). These modes arguably continue into the third, rooted period which developed from the late 90s and early 2000s (Ljubownikow et al., 2013).

The third 'rooted' (Jakobson & Sanovich, 2010, p. 289), bottom-up (Ishkanian, 2008, 2015) phase is differentiated from those prior as a period in which foreign actors are no longer the primary drivers of civil society's development (Salmenniemi, 2010). Instead, 'import substitution' (Jakobson & Sanovich, 2010, p. 279) develops a 'civil society *po-russki*' (Ljubownikow et al., 2013, p. 155). This is not to deny the existence of both Russian and foreign-funded NGOs which were well-contextualised and responsive to bottom-up needs

before the onset of the third phase. These NGOs existed with 'success achieved, as a rule, when the vectors of forces generated outside and within Russian society coincided' (Jakobson & Sanovich, 2010, p. 289). Before outlining contemporary regulation of civil society and CSO activity in the third period, I first step back to contextualise civil society within Russia's contemporary civilisational discourse (Tsygankov, 2016).

2.2. Legitimations of Civil Society

2.2.1. Russia's regime legitimation

In the period from Putin's first election in 2000 to his most recent re-election in 2018, Russia became more authoritarian by indicators including restricting press freedoms, electoral competition, and public gatherings and expression (Colton, 2007; Fröhlich & Jacobsson, 2019; Goode, 2010; Sperling, 2014). Various descriptors have been used for current regime type, each suggesting that is it 'a less than fully democratic political system' (Sperling, 2014, p. 31; see also: Levitsky & Way, 2010). To take one of these, Russia is defined as comparatively stable electoral authoritarian regime, with limited or managed political contention (Cheskin & March, 2015; Gill, 2012; Robertson, 2011; Ross, 2011). Electoral authoritarian regimes are defined as holding elections 'marked by an uneven playing field, based on: formal and informal rules that construct prohibitively high barriers to participation; sharply unequal access of competitors to financial and media resources; abuses of power by the state apparatus for the sake of maximising incumbent votes irrespective of voter preferences; and (often but not always) multiple instances of electoral fraud' (Gel'man, 2015, p. 7).

Against this background, Russia has used regime legitimation strategies which foreground conservative modernisation (Chebankova, 2015) and patriotism. The latter has been used as 'a means of legitimation' which 'seeks to fuse state legitimacy with regime legitimacy, collapsing the distinction between state and regime and threatening the people's sovereign choice by associating regime failure with state failure' (Goode, 2016, p. 421). Patriotism is linked with the mobilisation of spiritual and moral values which are claimed as traditional (Østbø, 2017; Stepanova, 2015). Thus, despite a secular constitution, Orthodoxy is mobilised as an important part of traditional Russian culture and being (Kovalskaya, 2017). Federal Law No.125 'On the Freedom of Conscience and Religious Associations' (1997) recognises Christianity, Islam, Buddhism, and Judaism 'as "respected religions"' with a long history in

Russia and 'mentions "the special role of *Orthodox* Christianity"'(Kovalskaya, 2017, p. 157, emphasis in original). However, Kovalskaya finds both that the Russian Orthodox Church has increasingly cooperated with the state and that Islam's definition as 'respected' and indeed 'traditional' depends on cooperation with and loyalty to the state (2017). Russian traditional values are opposed to those of 'the West' and feed into discourses of anti-Westernism (Østbø, 2017).

Militarism has also been used as a tool in building national identity in state discourse (Sperling, 2003, 2009) and popular culture (Gillespie, 2005; Norris, 2012), as well as in educational programmes (Konkka, 2020). This has been often associated with victory in the Great Patriotic War (*Velikaia Otechestvennaia voina*) (Mijnssen, 2010; Wood, 2011). Russia has mobilised this victory as a cornerstone of its post-Soviet national identity (Gudkov, 2005; Wolfe, 2006) in a pervasive politics of memory which 'stretches from official discourse and diplomatic rhetoric to mass media, cultural production (films, plays, even operas) and academic history writing' (Fedor, Lewis, & Zhurzhenko, 2017, p. 15). While Russia's foreign policy may not be nationalist per se (Laruelle, 2015b), ideas of nation are an important part of the regime's legitimisation project. Patriotic narratives synthesise values including 'the exceptionality of Russian culture and traditions, and the related importance of resisting alien (not exclusively foreign) influences to safeguard Russia's present and future; and increasingly the substitutability of Russian (*Rossiisskii*) citizenship with Russian (*russkii*) ethnicity' (Goode, 2016, p. 429).

These legitimation strategies have also foregrounded a hegemonic hypermasculinity (Wood, 2016), particularly through association with militarism and the invocation of 'traditional' roles and values (Foxall, 2013; Sperling, 2014). This mix has seen flashpoints such as the Federal Law No.135-FZ 'For the Purpose of Protecting Children from Information Advocating for a Denial of Traditional Family Values', or so-called 'gay propaganda law', passed in 2013. The 'denial of traditional family values' is positioned as a threat to social stability (Persson, 2015), often coming from a degraded Europe and an 'imperialistic West' which wishes to threaten and destabilise Russia (Bartholomew, 2014). Sperling has argued that 'gender norms and sexualization have been used in political advertising as a means of bolstering Russia's increasingly nondemocratic political regime' (2014, p. 28). The connection of such a dominant expression of hypermasculinity with political legitimisation has implications for what civil

society action is identified as legitimate and what becomes discursively threatening (Section 2.2.2.).

The period has also seen closer regulation of public space and speech, mass media, and collective organising. The timing of the amendments to laws around public organising can be associated with the 2011-2013 waves of 'for fair elections' (*za chestnye vybory*) protests. The Russian government was concerned to restrict organising which could lead to a 'colour' revolution, like those which occurred then in other authoritarian states (Fröhlich & Jacobsson, 2019; Horvath, 2013). The Russian government remains concerned to control protest for regime change. It has tightened the regulation of the use of public space for collective, non-state events, notably amending Federal Law No.54-FZ 'On Meetings, Rallies, Demonstrations, Marches and Picketing' several times since 2012 to make it harder to legally organize public events (Fröhlich, 2019). Furthermore, there are state controls to access to print and TV mass media on federal and local levels (Gehlbach, 2010).

2.2.2. (De)legitimised roles for civil society

State management of civil society has increased alongside and via other restrictions of public space and speech (Fish, 2005). While the regional level presents a complex picture (Salamon et al., 2020; discussed further below in Section 2.3.), on a national level this control has taken two overall forms. Firstly, the legitimisation of CSOs as a partner of the state, particularly in supporting social welfare provision. Secondly, the delegitimization of organising judged political, often operating through a link with foreign threat. In this section, I present these developments in more detail, as they form the broad lines dividing legitimised from delegitimised civil society. I also argue that the state's use of binary discourse does not mean that it is experienced in this way by civil society actors. My empirical research then nuances this division further by exploring, via disability organising, 'the creation of such categories and the moments in which they "fail to hold"' (Kafer, 2013, p. 10).

Russia's neoliberal redrawing of citizenship (Hemment, 2009) legitimises civil society as a state partner in responding to legitimised social welfare needs. These activities have the double role of responding to state welfare retrenchment (L. J. Cook, 2013) and legitimising the state (Fröhlich & Skokova, 2020). As described in contexts of authoritarianism more broadly, civil society thus has a role in filling gaps and weaknesses in state provision (Lorch &

Bunk, 2017; Spires, 2011; Teets, 2014) and monitoring need and discontent (Lorch & Bunk, 2017; Lorentzen, 2013). Legal and discursive steps have both supported this. Legal regulation has both generally placed the state in a more managerial position over registered CSOs and has developed specifically around the CSO as a social partner of the state. For example, the Federal Law No.18-FZ 'On Introducing Amendments into Certain Legislative Acts of the Russian Federation', commonly known as the 'NGO law', passed in 2006 gives the state increased powers of scrutiny over the financial and administrative workings of NGOs (Crotty et al., 2014) and permits the state to send representatives to NGO meetings (Maxwell, 2006). The legislation greatly increased the reporting and regulatory burden placed on organisations, making annual funding and activity reports obligatory and demanding re-registration with the state registration authority (Pape, 2014, p. 31).

Meanwhile, the new legal form of the 'socially oriented non-profit organisation' (*sotsial'no orientirovannaia nekommercheskaia organizatsiia*, SONKO), established in 2010 (Salamon, Benevolenski, & Jakobson, 2015; Article 31.1 of Federal Law No.40-FZ of April 5, 2010), gives this concrete framework. CSOs may now apply to receive state funding for providing necessary social services in certain forms and to certain groups (Bindman, 2015; for a list of the diverse activities which may fall under the scope of the law, see: Salamon et al., 2020, p. 4). Subsequently, a further legal status was developed for which SONKOs can apply: 'provider of socially-useful services' (*isponitel' obshchestvenno poleznykh uslug*). This status entitles a SONKO to prioritisation in receiving various measures of state support.[24] The state has thus encouraged, and clearly legitimised, so-called socially oriented CSOs via a number of financial and other support programmes (Salamon et al., 2015). Fröhlich and Skokova (2020) argue that the state makes double use of such funding for regime legitimation. On one hand, it legitimised CSO activities in specific, restricted, and non-threatening spheres and transmits state-led conservative discourse. On the other, it supports CSOs to contribute to public welfare as a (subordinate) partner of state.

A series of statements by Putin and other prominent figures have emphasised this compliant partnership relationship. In interviews for this research, participants themselves referred to

[24]See: Decrees of the Government of the Russian Federation of 27 October 2016 and 26 January 2017, respectively: No.1096 'On the approval of the list of socially useful services and criteria for assessing the quality of their provision' and No.89 'On the register of NGOs who are providers of socially useful services.'

key speeches from Putin as legitimising CSOs more widely as valid partners for state institutions. In another example, Putin is quoted as saying that, 'volunteers are becoming partners of the state' ('*volontyory stanovyatsia partnyorami gosudarstva*') (Gorlova, 2019, p. 4) at a ceremony celebrating volunteering in Russia in 2017 and 2018 was declared 'The Year of the Volunteer.' At the All-Russia Volunteer Forum 2015, Putin speaks about developing volunteering, as might be expected. However, he is quoted as adding that doing so is especially relevant going towards the 70th anniversary of the Great Victory ('*osobenno aktual'no v preddverii 70-letiia Velikoi Pobedy*') (Balakirev, 2015, p. 19). The quote suggests a discursive link between serving in war, including through volunteer movements, and being a present-day volunteer; both are constituted as projects which serve to build the nation.

These examples are contextualised by wider analysis suggesting that official discourse nationalises civil society (Belokurova, 2010), framing it as a legitimately a 'state-supported project allegedly for the benefit of "the people" and Russia as a nation' (Fröhlich & Jacobsson, 2019, p. 1152). The state thus does not normatively locate CSOs as either ontologically distinct from itself or as a location of resistance. Still apparent are legacies of *gosudarstvennost'* (Labigne, Kononykhina, & Mersianova, 2015, p. 19), or the declared loyalty of CSOs to government as central to any relationship (Fröhlich, 2012, p. 371; Golenkova, 2010). The state has been argued to take a binary approach to civil society (Fröhlich, 2012; Pape, 2014; Robertson, 2011; Salamon et al., 2015; Skokova, Pape, & Krasnopolskaya, 2018). According to this, on one hand, loyal civil society actors are engaged in solving legitimised social issues, which broadly fit into current policy and do not form discursive challenges, particularly to 'traditional' values as framed by Russia's conservative civilisational discourse described above (Section 2.2.1.). On the other hand are delegitimised actors whom the state characterises as bent on intervention in state affairs and political change (Belokurova, 2010; Robertson, 2009).

In particular, focusing on the delegitimate side of organising, scholars have noted 'repressive policies penalizing receipt of foreign assistance or too overt pursuit of human rights' (Salamon et al., 2020, p. 2; see also: Daucé, 2014; Evans, 2006; Javeline & Lindemann-Komarova, 2010). Much discussed as a key example of this, the so-called 'Foreign Agents Law' was adopted in 2012 (Federal Law No.121-FZ of 20 July 2012 'On Introducing Amendments to Legislative Acts of the Russian Federation regarding the Regulation of the Activities of Non-Commercial Organisations Performing the Functions of a Foreign Agent'). This law mandates the

registration as 'foreign agents' (*innostrannye agenty*) of CSOs who receive foreign funding of any amount and are engaged in political activity (*politicheskaia deiatel'nost'*).

After protest over the vagueness of the definition of 'political', in May 2016 the State Duma amended the law to define political activity as 'any kind of public activity' (Fröhlich & Jacobsson, 2019, p. 1152). The law also specifies that 'political activities do not concern, for instance, culture and art, health care and healthy ways of life, maternity assistance and child care, social support of the disabled, and charity' (Kulmala, 2016, p. 207). It is this naturalised depoliticization of 'social support' of disabled people which I question, and whose effects and limits I explore. While these areas are named as normatively not political, 'political activity' remains a floating signifier or a 'flexible discursive instrument' (Flikke, 2015, p. 9) which civil society actors perceive may be applied as and where the state choses, if the state decides that a behavioural line has been crossed. It is a tool of control with a chilling influence (Robertson, 2011), also affecting civil society which is normatively identified as non-political (Chapter 5). This is consonant with the broader identification of civil society actors' perceptions of 'formal rules, institutions, and rights' as not worthy of trust and 'arbitrary tools' (Clément, 2008, p. 72).

One mechanism through which the delegitimization of civil society actors operates is a discursive shorthand which selectively collapses the distinction between foreign and political organising in Russia, equating foreign civil society involvement with political threat: 'non-state public action, from civic education to mass demonstrations, can now be rendered as influenced by outside forces intending to harm Russia and its people' (Fröhlich & Jacobsson, 2019, p. 1153). This appears to be part of the re-nationalisation and restriction of civil society which occurs also beyond Russia, in response to period of strong foreign involvement (Howell et al., 2008). Russia has expelled high-profile international and supranational organisations; 2012 saw the expulsion of both USAID and UNICEF. For both, the reason provided was that Russia is no longer a recipient state, but rather a donor state. Additionally, USAID was criticised for attempting to 'influence the political process through the distribution of grants, including elections of different levels, and civil institutions' ("Comments of A.K. Lukashevich, Official representative of the Ministry of Foreign Affairs of Russia on the termination of activities of the United States Agency for International Development of the Russian Federation," 2012, n.p.).

The question of securing funding is a pressing concern for civil society actors. While Russian CSOs have therefore become more cautious about receiving foreign funding, international funders too are in retreat. The Russian state has developed funding programmes to replace this foreign funding, simultaneously using it as a tool of control over the sector (Gilbert, 2016; Jakobson & Sanovich, 2010; Salamon et al., 2015; Skokova et al., 2018). Thus, as initially outlined above particularly in reference to SONKOs and their funding, Fröhlich and Skokova observe that funding is used as an 'instrument of state governance […] to curb civil society development in a way that contributes to state legitimacy' (2020, p.1). Finally, the contemporary management of Russian civil society aims to contribute 'to regime stability by coupling public funding for CSOs with a state-led legitimacy discourse that supports the state's status-quo by emphasising conservative values, traditions and civilisational traits of the Russian people' (Fröhlich & Skokova, 2020, p. 2), as presented above (Section 2.2.1.).

State strategy suggests a strong benefit to an extra-political framing of activity (Kulmala, 2016, p. 207). It also strongly negatively associates the political with external influences, and with a risk to the security and stability of Russia. As well as LGBTQ+ organising, environmental and feminist activities have also been targeted by state sanction (Bindman, 2015; Sperling, 2014). The identification of threat demonstrates the role of the discursive norm as disciplinary. Feminist and gender-based organising challenge norms of gender and masculinity and are delegitimised (Sperling, 2014). In contrast, disability organising, as dominantly (mis)recognised, is normatively non-threatening; while disabled people disrupt the norm, they are dominantly understood as doing so in ways which do not emphasise their agency. Unlike other forms of organising, they are not subject to an a priori identification as politically threatening; I explore why and how this operates through my empirical work (Chapter 6).

CSOs are incentivised to position themselves as partners of state engaged in responding to state-legitimised, social issues. CSOs who do not position themselves in this way risk discursive exclusion, limited access to public space, and the repression of their activities (Robertson, 2011). In this context, some describe a bifurcation in civil society between 'well-resourced NGOs' which are 'agents of social policy, rather than informing or challenging it' and 'those without funding [which], although independent of the state, will struggle to engage in any activity at all' (Crotty et al., 2014, p. 1265). In broad lines, then, the state does create a discursive binary between legitimised and delegitimised roles for civil society.

However, the empirical experiences of this discursive binary and its application is far more nuanced. Research has not always presented this nuance. For example, the government's 'double strategy' is characterised as not 'leav[ing] *any* space of autonomous civic action, but rather requires civil society organisations to be compliant implementers of state policies' (Pape, 2014, p. 31, emphasis added). This characterisation particularly operates through emphasis on public, apparent actions, rather than the meaning-making and intent of actors, and the treatment of contention and service provision as in binary, and exclusive, opposition. According to the latter opposition, the government creates an environment in which 'room for civil action lies primarily outside the arena of political contention' (Fröhlich, 2012, p. 372) and CSOs are channelled into 'basic charity and service provision', which is not identified as political or possibly contentious (ibid., p.173). In response, it is necessary to explore why research on Russian civil society has reached this picture and some responses which aim to offer further nuance, recognising the potential political import of service provision and apparent 'charity.'

2.3. CSO Activity and Trends in Research

In this section, I first present an overview of forms of civil society activity upon which the bulk of research has focused in the third, rooted period. I demonstrate the limitations of how rights-based and political organising has been understood and the influence on the literature. I then present a more recently developing body of literature, which seeks to correct previous emphases in the literature by investigating social welfare responses and less visible, infra-political action. I argue for the importance of further research focusing particularly on the apparently legitimized 'social welfare' side of the state's binary, which remains under-researched. Although the state may use such a discursive binary, how civil society actors understand and instrumentalise this context requires further investigation.

'Social welfare CSOs' (Kulmala, 2016) or 'socially-orientated NGOs' (Bindman, 2015) are defined as focusing on the provision of social work and the delivery of social services. They now make up the largest group of CSOs in Russia (Cheskin & March, 2015; L. J. Cook & Vinogradova, 2006, p. 28). However, the bulk of research on Russian civil society has focused on internationally-funded CSOs engaged in overtly-claimed human rights and political organising, to the exclusion of other forms of organising (Bindman, 2015; Kulmala, 2016; Salamon et al., 2020). Western political and media discussion on Russian civil society has also

emphasised human rights groups (Evans, 2012). Salamon et al. summarise the state of the literature by noting that, 'prominent Western accounts of the Russian non-profit sector have tended to portray a sector composed chiefly of human rights, environmental, and democracy-promotion organizations that emerged, in the aftermath of the collapse of the Soviet Union, with support from Western funders and now seem threatened by widespread "closing spaces" for civil society' (2020, p. 4). Research which nuances this view of constrained civil society action tends still to look deeper into the 'political' side of the discursive binary of the state, presented above, rather than exploring the apparently 'social' side (Hemment, 2009, 2012; Laruelle, 2015b).

Much of this work has grown out of a democratisation focus in the wake of the end of the Soviet Union, which has been interested in investigating an active and diverse civil society as a force for strengthening democracy (Fröhlich & Skokova, 2020; Lyytikäinen, 2013).[25] This has resulted in research that has emphasised 'high-visibility activities with consequences for institutionalised social structures' (Kendall & Knapp, 2000, p. 11) and overwhelmingly looked at CSO relationships with the state (Spicer et al., 2011) to conclude that overtly rights-based activity is highly constrained (Evans, 2006; Henderson, 2002b; Quigley, 2000). Approaches focusing on such federal-level, state-focused CSO activity may elide a pervasive form of protest in electoral authoritarian regimes: disguised, everyday forms of resistance. These accounts have been criticised for offering a 'caricatured view of Russia' with 'exaggerated claims about Russia's roll-back of democracy' (Cheskin & March, 2015, p. 263; see also Javeline & Lindemann-Komarova, 2010), as well as for incorrectly identifying apathy and passivity (Greene, 2014; Salamon et al., 2020).[26] The result is the mischaracterisation of certain people as lacking a political life (Scott, 1990, p. 199).

This is not to discount the important body of work which has been generated through a focus on overtly human rights-based organising, which is hardly all caricatural or necessarily linked to a democratisation framework. Particularly research on gender and feminist organising, for example, provides an important foundation for considering aspects of contention and

[25]For a fuller overview of how democratization approach has influenced the foci of literature on Russian civil society, see Lyytikäinen (2013).

[26]Greene (2014) and Salamon et al. (2020) criticise accounts which present Russians as generally passive or apathetic. For accounts suggesting passivity, see for example: Blum (2006), McFaul (2003), Wallace (2003), and Rimskii (2008).

negotiations of (de)legitimised identities and themes for organising (Sperling, 2014). Work on state-organised youth groups also has demonstrated the agency of participants in going beyond the practices expected or advocated for by the state (Hemment, 2012; Laruelle, 2015a).

However, general critiques of democratization-based research have developed the field in two important ways. Firstly, problematisation of the link between democratisation and civil society (Babajanian et al., 2005; Lewis, 2008; Ziegler, 2010) has also seen the development of literature which explores the kinds of civil society which authoritarian state encourages or which becomes rational under ad hoc and unpredictable mobilisations of state power (Clément, 2015; Fröhlich & Skokova, 2020; Greene, 2014) and turns towards infra-political organising under these constraints (Fröhlich, 2019; Fröhlich & Jacobsson, 2019). Secondly, criticism of the under-researched nature of social welfare organising has encouraged exploration of SONKOs and their relationships with state (Bindman, 2015; Bogdanova & Bindman, 2016; Johnson, Kulmala, & Jappinen, 2016; Kulmala, 2016), as well as exploration of regional differences which seeks to nuance national-level conclusions (Salamon et al., 2020). Both of these trends have been brought together notably in the work of Fröhlich and Skokova, which looks at the political dimension of state support for CSOs 'providing social services and targeting social problems' (2020, p. 3) by arguing that, '[w]hile non-state social welfare delivery is often accessed as an apolitical sphere not posing a threat of political contention for the regime, […] state support for CSOs has indeed a political dimension' in its transformation of civil society (ibid., p.3). This latter work looks at the political utility of this construction from the point of view of the state; we also need to look at the political utility of claiming a social identity from the point of view of civil society actors, as I propose to do here (Chapter 5).

These literatures problematise the picture of Russian civil society as subordinated or 'quiet' (Salamon et al., 2020). Concepts of infra-political action also problematise the separation between rights-based and welfare-based organising. In the previous chapter, I argued that this distinction is both theoretically and empirically problematic. Building on feminist and (new) social movement literatures, I outlined an enlarged understanding of political action, which does not equate the private sphere with an apolitical sphere. This suggests that rights-based and political organising can be identified across a range of spheres, including that which

is overtly presented as service provision. Moreover, research focusing on less structured and infra-political organisation in Russia has identified several factors which mean that we might expect civil society organising in Russia to take liminal, fluid, and depoliticised forms. Both Fröhlich and Jacobsson (2019) and Greene (2014) argue similarly that a strong awareness of their 'political surroundings and of the opportunities and limitations those create for collective action' (Fröhlich & Jacobsson, 2019, p. 1154) means that '[o]pposition, then, reflects the power structure that provokes it: individualised, ad hoc, opportunistic, and unstructured' (Greene, 2014, p. 221). Clément discusses the 'rational choice' of performing an 'appearance of subordination and loyalty', arguing that, where those criteria are respected, 'one can exercise power as one wishes' (2008, pp. 70–71). This suggests a pathway for research which looks at what lies behind the appearance of subordination and loyalty, particularly given the value of the apparently legitimised 'social service' framing as part of this performance. It also indicates the importance of exploring further the limits and boundaries which civil society actor perceive to maintain that appearance.

Despite this ground, research is largely yet to bring developments in social welfare CSOs and infra-politics together. That is to say, on one hand, much of the work on civil society organising responding to social welfare need again focuses on relationships with state (Bindman, 2015). Where work resituates developing social service provision as political, it identifies the political role as that of the state in this transformation (Fröhlich & Skokova, 2020). On the other, much of the work on infra-politics looks at claims which are not related to social service provision. Thus, the possible infra-political role of civil society actors within social service provision and beyond is not explored.

To bring these two sides together means exploring apparently legitimised, social welfare organising through an awareness of infra-political action with the aim of analysing resistance both within and outside of state institutions of power through actors' claimed intent. The previous chapter provided a theoretical argument as to why disability organising is a productive sphere to examine this. The following section presents the production of disability in Russia, relating it back to the implications of disability's misrecognition as a social welfare issue.

3. Disability

In this section, I present Soviet and post-Soviet Russian policies around and responses to disability. By presenting only policies which more directly address disability here, it is not my intention to suggest that other policies do not also affect disabled people's lives; that would replicate the institutional misrecognition discussed below (Section 3.2.) (see also Iarskaia-Smirnova, 2011). However, the policies presented are reflective of understandings of disability, themselves contextualised by the regime legitimation discourses discussed above (Section 2.2.1.) and examined in relationship to disability organising below (Section 4). These wider societal attitudes to disability are also presented through and alongside key policies.

My presentation of neither of these is exhaustive. However, given that this research aims to explore the implications for civil society organising of disability's construction as a charitable and social welfare issue, the outline provided here aims only to be enough to demonstrate how disability has been constructed and dominantly understood. This shows how disability organising might within the legitimised sphere of organising and begins to suggest how the recognition of disabled people is limited by these restrictive legitimising discourse; this is the groundwork upon which I build theoretically and empirically through my research. The focus of this section is to sketch a picture of what disability as a category should do or look like according to the present-day policies of the Russian state, as well as to contextualise these policies in relationship to both disability theory and their historical development.

3.1. Soviet Period

In the Soviet Union, disability was regarded 'exclusively as an individual and medical problem rather than a social one' (Mladenov, 2016, p. 108), associated with loss of labour capacity (Phillips, 2009b; Thomson, 2002), and misrecognised through an interrelated combination of paternalism, segregation, medicalisation and productivism (Mladenov, 2015). The formal welfare system which was mainly delivered via state-owned enterprises (Szikra & Tomka, 2009), each acting 'as a micro-welfare state in itself' (Teplova, 2007, p. 289). Given that labour formed a mechanism of state control, lack of participation was not only counter to state rhetoric, but simultaneously both constituted a threat and removed a person from typical formal channels for accessing resource distribution (Tchueva, 2008, p. 106). The state system for those whose 'life situations [were] not constituted in the labour market' took a strongly centralised, institutionalised form (Alber, 1995, p. 133): state social care services were largely limited to long-stay residential institutions for various categories of citizen (older people,

disabled adults, children left without or removed from parental care, disabled children)' (Thomson, 2002, p. 110).

Closed residential institutions demonstrate extreme segregation from the wider population, as well as paternalistic total control and management of residents' lives. Residence in these institutions was encouraged by medical professionals above living at home and 'framed as a "right" accorded to vulnerable citizens by the beneficent Soviet state' (Phillips, 2009b, n.p.). Forcible placement in institutions was also a response to suspicion 'for "disrupting social norms" (e.g. begging or "wandering about" without permanent residence)' (ibid., n.p.; see also Iarskaia-Smirnova & Romanov, 2002, p. 325); the residential institution was thus an instrument of control in the face of the disruptive 'stranger' (cf. Hughes, 2010). Furthermore, medical services were hard to access without accepting permanent institutional residence (Dunn & Dunn, 1989, p. 209). A disabled person living at home was seen through a productivist lens as necessitating caring responsibilities from others which resulted in losing further members of the workforce (Golemanov & Popov, 1976, p. 32; cited in Mladenov, 2016). Disabled people not resident in such institutions still remained largely segregated, including via employment in separate workplaces for disabled people only and because of the inaccessibility of the built environment within and beyond the home. As disability was understood as individual deficiency, the state did not invest in overcoming barriers in the built environment (Mladenov, 2016).

Segregation also operated on an ideological level. The productivist slogan 'those who do not work shall not eat!' encapsulates the stigmatisation of social assistance (Zaviršek, 2014). Disability was constructed as a morally suspect category of pathologized dependency (Hartblay, 2014a) again identified through medicalised assessment of ability to participate in the labour force (Mladenov, 2011; Phillips, 2009b). Against the Soviet project of modernity and transformation, including through a 'cult of science' (Tamás, 2011), bodily control (Starks, 2008), and 'near fetishization of bodily strength, functioning and ability' (Rasell & Iarskaia-Smirnova, 2014, p. 5), disability was an individual failing, medically defined, and met with exclusion and erasure. The definition of disability as loss of work capacity meant that children born with congenital disabilities were long unrecognised as disabled, and thus unable to access state provisions for disabled people (Shek, 2005, p. 386); '[n]ot until 1967 was all-Union legislation adopted providing benefits to children with disabilities, and the term "child-

invalids" (*deti-invalidy*) emerged only in 1979 after the United Nations declared that year the International Year of the Child' (Phillips, 2009b, n.p.).

The much-cited response of a USSR official on being asked whether Russia would participate in the inaugural Paralympics – '*V SSSR invalidov net!*' ('There are no disabled people in the USSR!') (Fefelov, 1986) – demonstrates the degree of this public erasure. Thus, 'materially conditioned invisibility facilitated and was legitimised by ableist denial' (Mladenov, 2016, p. 110). Another form of invisibility was integration, possible only where 'disability [was] erased' (Stiker, 1999, p. 152). The extent of continued invisibility is addressed by present-day civil society use of the slogan '*my est'*!' ('we exist!') (Chapter 3, Section 3.3.), reflecting a continued situation where 'continuing to exist, to move, and to breathe are forms of resistance' (Butler et al., 2016, p. 26). Looking beyond the Soviet period, 'the medical-productivist system of classifying and assessing disability has proved as resistant to change after 1989 as segregated service provision' (Mladenov, 2016). In the next section, I present some continuities and discontinuities in disability provision.

3.2. Restructuring and the 'Post-Socialist Disability Matrix'

With the end of the Soviet Union came 'a collapse in [welfare] services' quantity, quality and accessibility' (Thomson, 2002, p. 110). In the Russian Federation, most of the 1990s nonetheless saw the obstruction of 'the government's liberalizing reform program' and 'the retention of inherited welfare programs and structures [...] despite a deep and ongoing recession and market transformation' (L. J. Cook, 2013, p. 5). Liberal restructuring came towards the close of the decade and involved institutional reconstruction, privatization, and the introduction of market mechanisms. An outcome of these reforms was the individualisation of welfare services, as responsibility was transferred to individuals and their families (Polese, Morris, Kovács, & Harboe, 2014) in a conscious neo-liberal 'restructuring of state-societal relations and [...] redrawing of citizenship' (Hemment, 2009, p. 28).

In relationship to disability, Mladenov examines this restructuring to argue that negative aspects of both the Soviet system and neo-liberalization[27] have created an exclusionary

[27]I follow Mladenov in using Springer's term 'neoliberalization' (2013), rather than 'neoliberalism', for its emphasis that 'what is at stake are flexible global processes that constantly mutate by accommodating and appropriating local idiosyncrasies, agencies, and resistances – rather than a rigid global framework that is

double bind. On one hand, 'the legacy of state socialism has underpinned: segregated service provision; medical productivist understanding of disability for assessment purposes; denial of disability on everyday level; and weak disability organizing' (Mladenov, 2016, p. 104). On the other hand, neo-liberalization has driven 'retrenchment of disability support through decentralization, austerity, and workfare; stigmatization of 'dependency' through the discourse of 'welfare dependency'; responsibilization of disabled people; and depoliticization of disability organizations by restricting their activities to service provision and incorporating them in structures of tokenistic participation' (ibid., p.104).

I agree with both the idea of the double bind and with the general description of what neo-liberalization has driven. However, I agree with the latter only up to a point. The equation of service provision with the depoliticization of disability organising is problematic; its recurrence here suggests the exclusionary categorisation to which I have drawn attention in the previous chapter and above. This categorisation implies a failure to recognise certain forms of less-apparent, ambiguous resistance. It also implies a failure to investigate the potential for resistance from a position which is dominantly understood as depoliticised. This epistemic oppression, I continue to argue below (Section 3.3.), can be challenged by taking seriously both infra-politics and intent. First, here I discuss some of the continuities and discontinuities in the present government of disability, in a context where stigma and individualistic, medicalised approaches to disability remain widespread (Mladenov, 2016; Rasell & Iarskaia-Smirnova, 2014),

Among the most salient continuities, Russian maintains the three official groups of disability from the most 'severe forms of impairment' in Group I to the 'mildest' in Group III (Kondakov, 2018, p. 74). These groups, based largely on labour capacity as defined by medical professionals (Mladenov, 2015; Phillips, 2009a), govern access to employment and public support of various forms (Mladenov, 2016). These three groups were initially developed by the Bolshevik government as two: those who could work or who could potentially return to the labour force, and those who could not (Shilova, 2005, pp. 107–108). In 1921, these groups were developed into six categorisations, again based on work capacity (Shilova, 2005, p. 114). In 1923, these six groups were redeveloped into three. These three groups remain today, each

imposed, from the outside, on a passive, docile economic, and socio-political local reality' (Mladenov, 2016).

category both granting different entitlements and benefits (Madison, 1989; Phillips, 2010) and circumscribing a person's right to work and access to certain occupations (Kurlenkova, 2017). Broadly speaking, the first group is for those defined as unable to work and in need of constant care. The second group is for those defined as unable to work and in need of significant, though not constant care. The third group is for people defined as unable to carry out their former profession under normal working conditions, but who maintain some capacity to work either irregularly, or with a shortened working day, or in a different profession with fewer qualifications for entry. Disabled children (*deti-invalidy*) form a further category. Such categorisation has been characterised as producing 'pronounced demarcation' and friction among different disability groups, creating a hierarchy of disability and disrupting the development of shared identity (Phillips, 2009b, n.p.).

Another continuity is use of psycho-neurological residential institutions (*psychonevrologicheskie internaty*, PNI), convincingly analysed as total institutions (Goffman, 1961) by Klepikova and Utekhin (Klepikova, 2011, 2013, 2014; Klepikova & Utekhin, 2012). Segregation and invisibility continue too, underwritten by stigma, direct refusal of entry to putatively physically accessible public spaces such as cafés and exhibitions (Verbilovich, 2017, p. 206), and lack of accessibility in the built environment (Hartblay, 2015a, 2017), including many homes (Kikkas, 2001). Disability continues to be a stigmatised identity and form of lived inequality (Iarskaia-Smirnova, Romanov, & Yarskaya, 2015; Romanov & Iarskaia-Smirnova, 2010). Socially dominant understandings of disability include the prescription of the 'sick role', infantilization, and exclusion (Iarskaia-Smirnova et al., 2015). While media representations of disability have increased in number, there remains a tendency to creates stories of '"struggle and overcoming", to exploit the image of "heroes" and "victims", and to appeal to pity (*zhalost'*)' (Verbilovich, 2017, p. 209). Growth in media coverage has often been associated with 'journalists seek[ing] to cover "social problems"; frequently portrayed in this idiom, people with disabilities come to be seen as social problems themselves' (Hartblay, 2014b, p. 113). This is an example of visibility without recognition (cf. Chapter 3); disabled people are made visible in coverage which does not necessarily support their fuller recognition beyond disability as a monolithic, medicalised, social identifier.

Stigma is felt around personal and sexual lives of disabled people in particular, demonstrating the restricted image of disability as associated with medical deficiency and permanent

childhood (Iarskaia-Smirnova & Verbilovich, 2020). Mladenov argues that the de-sexualisation of disabled people is a form of discrimination sustained through medicalisation, patriarchal stereotypes, and the stigmatisation of difference (2014). State administrative institutions are likely to de-gender and de-sexualise disabled people by emphasising medically-understood impairment (Iarskaia-Smirnova, 2011). Based on anthropological work in residential institutions for both children and adults with intellectual disabilities, Klepikova describes the policing, denial, and suppression of sexuality carried out by volunteers and staff (2018). Verbilovich and Iarskaia-Smirnova directly link the 'revival of religious discourses, traditional family values and patriotism in the society as a whole' with the construction of a 'cultural taboo' and even the illegality of open discussions about 'sexuality, sexual education and sexual needs' (2020, p. 433); I discuss this further below (Section 3.3.) in reference to how disability is (de)legitimised.

Unlike these broad continuities of stigma, discontinuities are rather found in the realm of policy and legislation. Neo-liberalization includes retrenchment and monetisation of benefits, both of which shift responsibility to the individual and away from the state (Wengle & Rasell, 2008). Change in both legislation and, to a certain degree, juridical practice has also stemmed from Russia's signature of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) in 2008 and ratification in 2012.[28] The process of legislative harmonisation of Russian law with the CRPD was largely not started until after ratification. The Federal Law No.419-FZ 'On Amendment of Certain Legislative Acts of the Russian Federation on Social Protection of People with Disabilities Following the Ratification of the CRPD' was adopted on the 1 December 2014, introducing 'generic requirements into various pieces of legislation' (Bartenev & Evdokimova, 2018, p. 361). While 'none of the amendments introduced by the law implementing the CRPD specifically addressed the needs of persons with mental (psychosocial) or intellectual disabilities' (ibid., p.362), a law on education which entered force in 2013 removed the legal possibility of categorising a child as 'uneducable' (*neobuchaemyi*). Furthermore, 'many legislative norms relating to legal capacity and consent to treatment' (ibid., p.362) have been brought in line with the CRPD, and a state 'Accessible

[28]As per Federal Law of 3 May 2012 No.46-FZ 'On Ratification of the Convention on the Rights of Persons with Disabilities.' For an overview of the legislative implementation of the UN CRPD in Russia, see Bartenev and Evdokimova (2018, pp. 360–363); an overview of Russian courts' use and interpretation of the CRPD is provided in the same chapter.

Environment' programme, again based on the CRPD, was approved prior to CRPD ratification in 2011.

Despite this progress on paper, shadow reports from CSOs, academic research, and the UN Committee on the Rights of Persons with Disabilities' concluding observations ("Concluding Observations CRPD/C/RUS/CO/1," 2018) on the initial report of the Russian Federation ("Initial reports States parties due 2014, CRPD/C/RUS/1," 2014) all indicate both inadequate legislation and a gulf between legislative change and implementation. To name a few of the areas covered: educational access remains patchy and unequal (Anastasiou et al., 2020), particularly outside of larger cities (Kulagina, 2013, 2015) and in the case of higher and professional education (Kuchmaeva, 2016; "The All-Russian Public Organization of Persons with Disabilities All-Russian Society of the Deaf assessment of the CRPD articles compliance with the national law and the enforcement of its main provisions," 2018). Obstacles, including discrimination, are identified in accessing employment (Foundation for Support of Deafblind "Connection," 2018; "Hum. Rights Watch Submiss. Russ. to Comm. Rights Pers. with Disabil.," 2017; "The All-Russian Public Organization of Persons with Disabilities All-Russian Society of the Deaf assessment of the CRPD articles compliance with the national law and the enforcement of its main provisions," 2018); the state 'Accessible Environment' programme is criticised as not fully implemented or demonstrating 'gross violations, errors and lack of knowledge of building regulations pertaining to the accessibility of environment' via a '"tick-box" approach' (Foundation for Support of Deafblind "Connection," 2018); the lack of community-based services and inadequate financial support are associated with pressure from medical professionals to place disabled people in institutional facilities ("Hum. Rights Watch Submiss. Russ. to Comm. Rights Pers. with Disabil.," 2017); and concerns are raised over practices of abuse, including forced sterilisation, carried out against disabled people particularly in institutional facilities ("Concluding Observations CRPD/C/RUS/CO/1," 2018, pp. 4–5). These issues are reflected in my research, which also suggests that much organising occurs around the realisation of individuals' access to already-existing legal entitlements. The policies, legislation, and attitudes outlined above have seen disability as dominantly produced as form of individual, medical deficiency responded to with exclusion and stigmatisation. Below, I present how disability is expected to be performed or appear (i.e., legitimised expressions of disability) and how it becomes delegitimised.

3.3. (De)legitimised Disability

The brackets of (de)legitimised are a conscious borrowing from Schalk, who writes (dis)ability in the same way. By doing so, she 'gestures toward the mutually dependent nature of disability and ability' via 'the curve of the parenthesis' which visually suggests the 'mutable nature of these terms' and how their boundaries are 'uneven, contestable, and context dependent' (2017, n.p.). I have argued for defining disability in the same way in the previous chapter; here I focus on disability's (de)legitimisation, which is also contextual and negotiated.

Disability in general has been identified as a spoilt identity (Goffman, 1963). However, without invalidating this, disability is also legitimised where presented and made visible in certain forms. In Chapter 3 (Section 4.2.), I explored the restrictions in how disability may be made legitimately visible to a dominantly situated audience without creating confusion, mistrust, or total rejection (Siebers, 2004). This is disability as masquerade (ibid.), where ableism demands projections of disability which match up to figures of medical need, pity and charity, inspiration and overcoming, and 'rehabilitation' and erasure.

The previous section suggests dominant views of disability in Russia as a personal deficiency and medical problem, particularly in how state systems of categorisation demand it be assessed and made legible. Media representations of disability too often rely on discourses of 'overcoming' the 'tragedy' of disability through rehabilitation in order to fit into a norm (Verbilovich, 2017). Such erasure of disability may also operate through 'assimilationist performances that reinforce the dominant logics of Russian masculinity and heterosexism' (Hartblay, 2014b, p. 111). The stigma associated with identification as disabled is temporarily, partially, and unstably rehabilitated by association with other dominant identities and discourses. The impetus to align oneself with dominant norms also creates hierarchies among disabled people, who may disassociate or disidentify from other disabled people (Deal, 2003). Disability has greater potential to be legitimate where is acts as it is expected to (Goffman, 1963). While it may remain stigmatised, disability is thus masqueraded in a legitimised manner when its performance aligns with dominant discourses, minimising perceptions of threat.

Conversely, where disability exceeds the bounds of its dominant recognition, it becomes delegitimised. Given the restrictive options dominantly recognised as legitimately associated with disability, this happens in many areas. In one example, intimacies and sexual agency demonstrate the complexity of (de)legitimisation. Hartblay demonstrates how heterosexism may be mobilised to temporarily reposition a male disabled person within a masculine norm (2014b). However, 'sexualities and sexual practices of disabled people are rarely conceptualised simply as just being present' (Goodley et al., 2019, p. 986). Instead, they are either deficient or excessive (Liddiard, 2018; Wiedlack & Neufeld, 2016). Thus, even a disabled person's expression of dominant masculinity and heterosexism risks tipping into being perceived as excessive and threatening. Furthermore, expressions of sexuality challenge the dominantly legitimised association of disability with an infantilised person with little agency.

This is linked to the conservative regime legitimation discourses (Section 2.2.1.). The 'revival of religious discourses, traditional family values and patriotism in the society as a whole' and cultural taboo around discussions of sexuality add further complications (Iarskaia-Smirnova & Verbilovich, 2020, p. 433). This link emphasises heteronormative discourses, with 'able-bodiedness, heterosexism, and misogyny […] an acknowledged, integral part of the government's policies' (Kondakov, 2018, p. 83). Kondakov (2018) and Iarskaia-Smirnova and Verbilovich (2020) argue that disability therefore 'calls for non-normative sexualities' (ibid., p.435). This suggests that, regardless of its nature and form, disabled people's expressions of sexuality challenge the bounds of what a disabled person is dominantly expected to be and do. However, I would argue that such expressions of sexuality are delegitimised further when they exceed the bounds of heteronormative relationship. The so-called 'gay propaganda' law (Section 2.2.1.) associates non-normative sexuality with pathologized, 'medical deviance' (Bartholomew, 2014). Given that disability is already dominantly understood as a medical problem, it risks easy association with such pathologizing discourses. Indeed, Kondakov has argued that the state marginalises and isolates both homosexual and disabled people through similar discourses of contagion (2018, p. 75).

Disability, then, while dominantly understood as a stigmatised but depoliticised medical issue, may be easily delegitimised when presented otherwise. Disability is then a liminal 'state of affairs' (Tremain, 2005, p. 1) which, in its dominantly legitimised presentation, is drawn as a medicalised, individualised tragedy to be responded to with pity and charity. These areas

would align with state-legitimised areas of civil society organising and place disability on the legitimised 'social' side of its discursive binary (Section 2.2.2.). However, disabled people's identities and experiences clearly transgress and transcend the narrow space legitimised for them; here discussion of disabled sexualities has provided an example which simultaneously exceeds the bounds legitimised for disability and for civil society organising.

This demonstrates the importance of examining both infra-politics and intent. The concept of infra-politics points towards a space of ambivalent, dissimulated resistance where dominantly legitimised understandings of disability may be challenged. Kondakov suggests that in Russia 'political activism takes forms of semiprivate interactions rather than conventional open protest' (2018, p. 83; see also: Kondakov, 2014). In a context of delegitimization and stigma, he argues that these semiprivate interventions are deployed as forms of queer kinship politics (Kondakov, 2018). In a situation of restricted access to public space, one response is the enhancement of mutual relations and communities of care in private realms[29] (Iarskaia-Smirnova & Verbilovich, 2020; Kondakov, 2018; Phillips, 2010), 'without paying any particular attention to existing institutionalized powers or openly making demands to authorities' (Kondakov, 2018, p. 85). This argument supports my emphasis on infra-political resistance as an important mode of resisting disciplinary power under conditions of power imbalance.

Emphasising the importance of intent responds to the fact that actions may be misrecognised, itself a form of epistemic oppression (Toole, 2019); misrecognition is made likely particularly where action (and its theorisation) are read and created by a dominantly-situated audience and particularly where actions' ambivalence is part of their strategy. Exploring actors' intent emphasises that apparently legitimised presentations of disability may be instrumentalised to continue organising where institutional power is firmly tilted towards state institutions and organs. The apparent vulnerability of the construction of disability as a target for charity may thus be instrumentalised as a source of resistance (Chapter 6).

4. Disability and Civil Society

[29]Here I use the terms public and private normatively to identify spaces more clearly. However, in the previous chapter (Section 4.2.), I have discussed how disability implies a bending and blurring of what is normatively identified as public and private space.

What we can know about disability organising during the Soviet period is, as ever, limited by the power relations inherent to any knowledge production; characterisations of limited organising in their period could be challenged in much the same way that I challenge emphasis on large-scale, publicly visible action, or the identification of contemporary disability organising as apolitical. However, the picture of curtailed disability activism where '[i]ndependent organisations of disabled people were not permitted, even for welfare purposes, and press censorship prevented open discussions of conditions in residential institutions and failures in state disability provision' indicates the far-reaching state control of organising of the period (Rasell & Iarskaia-Smirnova, 2014, p. 6). While there was some revival of pre-revolutionary traditions of philanthropy, including making charitable donations to disabled people (Fieseler, 2005), this volunteerism was largely initiated 'through local Communist Party structures, the Komsomol (Communist Youth Organization), and the trade unions', rather than by grassroots groups (Phillips, 2009b, n.p.). Categorisation and differentiation between disabled people also served to individualise claims and stymy collective action (Tchueva, 2008). Dissident movements such as the Action Group to Defend the Rights of People with Disabilities in the USSR, founded in 1978, were punitively policed and largely collapsed after key members of its leadership fled to West Germany in 1982 (Phillips, 2009b; Raymond, 1989; White, 1999).

However, disability organising continued. 'Networking-oriented groups' facilitated written correspondence between disabled people (Phillips, 2009b). Published informational bulletins were tolerated on the basis of their self-censorship and lack of opposition to state disability policy (ibid.). Although the All-Russian Organisation of Disabled People (VOI) stemmed from grassroots activists, its founding in 1988 relied on both Gorbachev's reforms and VOI's absorption into the state; 'the Cabinet of Ministers of the Russian SSR coordinated the actual formation of the VOI, and the group's leadership included Party functionaries' (Phillips, 2009b, n.p.). This period also saw the instrumentalization of non-threatening framings, aligning with state discourse, to continue organising. Disability sports (while segregated) chimed with state promotion of *fizkul'tura* ('physical culture', or physical education) as improving citizens' health and discipline (Grant, 2013; Jungen, 2010) and thus discourses of 'overcoming' disability by subjugating an unruly body. Therefore, basing disability organising

on sports was ‘was one of the only ways to officially register a civic organization with state authorities’ (Phillips, 2009b, n.p.; see also: Indolev, 1998, p. 97).

Since the end of the Soviet Union, multiple CSOs have been identified as mobilising around disability (Bindman, 2015; Fröhlich, 2012; Klepikova, 2011; Kulmala, 2016; Rasell & Iarskaia-Smirnova, 2013; Thomson, 2006), producing a wide variety of claims (Fröhlich, 2012). However, disability CSOs have largely been looked at within the bounds of a welfare-mix framework focusing on service provision. They are often characterised as offering gap-filling services in response to weaknesses in state provision (Rasell & Iarskaia-Smirnova, 2014; Thomson, 2006). Thomson (2006) suggests that, given the urgent needs of those approaching NGOs for financial and practical support to receive medical intervention, medical and charitable models in fact remain the most productive and reflective of service users’ demands. Rasell and Iarskaia-Smirnova comment that ‘self-empowerment and living an independent life can sound very hollow when families face chronic poverty and states lack the resources to provide even basic education and healthcare, let alone personal assistants, occupational therapy and an accessible built environment’ (2014, p. 8). Although not in relationship to Russian in particular, in analysis of disability organising in the Visegrád countries (Poland, Czech Republic, Slovakia, and Hungary), Holland observes that ‘most disability activists and NGO leaders in CEE are currently focused more on service provision than advocacy or implementation of disability rights’ (2008, p. 544).

However, the reality of medical need does not imply the relevance of restrictive medical and charitable models. As I have argued in the previous chapter, other understandings of disability also recognise embodied realities of disability. Furthermore, also discussed in the previous chapter, uncritical building on medical and charitable models of disability creates the false equation of social welfare with charitable response, thus detaching the former from recognition as itself a potentially rights-based claim (Revillard, 2018). The opposition in presenting ‘service provision’ on one side and ‘advocacy or implementation of disability rights’ (Holland, 2008, p. 544) on the other therefore cannot stand, especially where a characterisation of state channelling into service provision is associated with a lack of resistance.

Empirical research in Russia has indeed found that CSOs have introduced modes of understanding and relating to disability which go beyond charitable and medical models of

disability, challenging dominant discourses (Klepikova, 2011, 2013, 2014) and aiming to hold the state accountable from below (Dimenshtein & Larikova, 2009). Phillips too notes that 'interactions [with various CSOs] have offered persons with disabilities opportunities for self-realization and new ways of perceiving themselves as citizens' (S. D. Phillips, 2009a, p. 278). This itself marks a discontinuity with the Soviet period; scholars argue that an important difference between socialist, totalitarian states and others in their treatment of disability lies in the fact that alternatives to the dominant interpretations of disability were not permitted in the former (Rasell & Iarskaia-Smirnova, 2013; Raymond, 1989). Further research too has specifically criticised the research agenda driven by democratisation and welfare-mix frameworks for the limited analysis of disability organisation it engenders, particularly for elision of its political role (Bindman, 2015).

This research forms an important foundation for my own in suggesting that CSOs may, in challenging dominant discourses of disability, form counter discourses understood by the state as threatening (Lewis, 2013) and that they play a political role. I build on this in three interlinked ways. Firstly, current research largely focuses on the political as expressed through state-civil society relationships, including evaluations of CSO success in lobbying state bodies at various levels for policy or legislative change (Bindman, 2015; Bogdanova & Bindman, 2016; Johnson et al., 2016; Kulmala, 2011). It therefore does not respond to the more wide-reaching understanding of resistance and contentious action, and the more individualised, non-apparent change examined by the literature on new social movements and infra-politics. Secondly, where disability organising is presented among a portfolio of other social service provision CSOs (Kulmala, 2016), analysis does not focus on dominant medicalising or charitable discourses around disability in particular, how these discourses may be instrumentalised, and how disability may be (de)legitimised in intersection with other discourses and identities. Thirdly and finally, where disability organisations are the sole subjects of investigation (Fröhlich, 2012), social movements and their associated communities, infra-politics, and actors' movements and cooperation between different spaces are each excluded. This neglects an important interaction between, on one hand, actors' perceptions of (de)legitimised demands and action and, on the other, the spaces and forms in which they are made. Additionally, it replicates a 'preoccupation […] with high-visibility activities with consequences for institutionalised social structures' (Kendall & Knapp,

2000, p. 11), not taking into consideration advocacy with 'more proximate meso-level implications' (ibid, p.11).

Enacting these three further steps takes up a wider understanding of resistance, gives space to claims of intent and meaning-making over form of action, finds agency in the instrumentalization of charitable models of disability, and questions actors' perceptions of the limits of legitimacy in their context and how that itself influences action. In this chapter and the previous one, I have argued for the importance of extending research in these ways via an argument which I seek to bring together below, after first highlighting how the Russian context supports this endeavour.

5. Conclusion

In this chapter, I have presented some broad lines of the development of Russian civil society in the post-Soviet period and how disability is constructed and controlled in present-day Russia. Currently, Russian civil society is particularly encouraged by the state in a role of subordinate partnership to fill gaps in social welfare provision. I have demonstrated that disability is dominantly responded to with medical-productivist, charitable lens suggesting individual deficit. Thus, as so understood, disability is associated with action which is legitimised for Russian civil society. While other areas of civil society organising may be strongly repressed, disability appears to fall naturally into a legitimised sphere of organising.

However, apparently natural conclusions deserve questioning. We have seen that the Russian context is one where the state has taken strong steps to control civil society and certain actors perceive imbalances of power and potential sanction. It thus becomes a context where we might expect infra-political action which attempts to avoid sanction, while continuing to resist. Where disability is perceived as a legitimate area for organising, we might also investigate this organising with an eye to the instrumentalization of the relatively greater leeway for resistance which it might hold. This offers the opportunity to investigate the mobilisation of the assumed vulnerability as means of power. Disability's legitimacy is contingent on a misrecognition which elides many of disabled people's experiences and concerns. How actors respond to and negotiate these elisions demonstrates both the opportunities and threats of misrecognition for organising.

In Russia, these opportunities and threats for organising can be investigated in relationship to strong structural constraints which delegitimise action identified by the state as political. In this context, disability organising in fact becomes an eminently liminal space which reveals much about the limits of legitimacy. While disabled people have been naturalised as extra-political and often excluded from recognition as resistant, examining both the construction of this status and its limitations, conditionalities, and instrumentalizations challenges and extends the boundaries of resistance.

Understanding disability as a complexly embodied, contextual, and negotiated relationship of power attempts to simultaneously 'move beyond essentialism' (Alexander & Mohanty, 1997, p. xvii) while still articulating the processes which selectively enact vulnerability (Butler et al., 2016; Spade, 2013). To that end, I have demonstrated the construction of extra-political, infantilised, and medicalised identifications of disability through both wider theoretical discussion in the previous chapter and contextualisation in Russian policies and research in this chapter. Thicker state power is recognised in exclusionary policies, such as institutionalisation and other forms of segregation.

This power also acts through state-promoted discourse and regulatory steps which structure the roles and actions civil society actors may legitimately occupy and undertake. The question is, what can exploring how the control of civil society intersects with that of disability tell us? I argue that it has much to tell us about the nature of resistance; exploring disability organising bends and challenges frameworks which would not recognise resistance there. It reframes constructed and embodied vulnerability as in fact a source of resistance. Instrumentalising external misrecognition of disabled people as inherently vulnerable or lacking agency can fit within civil society's legitimised role in 'fixing' the 'social problems' which disabled people are portrayed to be (Verbilovich, 2013). Attributions of vulnerability may thus be mobilised as an opportunity to allow both the evasion of certain forms of control and continued action. Finally, it allows analysis of the limitations of this strategy, highlighting in particular the delegitimization which occurs where disability intersects with identities which state rhetoric and legislation pathologizes or defines as political and threatening (Kondakov, 2014, 2018).

These questions are dealt with in my four empirical chapters. The first demonstrates that people organising around disability perceive a risky environment for action and presents how they consequently adjust operations, relationships, and discursive framings to perform

compliance. I show that a major concern is to avoid being identified as political. In the second chapter, I analyse how and why this functions in relationship to disability. I ask why disability organising is dominantly perceived as social. I demonstrate how some actors instrumentalise that framing to resist. In the third chapter, I look at the non-apparent forms of resistance which actors use while seeking not to trouble CSO legitimacy. In my final empirical chapter, I reckon with one aspect of the exclusions created by the need for resistance to remain ambiguous and non-apparent. I do so by discussing the experience of LGBTQ+ disabled people and LGBTQ+ people working in disability organising. By virtue of their sexuality and/or gender identity, these people are excluded from legitimacy as civil society actors and as disabled people. I ask how they negotiate this exclusion.

Chapter Five

‘If you’re afraid of wolves, don’t walk in the woods’: Perceptions and Strategies of Legitimacy

RQ.1.: How do people organising in disability CSOs perceive their environment? How do they consequently enact compliance?

1. Introduction

‘On one hand, if you’re afraid of wolves, don’t walk in the woods,’ said Irina, ‘but, on the other hand [even going into the woods], no one wants to go looking for trouble.’[i] Who are the wolves? What are the bounds of the woods? How do people stay out of the woods? And, if they are going in, how do they make sure they are not ‘looking for trouble’?

These questions build on discussion of the state-led rhetorical distinction between legitimised and delegitimised CSOs. According to this binary, legitimised CSOs act as a consensual partner of state and respond to social issues which are not discursively threatening (Lewis, 2013). CSOs are legitimised where not ontologically distinct from the state. On the other side of the binary, delegitimised CSOs are characterised as bent on intervention in state affairs and political change (Belokurova, 2010; Robertson, 2009). These CSOs are associated with the ‘too overt pursuit of human rights’ (Salamon et al., 2020, p. 2; see also: Daucé, 2014; Evans, 2006; Javeline & Lindemann-Komarova, 2010) and challenges to state-led legitimacy discourses which promote ‘conservative values’ (Fröhlich & Skokova, 2020, p. 2).

This floating binary can be mobilised to discredit and delegitimise civil society organising. It is therefore difficult to cleanly sort CSOs into either of its sides. Nonetheless, much research investigates the experience of those CSOs which it more clearly identifies as on the delegitimised side (Salamon et al., 2020, p. 2). Less research questions the influence of this discursive binary on CSOs which apparently stand on its legitimised side. Presumed to be working in a legitimised sphere, and therefore less affected by restrictions in their environment, we know less about the experiences of actors involved in CSOs which are either

legally registered as socially oriented non-commercial organisations (*sotsial'no orientirovannaia nekommercheskaia organizatsiia*) or otherwise frame themselves as social actors (Bindman, 2015; Lawson & Beckett, 2021).

In this chapter, I thus make two primary contributions. Firstly, I demonstrate that civil society organising typically identified as 'social' in fact also negotiates the binary between social and political organising. Secondly, I demonstrate that civil society actors' performances of compliance are in themselves a strategic, agentic response to the environment for organising as they perceive it. Rather than accenting the need to '*accept* the supremacy of the state' (Toepler & Fröhlich, 2020, p. 1, emphasis added), I illustrate how actors strategically enact compliance to enable action and organisational survival. This supports my wider argument against the equation of social action with apolitical, non-resistant organising.

The chapter proceeds as follows. First, I present actors' perceptions of their environment. Second, I examine how actors negotiate the distinction between social and political organising, asking what compliant behaviour looks like in this context. I thus demonstrate actors' perceptions of the vague and floating divisions between legitimised/delegitimised action and how actors strategically negotiate these boundaries to perform compliance.

2. Identifying Legitimacy in Ambiguity

'We don't know what will happen next year,' 'We don't know what will happen next month,' '… next week,' '… tomorrow.' This sentence reoccurred throughout the interviews, only the timeframe changed. 'We don't know what will happen next…' was how many participants both resumed and closed their discussion of the threatening unpredictability of their environment, and their uncertainty about the possibilities of continuing to organise.[30]

In this section, I illustrate how participants perceived their environment. This forms the initial ground for demonstrating if and how people organising around disability perceive any binary division between legitimised and delegitimised organising to be proposed by the state (cf. Fröhlich, 2012; Fröhlich & Skokova, 2020; Pape, 2014). I begin by presenting respondents' fear

[30]Although beyond my focus here, it is important to note that uncertainty was also often connected to difficulties in financial planning. Participants spoke of grants allocated for one year only, competition for grants, limited resources which did not allow them to even make applications, relying on an uncertain stream of donations, concerns around losing cooperate sponsorship, or discomfort with receiving foreign funding.

and anxieties around their environment's unpredictability in general, before examining how these feelings affect organising. Participants' identification of ambiguity in their environment illustrates how they understand rules as fluid and able to be applied as state actors choose. They perceive that those with greater power may determine the boundaries between social and political action and that they or their organisations may fall subject to state sanction, sometimes even independent of any intention on the part of state actors. In this context, one clear rule emerges: being identified as 'political' may result in sanction. Extending Flikke's commentary on the Law on Foreign Agents[31] as a tool of control (2015), I suggest that this identification is in itself a fluid tool of control.

2.1. Wider Unpredictability

Viktoria exemplifies participants' perceptions of the unpredictability of their environment. She says, 'I understand every day that absolutely anything can happen, that there is no logic here at all.[ii] She then describes it as a kind of game of Tetris, where unpredictably shaped objects fall on top of you without warning. Evgenia too says that life is,

> …like walking through a swamp, you poke a bump [of ground], OK [i.e., it's clear]… or like walking through a minefield. In a hybrid post-modern society, there isn't a boundary [between what you can and cannot do], laws don't work, 'telephone law' (*telefonnoe pravo*) exists. […] We live by concepts, we don't live according to the law, we can't say that this law is fulfilled in this particular way. There is a wonderful saying which goes, *zakon, chto dyshlo, kuda povernyosh', tuda i vyshlo* [approximately: 'law is like a drawbar, it comes out where you turn it'].[iii]

'Telephone law' refers to 'a practice by which outcomes of [court] cases allegedly come from orders issued over the phone by those with political power rather than through the application of law' (Hendley, 2009, p. 241). The saying italicised in the last line of the quote compares the law to a drawbar ('*dyshlo*'), which can be turned and directed to carry its load wherever the driver wants. Viktoria and Evgenia exemplify how participants reflected on the weak rule of law ('laws don't work', '*zakon, chto dyshlo*') and lack of stable, institutionalised rules ('there is no boundary', 'anything can happen'). They express their anxieties about this uncertain context in which the concentration of influence among elites means that those in power may turn the drawbar or make a telephone call to shape outcomes in their own

[31]Federal Law No. 121-FZ of 20 July 2012, *On Introducing Amendments to Certain Legislative Acts of the Russian Federation Regarding the Regulation of Activities of Non-Commercial Organizations Performing the Functions of Foreign Agents*.

interest, whether that interest is theirs directly or indirectly (i.e., that of their acquaintances or allies).

Hendley argues that Russian people perceive telephone law as a problem in cases 'involving the state and/or individuals or entities with disproportionate economic or political power,' but less pervasive in cases 'involving ordinary citizens' (2009, p. 253). In my research, participants figured themselves as ordinary citizens often working against various instances and institutions of state, or as CSO actors teaching ordinary citizens how to do so. They thus fall into Hendley's first category of cases 'involving the state' (ibid., p.253). However, they extend her categorisation in two ways. First, they suggest a belief in the use of telephone law also in non-important court cases involving the state in any way. Second, participants use telephone law to refer to the resolution of any issue by a telephone call or other contact from those in state power; their use of the term is not necessarily restricted to the resolution of a case being adjudicated in a court of law. Discussion of this practice often went together with other modes of negotiating the state as 'ordinary citizens.' These commonly included the importance of contacts and resolving issues in 'manual mode' (*ruchnoe upravlenie*) by finding the people with influence in the right domains. This also suggests lack of trust in the institutionalisation of rules and law.

Like Evgenia and Viktoria, Oksana also described the anxieties of living in a context where 'just about anything can happen.' Touching on how this interacts with civil society organising, she provides an illustration of how these anxieties transform perceptions and meanings of an action for participants. Below, Oksana describes her experience of engaging in a street action:

> I […] was trying to understand why I am so scared, and whether my fear is linked to the real situation of things in Russia, the political and social situation, or is this fear more linked to my anxiety. And that's a question I've basically been wondering about my whole life […]. And I just […] I just forced myself to relax. And in that forcing myself to relax I saw… really some kind of metaphor for my life in Russia. […] I hadn't planned to make the action more political, but it became political from the moment I was getting ready to leave home. […] It went from personal to political as I started to get my things together in my rucksack, thinking that they could arrest me. Many of my acquaintances have been arrested the whole time at pickets, at peaceful pickets, at solo pickets. I mean, in places where they shouldn't have been arrested, but they were. […] I just know… that's the thing, you're living in a place where just about anything can happen. Your freedom can be closed off, - I mean, taken away at any moment. Maybe only for a time,

> maybe you won't go to prison, but still you can just disappear for a few hours, for ten hours, be picked up, your freedom of movement violated.[iv]

Oksana's telling not only identifies uncertainty and a threat of negative consequences, but also demonstrates how these conditions transformed how she thought of her action. While the form of the action did not change in that moment, preparing for and enacting the street action became for Oksana a political commentary on actions of state. Later, Oksana drew this out by writing a text recreating her train of thought during the action. She associates the political meaning of her action primarily with commentary on the instability of her environment, but also with the danger of behaving in an unpredictable way which publicly violates norms in such a context. With her street action, Oksana makes herself visible as an 'unruly body' (Mintz, 2007), disrupting performance of the norm (McRuer, 2016). The initial transformation of how Oksana thought about her action illustrates the importance of attending to actors' intentions and meaning-making. It confirms that resistance is not restricted to direct unambiguous action which specifies its claims, as is suggested by much classic social movement literature (cf. Scott, 1985, as discussed in Chapter 3). Here, Oksana's example illustrates how perceptions of uncertainty and a threatening environment transform the meanings of actions, fracturing them into different times and for different addressees. I will discuss this latter point further in Chapter 7 in analysing how actors transform their enactments of resistance in this context.

The examples drawn from the three participants cited here (Viktoria, Evgenia, Oksana) all demonstrate a strong awareness of unpredictability and imbalance in power relationships. This awareness is reflected in actors' strategic negotiations of power, including performances of compliance, in organising spaces and communities (Clément, 2008; Greene, 2014).

2.2. Unstable Definitions

Participants identified the distinction between social and political action as particularly liable to be instrumentalised against them at will by state actors. They highlighted how intentionally vague and subject to transformation by state actors the definition of 'political' could be. Some questioned any actual distinction between 'political' and 'social,' while still identifying such a division as believed in by the majority of the Russian population.

In identifying this distinction, participants overwhelmingly referred to the Law on Foreign Agents of 2012 as codifying political action as delegitimised for CSOs. The Law on Foreign Agents mandates the registration as 'foreign agents' (*innostrannye agenty*) of CSOs who receive foreign funding of any amount and are engaged in political activity (*politicheskaia deiatel'nost'*). Participants' references were consonant with literature that, regardless of the relatively low frequency of its actual application, the law gives a clear signal that political activity should be avoided (Toepler & Fröhlich, 2020). However, participants also importantly used this law to call attention to the possibility that laws more generally be instrumentalised by those in power. This reflects Flikke's characterisation of the Law on Foreign Agents as a 'flexible discursive instrument' and tool of control (2015, p. 9), which may be used by power holders in an unpredictable way. It also extends this characterisation to laws more broadly.

Commenting on the Law on Foreign Agents, Marina said that its interpretation (*traktovka*) is very wide and therefore, 'basically, any reason (*liuboi povod*) [is enough apply the law] and so the whole time you feel like you're under the axe, I mean, like, today they haven't touched us, but tomorrow of course without any problem they could shut us down because, well, we are not going to refuse foreign money.'[v] Marina explains that they adjust the actions of the organisation and their presentation of these actions to minimise threat from the state, driven by the fear of sanction. She said, '[we] are seriously limited, I mean, by this fear, I mean we understand that the state (*gosudarstvo*) always has the possibility of stopping the activity of the organisation. […] Again, if they want to find fault (*pridrat'sia*), they'll find a reason to.'[vi]

Ksenia had the same opinion: 'Ending up a foreign agent doesn't depend on how the law is formulated, because they'll find a way to apply it to you, if they want. Here, if we get on someone's nerves at some point for some reason, this is one of the ways to, well, if not close us down, then kind of make our life difficult (*otravit' nam zhizn',* lit.: poison our life).' Ksenia immediately continued the sentence by emphasising her perception that the Law on Foreign Agents is one among many potential tools of control: 'It's far from being the only way, you can find a load of different ways.'[vii]

Marina, Irina, and Ksenia represent a view of the law which see it as a convenient instrument available to state actors or, given the mobility of power, to those people with connections to people in state power. Irina specifies that 'you can call whatever you want political activity.' This is consistent with literature which has noted that there are no precise, coherent, or

consistent criteria according to which CSOs face state sanction (Daucé, 2015). Furthermore, the categories may not actually be exclusive as they are used in practice by the state. At its extreme, as Daucé argues (ibid.), the state may sanction a CSO by declaring it a foreign agent, while simultaneously offering it grant-based financial support.

Some actors' descriptions of the arbitrary and unpredictable nature of laws, rules, and concepts were linked to assertions that they did not perceive any objective, absolute distinction between political and social action. These assertions were generally presented as statements about 'other people,' often characterised as the majority of people in Russia. For example, Viktoria insisted that personally she saw no distinction between political and social action, but that this was not widely understood by others:

> It's wrong, but Russians generally in Russia really think that politics is separate from *sotsialka* (approximately: social welfare), they don't understand that *sotsialka* is politics too (*sotsialka i est' politika*). And I think that we definitely can't change that. It's the mentality.[viii]

Any division also did not make sense to Aleksandr, who felt that:

> Any social organisation is all the same, to some degree, politicised, I mean it's rare that a non-commercial organisation in Russia is entirely not linked with political activity. Why? Because *sotsialka* is politics too (*sotsialko – eto tozhe politika*), and many social issues are solved by political means. You cannot divide the two spheres.[ix]

While Viktoria and Aleksandr stress that there is no distinction between social and political action by CSOs, Evgenia believes that all CSOs are by definition social, by which she means that they respond to society within which they operate. Evgenia thus includes those CSOs typically seen as political, such as those responding to human rights violations (Daucé, 2014), in her definition of social. However, she notes that not all organisations met the criteria to be able to claim social orientation, particularly as per the legal status of a 'socially oriented NGO':

> This monstrous combination of words has appeared: SO NKO, socially oriented NKO. I mean, I'm sorry, are any NKOs not socially oriented, what kind are they then? I mean, it's just this kind of monstrous thing and as a result, completely awfully, many organisations [not classed as socially oriented] just got steamrollered…[x]

The assertion that 'most people' perceive a clear difference between political and social action suggests that these actors believe that the categorisation, regardless of whether or not they themselves support it, has what McCall refers to as a 'strong social reality' (2005, p.

1779). Fröhlich and Skokova (2020) have argued that the state supports such a binary distinction, exporting it into wider society by rhetoric and administrative means. Actors may perceive the meaning of 'political action' (*politicheskaia deiatel'nost'*) to be vague and arbitrary, but the impact on organisations of being identified is tangible. As Evgenia notes, 'many organisations just got steamrollered.' Regardless of actors' perceptions of the objective existence of such a distinction, they typically described the distinction as believed in by others and acknowledged remaining on its legitimised, social side as a necessary strategy to continue action.

Marina, Irina, and Ksenia also suggest that the risk of repression is not entirely arbitrary. On one hand, they describe the risk as unpredictable and ever-present, as 'if [the state] want[s] to find fault, they'll find a reason to.' On the other hand, they describe adjusting their actions and behaviours, suggesting that there are nonetheless ways of minimising this risk. This indicates that actors perceived that the situation is not entirely arbitrary and had distilled some broad modes of action and positioning which seek to manage risk. Performing 'being social' and avoiding identification as 'political' is a strategic response. To do so is to avoid 'looking for trouble'(Irina). Examining how actors negotiate risk suggests what it means for disability CSOs to be legitimatised actors in the civil society sphere. I come to these negotiations of compliance in Section 3.

2.3. Who Holds Power?

Actors' perceptions of the unpredictability of their environments were largely expressed through mistrust of rules and laws, but also a belief in the deciding influence of those in positions of state, political power. Actors suggested a power hierarchy which could be instrumentalised directly or indirectly, either by those in formal positions of power or those who are able to build links with people in formal positions of power. Civil society actors often referred to unspecified actors, political actors and other elites, and those who might use links with them. This lack of both specification and institutionalisation again suggests a threatening and ambiguous environment.

Maria described how CSOs she works with have become more united against… and then paused and completed the sentence only by pointing upwards; her later conversation indicates more clearly that she refers to those in government. However, the threat she

identified again emanates from unnamed and unspecified actors. Meanwhile, Ekaterina spoke about being afraid of being shut down if an unspecified 'someone (*kto-to*)' should 'happen to evaluate [their actions] as a political fight.'[xi] When I was speaking with Maksim, he repeatedly spoke about a 'they':

> Even our festival, it's very soft by European standards, it's not an anarchist rally, I mean, it's not a summit, it's, damn it, just some normal kind of cultural event, where we are just discussing something, experimenting with meeting space. And all the same, all the same for them it isn't acceptable. I mean, they want there to be absolutely nothing.[xii]

Finally, at this point of the interview, I asked, 'Who are 'they'?' ('*A 'oni', eto kto?'*). Maksim replied, 'Yes, who. Who are they? Who are they? I don't know who they are [*laughs*], there you go.'[xiii] His reply continued with stories about meetings and events of theirs which had been broken up by the police ('*militsia*') on the claimed basis of 'someone' reporting a bomb threat and, on another occasion, drug use. He did not know who had made the report, why they had done so, and whether the person who had made the report even existed and was not fabricated to justify the police intervention.

Marina, cited above (Section 2.2.), at most precise referred to 'the state' (*gosudarstvo*). Otherwise, as was common among participants, she repeatedly used an indefinite-personal construction (Schlund, 2018, p. 158) which allows the third person plural pronoun '*oni*' (they), itself unspecified, to be dropped. For example, the sentence 'they have not touched us' in Russian is rendered '*nas ne tronuli*.' The verb (*tronuli*, touched) is in an active form and implies the subject '*oni*' ('*they*', as in '*they* have not touched us'), but the '*oni*' remains unspoken. Similarly, Irina said, 'Here (*u nas*) you can call whatever you want political activity. […] I mean, here, if you want to find fault. […] In our country if someone wants to put someone in prison, to shut [down an organisation], then they'll find something to find fault with (*to pridrat'sia naidut k chemu*), even if you've done everything perfectly.'[xiv] Again, the 'they' present in the English ('they'll find something') is present in the verb form only in Russia, without the subject marker '*oni*', and is unspecified by the indefinite-plural construction. Otherwise, Irina uses 'someone' ('*kto-to*'), again without specifying whom. These are entirely typical constructions in the Russian language. However, their use allows the actor exercising the power to remain unspecified, whilst participants still refer to their ability or intent to use that power.

The Russian '*zakhotet"* used by Marina suggests intent as in the English, 'if they decide [to do X]' or 'if they take it into their head [to do X]'. Similarly, Irina suggests intent and will behind action ('if you want to find fault').[xv] However, more rarely, unpredictability and negative consequences were also presented as a side effect of state actions which did not intend to target CSOs. In one example, discussing the so-called Dima Yakovlev law[32] and its effect on her work, Ekaterina said, 'Of course, these are ugly political games which go on behind the scenes because, again, nobody cares a bit about the children. They weren't anyone's target. They [the children] just lost out as a side effect of them [Russia and the USA] butting heads.'[xvi] The passing of the Dima Yakovlev law altered her sense of the predictability of the environment:

> Honestly, I think that here [in Russia] anything is possible since the Dima Yakovlev law, which was signed two weeks after, – a month after a Russian-American agreement was signed saying that if one side wanted to stop foreign adoptions they had to give one year's notice. […] And a month after that, in two weeks the Dima Yakovlev law was signed. Since then, I understand that absolutely anything is possible, whatever it is, in a very real way.[xvii]

Actors' references to unnamed and unknown actors who could threaten organising, alongside the general unpredictability of the operating environment and the unstable definitions, suggested that they perceived a generally hostile environment for civil society. The multiplicity of these threatening actors and the inability of civil society actors to name or even specify them suggested the difficulty of predicting their responses. Civil society actors did not know which of their actions could potentially upset these unknown actors and what effect that would have on their work. The potential to be caught in the crossfire, even independent of any intention on the part of those in power, created a difficult, unpredictable environment for organising. It also heightened CSO actors' vigilance around ensuring that their CSO be perceived as engaged in legitimised action. Through exploring actors' perceptions, I have demonstrated that actors in disability CSOs also experience anxiety in negotiating their environment and the blurred lines between legitimised and delegitimised action.

3. Strategic Negotiations of Compliance

[32]Federal law of Russian Federation no. 272-FZ of 2012-12-28 *On Sanctions for Individuals Violating Fundamental Human Rights and Freedoms of the Citizens of the Russian Federation*. The Dima Yakovlev Law prohibits the adoption of children who are Russian citizens by citizens of the United States.

Now I discuss how actors nonetheless adopt some broad modes of action and positioning which seek to minimise risk and thus navigate this unpredictable environment. I examine how participants navigate the division, however fluid, between social and political action. I thus explore the implications of their perceptions of context on how CSOs enact compliance.

The division between legitimised social organising and delegitimised political organising was the widest umbrella distinction commonly used by a variety of civil society actors. Svetlana offers a common view in outlining the difference between the state's relationship to social and political action, and its implications on the civil society sphere:

> In recent years, the accent has really changed towards encouraging social and charitable non-commercial organisations. The state really tries to facilitate (*sodeistvuet*) their work, tries to encourage them, promotes them, helps them to come out onto the social services market. Of course, rights defence organisations (*pravozashchitnye organizatsii*) have a much harder time of it. If they have conflict with state organs, then it's really hard for them to work. Not everyone is prepared to constantly be in conflict, so here, I think, rights defence organisations have decreased in number, and they've become less active and noticeable, while on the other hand all kinds of social, charitable [organisations] have really become active, become more noticeable, visible.[xviii]

In suggesting that the state encourages and facilitates social, charitable organisations and tries to restrain rights-based organising, Svetlana identifies a dual strategy driven by the state, consonant with much previous literature (Fröhlich, 2012; Fröhlich & Skokova, 2020; Pape, 2014). She perceives rights defence organisations as oppositional and in conflict with the state, and thus outside the legitimised role for civil society of nationalised partnership with state (Belokurova, 2010; Fröhlich & Jacobsson, 2019; Labigne et al., 2015). However, as I have demonstrated thus far through the example of disability organising, the apparently 'social, charitable' CSOs to which Svetlana refers nonetheless experience tension in this environment, and a need to distance themselves from delegitimised action.

Given actors' perceptions of a boundary between legitimised social action and delegitimised political action, a key strategy for CSOs to survive and continue operating was to be broadly legible as 'social.' This legibility was primarily directed towards state actors. However, these state actors often remain vague and, given the lack of institutionalisation and use of 'telephone law', power is perceived as mobile. Furthermore, actors believe that most other people saw political action as delegitimised. Therefore, civil society actors also felt it

necessary to project this 'social' identity for their CSO more widely. Actors' claimed motivations suggest that compliance remains a matter of strategic choice to permit action.

The creation of a depoliticised, social, and therefore legitimised identity for CSOs operates via various means. Here, I outline discursive, operational, and relational negotiations. By discursive negotiation, I refer to how CSOs adjust their language and framing. By operational negotiation, I refer to how CSOs navigate what actions they will and will not do to maintain legitimacy. By relational negotiation, I refer to how CSOs engage with the state and other actors.

These categories are not discrete. Rather, working for legitimacy requires engagement with each of these areas as mutually constitutive of compliance. For example, developing a reputation as a trustworthy partner of state demands alignment with state terms in the presentation of activity (discursive negotiation), restriction of activities to avoid overt protest and public contestation and to reflect state timelines and concerns (operational negotiation), and work within state fora and with state officials to develop relationships based on both apparent discursive and operational compliance (relational negotiation). Here, I present each category individually to give an overview of how CSOs strategically project compliance. However, the categories act in concert and are clearly mutually reinforcing.

3.1. Discursive Negotiation

In this section, I show how CSO actors strategically shift how they present action and use language to position their CSO as legitimate. These shifts to discursive framing aim to remove friction with the state, both by using the latter's language and by avoiding framings which state rhetoric has delegitimised, often through their politicisation.

CSO actors adjusted the terms they used in order to align with the institutional terms of state actors. Viktoria said, 'first we need to learn how they call things, and then understand what they mean by their terms. It's not like they want to understand us. They straight away say, "you're fools (*duraki*), you don't understand anything." […] So, we were reborn, we started to speak differently, because otherwise they weren't listening to us.'[xix] Viktoria described adaptations in language, as well as their research work to understand and use terms from laws and state policies. This alignment means that CSOs speak the same language as state,

thus projecting themselves as part of the same wider project and blurring the boundaries between themselves and the state as actors.

Framing action as seeking the fulfilment of the state's own pre-existing laws attempted to collapse the distinction between CSOs and the state. Some actors noted that they preferred to use Russian laws, rather than refer to the UN CRPD. Actors thus frame themselves as supporting the state in fulfilling its own obligations. This reflects descriptions of legitimised civil society as (1) acting as a consensual partner of state, (2) not ontologically distinct from state, and (3) responding to social issues which are not discursively threatening, as they are already represented in national law (Lewis, 2013). By framing their work from the position of existing law, CSO actors leveraged greater power in a compliant manner disassociated from their own person or organisation. For example, Ivan said:

> I'm saying, 'Do what we are entitled to in law.' […] I'm precisely standing up for (*otstaivaiu*) the position of the state. Because it's the state itself that passed these laws, actually. And you are state officials, and therefore you should fulfil what the state has passed.[xx]

Thus, Ivan positions himself as representing the position of the state. Failure to fulfil a particular law is framed as an affront to the state, rather than to Ivan's person. This places pressure on the person addressed to demonstrate their appreciation of and loyalty to the state's position by fulfilling state law. Furthermore, this framing was a mode of depoliticising action by aligning with the current government, rather than by emphasising working towards legislative change.

While CSO actors describe attempting to introduce new terms and concepts to state, and even to work for legislative change, they broadly ensured that their discourse remained legitimised. They therefore made strategic changes to language particularly aimed at disassociating the CSO from political action, lobbying, and proposing change to government. This occurred in how actors described their CSO's work, particularly in public-facing documents. For example, Marina describes how they have changed their framing to try to ensure their formally registered CSO's legitimacy in the eyes of the state:

> We've stopped publicly using the word "lobbying", "influence social policy." […] So, we, I don't know what we write, we're "carrying out legal monitoring" and "making conclusions about the situation" or something, basically, yeah, some kind of rubbish, […], but we really rephrase, like that, so that, well-, well, or

> often, most often we have started to write about "social work" which is clear and plus, like, we "defend rights in individual cases", I mean, that's not illegal, representing people in court, doing consultations, and doing, accompanying individual cases for rights protection. Well, and then the fact that from accompanying these cases a systemic picture comes together and we can make proposals to those in power (*predlagat' chto-to vlastiam*), we either completely keep that part silent or we write it somehow, like we are "informing" them or, – basically, we think something up.[xxi]

Marina suggests a conscious effort to depoliticize through avoiding presentation of the CSO as working for system-wide change and emphasizing the social nature of their work. Her CSO thus aims to avoid association with the terms delegitimised by the Foreign Agents Law, which specifies that organisations which exert political influence and attempt to form public opinion for political reasons may be registered as foreign agents. The law specifies that the social support of disabled people is not political action under its terms (Kulmala, 2016). However, CSO actors do not interpret this as meaning that all disability action is legitimised, but rather maintain care to present their action as depoliticised and social.

In mentioning 'defend[ing] rights in individual cases,' Marina illustrates the possibility of invoking individualised social rights, while maintaining a strategically depoliticised framing. This reflects some potential for social rights to still be considered a legitimate basis for making claims and describing CSO action. However, many people were uncomfortable with using rights-based expressions and preferred to emphasise social work, without mentioning 'rights.' This was largely based on the equation of rights with specifically political rights alone.

This suggested a restriction of the meaning and use of 'rights'. In reference to civil society action, the term 'rights' appeared to be either discredited or easily discreditable through its overwhelming association with political action; participants primarily discussed rights-based work as either political or politicised. For example, Eva described not referring to their CSO as 'human rights' based:

> We don't really put ourselves in that category [of human rights groups], although we're definitely doing rights work. Definitely. […] But here, the word, unfortunately human rights has got kind of a negative connotation, so we might sometimes avoid it. Just because of the whole thing with foreign agents, not being too political, because you're not supposed to be political, and if you're political and you have foreign funding, and we do have foreign funding, then you can be put on the foreign agent list, exactly. So that is something we also might want to avoid.[xxii]

Post-Soviet Russians have been identified as mobilising 'diverse political strategies that draw on multiple discursive patterns [and] moving deftly between logics of social rights, civil rights, and neoliberal selfhood' (Hartblay, 2019, p. 547; cf. Hemment, 2007; S. Phillips, 2010; Shevchenko, 2009). However, in my interviews, this multiplicity manifested itself differently. In terms of their framing of action and their perceptions of the discourse of the majority of others in Russia, participants understood rights as political, civil rights. They opposed this to 'social action', which was generally not discussed in the language of rights. Above, Eva indicates that she does see their organisation as doing human rights work. However, she avoids talking about their work in these terms, which she suggests as delegitimised through politicisation ('we might sometimes avoid it […] because you're not supposed to be political'). As she says later in the interview, she does not identify with other human rights groups. Thus, Eva represents a narrowed understanding of rights as political, politicised, and contentious; to 'do rights' is to 'be political'. The shift in discourses around rights was both identified and criticised by Andrei, who himself did indeed distinguish between social and civil rights:

> And I say [to other CSOs], "You know what? No, of course I understand that you defend rights, but the rights that you defend are, mainly, political. And, all the while, there are social rights, which disability NGOs work on: the right to education, the right to employment, receiving other social services. You [other CSOs] don't think that those are rights." I find that really amazing because, after all, traditionally there was this division into two baskets. The Soviet Union was always faced with the complaint that it did not observe political rights. And the Soviet Union used to say the whole time that Western countries did not observe social rights. And [now] at the same time, the organisations which call themselves rights defence organisations in Russia, they only work on political rights. They are gradually beginning to realise that they won't be popular until they work on social rights, because this [working for political rights], actually, just worries people.[xxiii]

For Andrei, disability CSOs clearly work for social rights. He continues to say that, because of that, disability CSOs find it 'quite easy to build cooperation (*vzaimodeistvie*) with state power (*s vlast'iu*).' The opposition between political rights and social rights is claimed by some actors to justify disability CSOs as legitimised partners of state. This occurs explicitly, as in the case of Andrei. More commonly, it occurs implicitly through framings which emphasise 'social' and efface or obscure any language of 'rights.' In these framings, as Andrei points out, the organisations which refer to themselves as engaging in rights defence are those working on delegitimised, political rights. This is an example of the reduction of the meaning of rights and why disability CSOs take care around invoking them to describe their own action.

The dominant politicisation of rights within the civil society sphere can be connected to that used by foreign-sponsored civil society development in the 1990s, which often operated on the normative liberal premise that a stronger civil society necessarily builds a stronger democracy (Linz & Stepan, 1996). As with the wider backlash against civil society, which has some roots in the civil society and democracy promotion efforts of the 1990s, it is now these politicised claims around civil society which the Russian state turns back against it to delegitimise it. Still, some use of social rights remains possible; I discuss the differentiation between types of rights in addressing how discursive framing is reflected in CSO action.

3.2. Operational Negotiation

In this section, I build on discursive negotiations to present how CSO actors operationalise compliance to manage risk and continue action. I look at how actors move disagreement with state out of the public eye and their negotiations of rights-based claims.

A primary concern of actors was to avoid being perceived as involved in work for rights. CSO actors in fact drew a distinction between being working for rights and being able to work with people. As Eva's example, above (Section 3.1.), shows, this went as far as collapsing the distinction between 'rights' and 'be[ing] political,' suggesting that all rights are politicised and to be avoided. Igor again describes the division between social action and politicised, rights action and what is encouraged by the state:

> In Russia and in [City] in particular, organisations are divided into those who do rights defence activities (*zanimat'sia pravozashchitnoi deiatel'nost'iu*) and those who do social welfare activities (*zanimat'sia sotsialkoi*). The state encourages social activities and really does not encourage doing rights defence activities. So that's why [the organisation] does not do direct rights defence activity as such (*kak takovaia*). Because, if we work with people, it's not desirable to do rights defence activities. Unfortunately, those are the conditions (*usloviia*) of our game. […] Direct rights defence activity of course we do not do because, I repeat, here (*u nas*) the division between social welfare (*sotsialka*) and rights defence is very clear. Because then, [it can go] right up to you becoming [i.e., being registered as] a foreign agent if you do rights defence activities.[xxiv]

Igor describes a strong binary division between delegitimised rights defence and legitimised social organising. He stresses that their informal organisation does not 'do direct rights defence activity as such' because it is 'not encouraged.' Igor thus suggests that their perception of the rules for CSO action ('conditions of our game') results in their avoidance of

rights activity. Indeed, Igor equates rights defence activities with action which can lead to your CSO being registered as a foreign agent. This reflects actors' association of rights defence action with the political action (*politicheskaia deiatel'nost'*), which the Law on Foreign Agents directly names as grounds for a CSO to be registered as a foreign agent. The law directly names political (*politicheskaia*), not rights defence (*pravozashchitnaia*) action. However, participants' strong association between rights-based activity, political action, and delegitimised action for CSOs demonstrates that they perceive them to be interlinked.

Igor does not frame social action as concerning rights. Not explicitly naming social rights as, indeed, rights is a strategic choice where 'rights-based' action is widely politicised and delegitimised. However, his caveats suggest some rights work which is potentially permissible, even if its nature as rights-based may be elided in framing. His specification of 'rights defence action *as such*' and '*direct* rights action' suggested some implicit 'other' kinds of indirect, permissible rights action. This nuances the notion of all rights action as political and delegitimised and returns to actors' negotiations of the distinction via apparently compliant forms of action.

Ekaterina's example draws out the distinction between social and political action. She works in a CSO which both provides various services and raises funds for disabled children and characterises the situation similarly to Igor, suggesting that such rights-based activity was avoided to enable the CSO to continue work with children and their families. She comments:

> We are, of course, a social NGO, and often we really run into things in some areas that are really close to the rights defence theme (*pravozashchitnaia tema*). That means, again, I see that [the director of the NGO] […], when she participates in these discussions, is really afraid the whole time for the fund. When someone turns to us with something that puts us into a tight corner ethically, both I, following [the director] and [the director] chose to place the safety of the fund first because we constantly remember that behind us stand concrete children, concrete families, and if we start pushing hard on some rights defence issues – and rights, of course, are being violated everywhere and all the time, and patients' rights [too], endlessly – but we try not to really get into such fights directly. We've got enough with fights for individual cases, […] on a different level, not in the political field, but in the social field.[xxv]

Ekaterina claims a social identity for the CSO ('we are, of course, a social NGO'). This naturalised ('of course') framing positions her CSO as clearly on the side of legitimised action. It is an example of actors' frequent disassociation from rights-based work in an attempt to

manage or mitigate risk to a CSO. It acts as a distancing caveat to her subsequent admission that they very frequently encounter rights defence issues. This admission again demonstrates the presence of rights-based work in organising claimed as social. However, Ekaterina still opposes the legitimised 'social field' to the political one. She also associates this political field with 'the rights defence theme' ('*pravozashchitnaia tema*'); this aligns with work which suggests that human rights work is politicised and delegitimised (Daucé, 2014; Fröhlich & Skokova, 2020). Consonant with previous discussions of uncertainty and anxieties in organising, Ekaterina mentions the constant fear of the director of the CSO, who is 'really afraid the whole time for the fund' because of their potential association with delegitimised rights defence work. This fear is striking in a CSO working in what has been broadly naturalised as a legitimised sphere. Ekaterina and her colleagues respond to it by seeking to safeguard the continued existence of the fund through strategic choices around their action.

This is operationalised through restriction to social rights and entitlements, often as already codified in law. Ekaterina's example thus indicates how CSOs attempt to negotiate via restriction to social rights. Ekaterina indicates that helping those whose cases can be deemed rights-based and political would put the fund in danger and thus prevent them from helping anyone at all. Therefore, they have decided to privilege those they can help while remaining 'in the social field.' Ekaterina demonstrates both strategic agency and the presence of rights-based organising in organising framed as social. Both she and the director of the CSO are aware of threat. Their negotiations of their context are thus an intentional, strategic response in enacting compliance to be able to continue action. Ekaterina and others strongly claim the framing of 'social', while still 'fight[ing] for individual cases' and, indeed, ensuring rights.

Within the legitimised spheres described, individualisation of claims was a clear strategy to make action for rights less contentious. Ekaterina's emphasis on working to resolve individual cases echoes Marina, cited above, who emphasised that they work to 'defend rights in individual cases.' Many organisations ran sessions to teach people about their rights and how they could claim them according to Russian laws. At times, this also operated in an individualised manner similar to that identified by Fu (2017), where the organisation teaches the individual how to negotiate with the state on the latter's terms, then stepping back and become unseen at the point of the interaction between the state and the individual. This provides an additional layer of protection to the CSO. Educating people about how to claim

their rights according to existing laws and regulations also implies using a compliant, legitimised framing which teaches people how to subject themselves to the eye of the state, as I discussed above in terms of CSOs' discursive negotiations (Section 3.1.). Thus, CSOs train people to behave as good citizens by teaching them how to make themselves visible according to the terms and framework of the state.

Alongside strategically individualised claims often around social rights, CSO actors suggested that certain forms of action to support rights were also permissible. Above, I referred to Igor's telling concession in saying that his CSO does not do rights work 'as such' (*kak takovaia*). His specification suggests an ideal type of overtly political, rights-based organising which is delegitimised and therefore avoided and, implicitly, another which CSOs may carry out. This categorisation also depends on the form of action. Actors characterised classic, rights work 'as such' as louder, less discreet, and more directly oppositional. In contrast, Galina's example illustrates CSO actors' identification of more indirect, and thus more permissible, rights-based work. She previously worked for a registered CSO before beginning her own, currently unregistered, art group, which is active in residential institutions. She discussed her work:

> I don't feel like a classic rights defender (*pravozashchitnik*), I mean, I [work in the arts], and the only thing I can do is put on exhibitions and work in whatever part I have. I mean, for the moment I can do something in this sphere and there is a field for work, I mean I see that this is also connected with some kind of rights defence. It's just that rights defence is made up of different structures, and it's not that you always need to stand up for (*otstaivat'*) rights in court, sometimes it's just about informing and giving people the possibility to speak out – that's also a kind of rights defence. We have a rights defence grant [i.e., a grant given by a human rights organisation], of course, we have this kind of, maybe, not exactly direct, classic rights defence, […] but all the same I think, that we have rights defence potential, just it's kind of more indirect, rather than direct. […] I mean, any attempts to declare directly about [doing] rights defence work in a residential institution, like, "I do rights defence work" – then it's, like, goodbye. I mean, it's impossible [to do that] there, and so we as artists have more possibilities to go there and do something. Plus, we do exhibitions, where we can, and again, public awareness raising, and through the exhibitions we can talk about more problematic things, rather than like through some kind of rights defence texts.[xxvi]

Galina associates 'classic rights defence' with court cases. Other actors associated it with protest marches, slogans, and other such actions which go beyond the realm of the everyday and they saw as direct challenges to those in power. Galina says that framing her work as direct rights defence would immediately end any possibility to continue action. She sees her

work as more indirect and hidden, while still supporting people's rights. Using dissimulated, and therefore less politicised, threatening methods, to defend rights allows work which goes further than individualised social rights, at least in terms of beginning broader discussions. It may also confound any clear distinction between social and political rights. As such, Galina is able to discuss such questions as the right of disabled people to self-determination and independent living, as well as to support disabled people to make claims to worth, as people who are segregated and excluded from wider society by placement in large-scale institutions. Galina's example suggests that the form of action used to claim a right is also important to continuing action, as well as the type of right.

Many people described running art and activity groups as an indirect way of protecting people's rights. Tatiana and Galina both work with small groups. This individualisation and 'social work' facade allows them to continue to engage in rights-based work. Thus, actors still identify their work as promoting, safeguarding, or defending rights, although dissimulated. They turn away from interaction on a systematic level to individualise their work for rights, thus making it harder to identify and disrupt. However, there remains a tension in how they operationalise their work for rights. For example, Nadezhda described how the presence of 'social work' (*sotsial'naia rabota*) legitimised the formal CSO with which she worked, becoming a cover which allowed the CSO to continue to defend individuals' rights both through that social work and elsewhere, however indirectly. She said:

> Difficulties always come up […] But with [CSO] actually it works out because of the organisation's reputation and also the fact that we don't just have a rights defence part, juridical support, but most of the work [of the CSO] is actually social work.[xxvii]

When I asked, then, if doing social work supported and legitimised doing rights work, Nadezhda in fact replied:

> There's actually this kind of negative effect, because actually of the fact that, for example, our programme happens in one of the residential institutions for adults, we often run into problems with legal work because, on one hand, we're working together with them, because our employees come to work with the same people who live in the institution. [Our programmes] also completely depend on the institution, because the institution is the boss there. They can create some kind of bad conditions for our employees. At the end of the day, of course, it's the people who live there who suffer, but that often doesn't worry the institution. For example, because of that we can't take some kind of active measures against the institution, even when there are legal grounds for a complaint. We always need

> to think about whether our wards (*podopechnye*) will end up worse off, and that's the complication.[xxviii]

Nadezhda observes that, for that reason, they in fact find it easier to work on a systematic, higher-level, away from such individual concerns. While some actors find individualising how they engage in rights work is enough to dissimulate it and make it less threatening, Nadezhda suggests that individualised rights work may still become problematic in the case of working within residential institutions, where there is a clear power imbalance in favour of the latter. Thus, however individualised, where it comes to rights defence through the courts or through 'active measures', as Nadezhda says, we still find a limitation. I propose that individualisation of rights-based work is not enough. There is also strong pressure for rights-based work to be more dissimulated or compliantly framed (i.e., as with the art activity groups) and to avoid direct confrontation through formalised, public channels.

As with the indirect operationalisation of rights action, civil society actors also avoid public contention more generally. Registered CSOs in particular often commented on avoiding scandals, petitions, and protests, except for some actors who proposed such actions as permissible for a CSO as a matter of last resort. Strategically enacting compliance involves moving contention out of the public sphere or using indirect, liminal methods of contention, such as Galina and her unregistered art group. We see the delegitimization of direct confrontation in how Vera describes petitions:

> Petitions, let's say, they're already a way not to declare (*zaiavit'*) but to shout about your problem, it's already a different thing. And then the petition change.org, it's unfortunately not a Russian resource, but a foreign one and it's not well-liked here. When you create a petition, it's a kind of hammer, when you already need to shout, and then already after shouting, [you need to] stop shouting and start working through everything systematically. I see it like that. Petitions are more than anything for the media.[xxix]

Vera adds the thought that perceptions of change.org as 'foreign' are part of why it might be not liked. This suggests the social resonance of discourses more broadly which link foreignness with threat (Fröhlich & Jacobsson, 2019). However, the main issue which Vera and other participants commonly identified with petitions is that they are a way of 'shouting' and getting media attention. It is not seen as constructive and, after its use, Vera nonetheless advised stepping back to work with the state. While petitions are not particularly unusual, actors generally characterised them as a somewhat conflictual step to be used where urgently

necessary and after exhausting other possibilities. Otherwise, actors described the need to work as a subordinate partner of the state. As well as the discursive and operational negotiation presented so far, reducing their degree of friction with the environment also involved negotiating such a relationship with the state, as well as bearing in mind their relationship with society more broadly.

3.3. Relational Negotiation

By relational negotiation, I refer to how CSOs engage and partner with the state and political elites, such as state deputies. I also explore how CSOs engage with more contentious actors. Where such relationships are present, CSOs may still project a compliant organisational identity by drawing these relationships out of the public sphere or away from any apparent identification.

These points again show how discursive, operational, and relational negotiations overlap and are mutually constitutive. Building a relationship with state actors is permitted by discursive and operational alignment, which includes refusing or obscuring relationships with more contentious actors. CSO actors thus seek to frame their work compliantly as social and not engage in direct confrontation. These operational and discursive aspects permit CSOs to build a reputation as a good partner of state. Accepting the overlap of these areas, here I focus on how these relationships are then maintained and leveraged.

CSO relationships with state are based on the CSO understanding, and adapting itself to, the state's institutional system, priorities, and resources. This implied a willingness to compromise in demands so as not to put undue pressure on state resources. It meant being willing to work at a slower pace, adapting to the state's timeline. Aleksei, who is employed at a GONGO, offered one example of this attitude. He related how an unfavourable policy was adopted, restricting the employment rights of members of the GONGO. It had taken years of slow work to change this policy, but he had not rushed: 'That's how it all goes, in this calm tempo because haste will make you no friends (*pospeshish' – lyudei nasmeshish'*), you won't do any good that way.'[xxx] He comments on the role of CSOs as a good partner of state:

> NGOs have begun to understand, and the state too, that you have to be partners of the state. […] We know that, if we go to court and the court says, "yes, [this accessibility measure has to be put into place]." Well, OK, and then what? They won't do it tomorrow, because there aren't the resources, you understand. And

> the state already won't look on us as a friend. […] In this instance, it's really important to maintain the balance of relationships with the state as well as in the interests of [the target group].[xxxi]

To build a relationship with state, Aleksei describes the need not to rush change and to be ready to compromise in demands. A related perspective came from Oleg, who described the need to understand the state system, the remit of different state actors, their priorities, and to formulate their demands by taking these aspects into consideration and addressing the correct person:

> Sometimes what happens with various NGOs, grassroots NGOs and NGOs created by people with disabilities or parent groups, they are very loud, but they cannot formulate what they want. And they don't know the limitations. So, they come up, start shouting, and actually the government officials get irritated, and this does not lead to a solution. […] So, when you understand the limits, for instance, of the powers of a certain regional authority, when you know their constraints from the point of view of the budget, then you can […] make sure that your interests are taken into account. […] The idea is that when you come up to a government official you should actually know […] his priorities because otherwise it won't work, you know. […] So, it means that people should know the legislation. That people should know the trends in the government social policy and some other things. People should know the top priorities for the region and the key people in the region whom they should address. Because sometimes they come up to the ministry which has no powers to resolve their problem, you know. […] So, if you understand their logic, because they do have some kind of institutional logic as well, so then you can, well, if not manipulate, then easily work with it. And you see the opportunities, the windows of opportunity, which you can jump in.[xxxii]

Both Aleksei and Oleg reflect the idea of legitimised CSOs as good, compliant, and compromise-oriented partners of state. These CSOs understand and bend themselves to fit with state structures, organisational divisions, and priorities. They are part of a project of national development, neither necessarily particularly distinct from the state (Belokurova, 2010), nor involved in creating discursive challenges (Lewis, 2013). They may be able to 'jump in' windows of opportunity within the state system, but they do so by learning and adapting themselves to its institutional logic. Oleg further discusses the importance of having friendly relationships with state officials and being able to speak to them informally to promote certain goals:

> Work[ing] with the government […], actually it means that you should be present in the various working groups that are created, it's a kind of more bureaucratic work which takes time. But sometimes it's very important not only because you can sit for two hours somewhere in the government and listen to nice speeches,

> but also because you do networking, and sometimes in the corridors you can do much more from the point of convincing the officials and preparing the final decision than during this kind of formal session, which you have to attend.[xxxiii]

Oleg attends formal meetings to build relationships, aiming then to influence discussion from the corridors. His form of influence took place not through public protest or scandal, but through aiming to work constructively out of public sight in the corridors of state. Refusing public protest was part of how Oleg described aiming to build a good reputation for himself and his CSO as a trustworthy partner of state. Such behaviours are what Evgenia resumed by saying that CSOs now 'need to somehow be very good friends with [state] power (*s vlast'iu*)' and to work closely with them.[xxxiv] This characterisation has been identified as accepting the supremacy of the state and performing loyalty (Clément, 2008; Toepler & Fröhlich, 2020). However, actors make a strategic choice in doing so, identifying this approach as allowing them to have more leverage and to continue action, including that which is dissimulated and occurs out of the sight of state (Chapter 7). Oleg, for example, described feeling that his care to safeguard his reputation and make arguments couched in legal terms and analysis of the state priorities and budget also allowed him to challenge what he saw as bad decisions more directly. However, this challenge remains out of public sight, in the corridors of state, private meetings with officials and members of the Duma, or in other state fora.

Although Aleksei and Oleg are respectively from a GONGO and a formal NGO, and Oleg has some connections with state actors from prior involvement in politics, similar tactics are also identified by those who had fewer prior connections to the state before either beginning to work with or founding a CSO. They also identify tactics which bring any disagreement into private, out of the public sphere, and ways of aligning themselves with state actors to leverage their institutional power. For example, participants among smaller CSOs, registered and unregistered, and individual activists both not uncommonly described building a relationship with a Duma Deputy to then have the unofficial, voluntary position of their assistant or helper (*pomoshchnik*). They aimed to use this relationship to achieve change in a range of areas, from campaigning around national policies to putting pressure on local politicians to resolve issues, for example, with doctors or parking permits.

Developing a relationship with the individual in this state position allows civil society actors to rebalance power by occupying, via the deputy, a comparatively higher position and being able to create downwards pressure. Many people spoke about issues which were impossible

to resolve until they used a higher-placed individual with access to formal channels of governmental power. Aleksandra explained how she, 'had to become the assistant of a deputy of the State Duma (*pomoshchnitsa deputata*; a voluntary helper of the deputy) so that I could make requests (*zaprosy*) and put pressure on [those in] power (*davit' na vlast'*).'[xxxv] The 'requests' Aleksandra mentions are *deputatskie zaprosy* or 'deputy's requests'; enquiries from members of the Duma which must by law be answered, unlike her own requests as a private citizen. When I asked Aleksandra further about what she asked of the deputy, she said, 'I ask for "deputy's requests" (*deputatskie zaprosy*), I don't need them [deputies] for anything else.'[xxxvi] While other civil society actors may have other hopes to leverage their relationship with members of the Duma for other goals, Aleksandra offers the starkest version; all she claims to need is the power they hold to make requests which must be answered.

Civil society actors highlighted approaching the correct person and building a relationship with them as particularly important in the face of the ambiguity and lack of certainty around laws (Section 2). Anna said, 'Here, we all the same don't have the rule of law, but the rule of the personal factor. The rule of a concrete person who is right there at this point and bears responsibility [for the specific issue at hand].'[xxxvii] This is echoed by many actors who discussed the importance of 'telephone law' (like Evgenia), developing personal contacts, and working 'in the corridors' (like Oleg). Aleksei sums it up: '[we do] basically everything in manual mode (*v ruchnom upravlenii*; by hand). It's essential to look for those hands which can turn on the right levers.'[xxxviii]

These relationships are not only predicated on building trust through working as, in Oleg's words, 'a constructive partner.' They also in themselves act to bring potential contention out of the public eye. Oleg speaks in the corridors, Aleksandra disappears behind the deputy to make her requests, and Anna and Aleksei make telephone calls to a state actor with influence. Importantly, these modes of informal fluidity of state power occur out of the public eye and are not widely signalled. These quiet, hidden resolutions are part of compliant, but also very strategic, behaviour.

In some cases, this informality serves another purpose too. In maintaining the informality of a relationship with state actors, CSO actors also defend themselves from the loss of legitimacy associated with publicly formalising relationships with state actors, in the eyes of other CSOs.

Oleg speaks of his CSO as 'between the two fires,'[xxxix] explaining that some CSOs criticise it for being too loyal and close to government, while some CSOs say that it is too critical of government and collaborates with disloyal CSOs. Kristina discusses the reputational damage she perceives as done to her CSO by openly formalising a link with a member of the Duma, even while insisting this link is in his personal, rather than political capacity:

> This project is run together with Deputy [Name]. […] He, as he has the status of deputy, can send out requests [*zaprosy*] to local ministries, some authorities. […] A normal person can write too, but [then] it gets stuck. But when it's done as a *deputatskii zapros* or a lawyer's request (*advokatskii zapros*) it's already a different level of, let's say, appeal (*obrashchenie*). We have a position of principle that he be presented with our organisation as a private individual, we don't have it written anywhere on our site that he is [Kristina names his political appointments]. And we very deliberately move away from doing that, because actually from the side of some organisations people express mistrust just because we have some kind of 'private service' with a deputy. […] In my opinion, we've had some reputational damage because we accepted this cooperation, and that's a fact.[xl]

The rejection of the public sphere was also seen in how actors managed their partnerships with more contentious actors. Actors involved with registered CSOs described dissimulating relationships and collaborations with formal and informal CSOs, as well as with grassroots movements and groups, in order to maintain their partnership with the state. For example, Marina said:

> We have to think about our reputation a lot, who we can be linked with, who we can't, who we can openly enter into a coalition with, who we can help but clearly not, well let's say, be seen out together, if it's some kind of very drastic people, because well there are these really total rights defenders [*pravozashchitniki*] who, well, the whole time we have to try to balance between partnership with the state and attacking the state, that is be good enough, but not become too convenient [in the sense of malleable, comfortable for the state: *udobnyi*]. […] So, we also have some kind of half-hidden partners, well, not partners, but let's say we work with them [*vzajmodejstvuem,* cooperate with]. […] That [group] is their target group too, and so we overlap, and they often come to us, couldn't you defend there or there, but we basically don't participate in public events and we don't unite with them to write public petitions.[xli]

Reputational work to maintain a good relationship with the state involves dissimulating partnerships with other actors. Actors in formal, registered CSOs described their informal or hidden links with social movements and other communities, where they often participated as an individual, specifying that they are not there as a representative of any formal

organisation. Above, Marina specifies the need to maintain public distance from rights defenders. This distancing again is contextualised by conscious positioning of their CSO on the legitimised social side of binary for civil society organising.

4. Conclusion

In this chapter, I have demonstrated that civil society actors organising around disability perceive their environment as unpredictable and threatening. While this has previously been largely demonstrated about other, overtly 'human-rights' focused organising, this has not been so fully demonstrated for apparently 'social' organisations. This is a significant finding as it demonstrates that even 'social' CSOs perceive and negotiate threats of sanction, disassociating themselves from actions or discourses perceived as political or risky and engaging in reputational work. Although disability is widely perceived as a social or medical issue, actors organising in this field nonetheless see themselves, either as an organisation or as an individual, as potential targets for sanction.

Perceptions of uncertainty, potential sanction, and power imbalance elicit caution and reports of much consideration over what action, and what risks, to take. They increase the importance of personal contacts and networks, 'telephone law', reputational work, and other attempts to rebalance power and navigate the risks of organising. To manage risk, CSOs adjust how they act, present action, and build relationships. These adjustments aim to minimise friction between themselves and the state, by using behaviours and framings which align with those which they perceive the state to accept as legitimate.

The strongest overall opposition drawn by actors was that between social and political organising. A perhaps seemingly counter-intuitive opposition was also made between 'doing human rights work' and 'helping people.' However, given that social organising is legitimised, framing disability organising as related to social welfare, helping people, and charity is a way of protecting the organisation to continue action. Actors see human rights framings as more likely to draw sanction and prevent continued action. I find, however, that actors still see themselves as doing rights work, although that rights work may be not referred to in those terms, dissimulated, characterised as 'not classic' rights work 'per se', or otherwise distanced from 'radical' or 'total' rights defenders, whom they see as confrontational and highly political.

These adjustments to action and its framing support the identification by Fröhlich and Jacobsson of actors' strong awareness of their 'political surroundings and of the opportunities and limitations those create for collective action' (2019, p. 1154). Here I have focused on how this awareness is operationalised by actors to project compliance. In the next chapter, I look at how this compliance intersects with constructions and discourses of disability. I thus explore how actors' claiming of social, as opposed to political action, works through association with certain 'legitimising myths' (Toole, 2019) surrounding disability, as well as the space for resistance which this might open.

Chapter Six

Constructing and Instrumentalizing Disability as Apolitical

RQ.2.: Why is disability organising dominantly perceived as social and, therefore, legitimised? How do some actors subvert and instrumentalise that positioning of disability?

1. Introduction

In the previous chapter, I outlined how CSO actors enact compliance. I showed that disability organising is affected by a broader restrictive environment which delegitimises political organising. I suggested that this was significant particularly as disability organising has been naturalised as social and apolitical, and thus apparently legitimised. In this chapter, I further explore why disability organising is naturalised as social and apolitical, or unrelated to the sphere of political contention. I argue that this misrecognition intersects with the action which the state legitimises for civil society, and I demonstrate the implications and opportunities of these intersections. I address three questions: how is disability constructed as apolitical? How do these constructions of disability interact with enactments of compliance? How do some actors instrumentalise dominant (mis)understandings of disability, and what does this tell us about strategies which mobilise assumed vulnerability to resist?

This approach sheds light on the complexities of organising in Russia and bring together the disability and civil society literatures to demonstrate how disability often occupies a legitimised, safer space for organising through medicalising, charitable, and individualising understandings of disability and the limited recognition of disabled people's identities which these imply. Through addressing these questions, this chapter demonstrates how naturalised legitimacy is created and identified, and how this legitimacy is instrumentalised to resist.

If civil society action is legitimised where depoliticised, this drives both opportunities and restrictions. As with power and resistance, these opportunities and restrictions are also in a fluid, contextual, and mutually constitutive relationship. The use of claimed vulnerability as a channel of power is an opportunity to continue action (cf. Butler et al., 2016). Disability is

discursively and materially constructed as apolitical and non-agentic, and associated with vulnerability, charity, and pity (Satz, 2008, 2014). Disabled people's removal from the political sphere also operates through a problematic opposition between 'the notion of "rights" (reduced to civil rights) and that of "welfare" viewed as synonymous to charity' (Revillard, 2018, p. 3). Misrecognising disability as a charitable, welfare issue is supported by dominant medicalised understandings of disability (Heyer, 2005; Revillard, 2018). These depoliticise disability by casting it as an objective, technical matter to be dealt with by medical experts and, therefore, outside the field of power relationships (Chapter 3, cf. J. Morris, 1993; Revillard, 2021). These misrecognitions legitimise disability and permit disability organising.

However, 'welfare is not necessarily synonymous with charity and paternalism' (Revillard, 2018, p. 3). These claims require rights-based, political action (H. Dean, 2008, 2015; T. H. Marshall, 1950) and, as I suggest in my theoretical framework (Chapter 3), are inflected by power relationships and resistance. While the misrecognition of disability as an apolitical sphere of charity and paternalism engenders possibilities by rendering disability a legitimised sphere of civil society action, it also restricts that organising. If action continues on the basis that it perpetuates the misrecognition of disability, and thus is legitimised and non-threatening, it may itself enable or fail to challenge restrictive understandings of disability.

The chapter proceeds as follows. Firstly, I examine how disability is constructed as apolitical, and thus legitimised. These constructions misrecognise disability by restrictively identifying it with the private sphere, victimhood, and infancy. They enforce a need for positive discourses to address stigmatisation. Both how disability is constructed and how CSOs interact with these constructions may position disability organising as a legitimised, apolitical sphere for organising. Secondly, I explore a case of the instrumentalization of the relative legitimacy of disability organising. The deliberate movement of some actors from more delegitimised organising spaces, such as campaigning for change to the political regime, into disability organising shows that these actors identify disability organising as relatively legitimised, and thus less subject to state sanction and repression. Moving to this sphere with the aim of continuing resistance exemplifies strategies which use presumptions of vulnerability as a source of power and agency.

2. Constructing Disability as Apolitical

Civil society actors are intent on avoiding identification as political and make great effort to be seen as social actors. With a perceived need to depoliticise action, both how disability is constructed and dominant discourses around it offer actors resonant framings and modes of action which are normatively depoliticised. Artyom sums up the identification of disability as apolitical, and therefore as a legitimised sphere for civil society action. Referring to the formal, registered CSO by which he is employed, he says:

> They don't work with [people who are] LGBT, they don't work with migrants with disabilities, but this [he refers to a previous sentence about "working with disabled people"] is a kind of politically comfortable image in Russia to show how good we are, [to show] that there is some kind of social responsibility in the country.[xlii]

Artyom outlines the idea that disabled people are unthreatening and 'politically comfortable.' He suggests that his CSO could not legitimately, in the eyes of the state, use working with migrants or LGBTQ+ people to signal that they are 'good.' However, disabled people are considered unthreatening and apolitical, and therefore may play this role. The role is conditional; disabled people are perceived unthreatening on the condition that disability acts as a 'trump card' (Stienstra, 2015), overriding other facets of more politicised identities ('migrants', 'LGBT'). As I discuss later, if the CSO does work with disabled people who also identify as LGBTQ+, this identification would not be publicised and could be unwelcome (Chapter 8). Here, what Artyom refers to as 'politically comfortable' (*politicheski udobnyi*) reflects what I have been referring to as dominantly legitimised. Here legitimacy is connected explicitly with politics, suggesting the power of state to shape the field of possibilities for action.

In this section, I question the legitimising myths which suggest that disability is naturally depoliticised. The depoliticization of disability operates both through its construction outside of the public sphere, as well as by the misrecognition of disability through restrictive discourses of victimhood, passivity, infancy, and enforced positivity. Both exclusion from the public sphere and the availability of these discourses draw disability closer to legitimised action for civil society action. By availability of these discourses, I mean that they are commonly associated with disability. I do not suggest that CSOs necessarily agree or disagree with these positions. However, I note that describing CSO work against these discourses also

services as an indication of their dominance; these understandings are so pervasive as to set a target of CSO action.

2.1. Exclusion from the Material Public Sphere

Disabled people have been constructed outside of the public sphere by institutionalisation and segregation (Klepikova, 2018), lack of accessibility in the material, built environment (Hartblay, 2015b, 2017), and stigma, shaming, and other negative attitudes in public space (Iarskaia-Smirnova et al., 2015). There is a commonality between civil society legitimation strategies which draw protest out of the public sphere (Chapter 5) and the dominant association of disabled people with the private sphere. Protest and contention have also been often reductively associated with action in the material public sphere (Chapter 2). Similarly, disabled people's exclusion from public space has been naturalised as indicating their belonging to an apolitical, private sphere (J. Morris, 1993; Revillard, 2021). While the construction of the private sphere as apolitical is theoretically and empirically problematic, its dominant social reality nonetheless constructs an association between disability and legitimised action.

How disability organising interacts with the material public sphere is shaped by different forms of inaccessibility. It therefore often moves out of public view. Participants related various ways in which access to material public space is made difficult or impossible. These included an inaccessible built environment, a lack of information accessibility, insulting comments, and other negative reactions. Fyodor connected inaccessibility of the material environment with a lack of participation in public demonstrations:

> There really is a huge number of people with disabilities who basically can't leave the house. So, as a result, what do they care about freedom of assembly, or violations [of the right to hold] demonstrations, if they can't even get to those demonstrations.[xliii]

The conditions which Fyodor describes are part of the fragmentation of disabled people, making collective participation in public marches or demonstrations difficult. This interaction can make disability organising seem more compliant than other forms of organising, as it has a case-based, individualised approach and often does not use public actions. It also emphasises the importance of paying attention to resistance which is made invisible or choose invisibility or ambiguity as strategy (Chapter 7).

As well as physical inaccessibility, a lack of acceptance also led people to avoid certain places. For example, one woman described how she stopped attending church because of other congregants' negative reactions to her child. In other cases, people responded with a protective segregation. In that case, they no longer aimed to create mixed spaces, but rather aimed to create spaces within their own group where they could feel comfortable. Aleksandra described group holidays:

> So, let's say you go somewhere alone with a disinhibited (*rastormozhennyi*) child, everyone is going to tell you off, everyone's going to kick you out of there. You're not going to be happier out from that, right? And then basically you're not going to want to get out anywhere after that, you're going to sit alone and grieve. But if there are five kids like that, 10 kids like that, then no one is going to tell you off and no one is going to point at you.[xliv]

Organising their own space creates a form of invisibility. Aleksandra describes how a mother-child pair becomes unremarkable by forming a group. More widely, participants described a disabled person appearing in public in Russia as a jarring, resistant presence often remarked upon or excluded (cf. Hughes, 2010; McRuer, 2016). A retreat to a group controls the perceived threat of disability and of a disabled person who is not fulfilling the masquerade of ability (Siebers, 2004). The disabled person is not at large in society, but bordered off within and by the group. I contend that the group, as seen by others outside it, acts as a clear reason 'excusing' the disabled person's presence; it is something organised, controlled, and separated by the category 'disabled'. Grouped together by this category, onlookers may perceive no need to look for further identifiers or explanations and can clearly see the group as separate from them, and thus not destabilising or threatening to themselves. Even a public space, where segregated, becomes closer to a private and invisible one in that sense. Kristeva conceptualises the appearance of, or interaction with, a disabled people as inflicting a narcissistic identity wound, threat, and anxiety on the person who is not disabled (2012, p. 30); here I propose the group as acting to define, bound, and thus diffuse that threat in relationship to those outside it.

As Aleksandra already suggests, the group serves a different purpose to those within it. Where material public space is hostile, participants experience these kinds of shared, private spaces as protective and energy-giving. Aleksandra further described how she saw the mothers on their group holiday coming together in one hotel room to talk all night. She spoke about the aim of her project in creating such a space:

> Mums sometimes just need to be together a bit, just be somewhere where you aren't alone and understand that, in the end, living is possible (*mozhno zhit'*). To understand that living is possible, you need to talk with people like you.[xlv]

Separate spaces thus play a different role for those inside the group and those outside the group. For disabled people and their family members, creating their own group is a form of self-preservation and creates positive resources to be drawn upon by the group (Villalpando, 2003). For others, the rejection of disabled people from 'their' space is a form of policing and segregation, reflecting images of disability as social threat. Creating their own spaces, either by moving outside of the public sphere or by moving through that public sphere in protective groups, can be a positive resource for disabled people and their members. However, it does not challenge the collocation of disabled people with the private sphere, and thus their association with less confrontational, depoliticised forms of action. These forms of action happen beyond the public view, like the hotel rooms where Aleksandra describes mothers talking together into the night and, as we saw in the previous chapter, the corridors of government and direct relationships with members of the Duma through which other problems are addressed.

2.2. Discourses of Apoliticism

In addition to the construction of disability outside of the material public sphere, disability is also depoliticised by various discourses. Here, I present how discourses of victimhood, passivity, permanent infancy, and responses to negative understandings of disability which enforce positivity coincide with legitimised forms of civil society action. These discourses combine to position disabled people as worthy recipients of charity or, in Artyom's words, a 'politically comfortable image in Russia to show how good we are.'[xlvi]

2.2.1. Passive victimhood

Discourses of victimhood understand disability as a personal tragedy which disabled people suffer. It is commonly used to discuss disability in Russia (Verbilovich, 2017). These discourses associate disabled people with passivity and lack of agency. Disabled people are decentred to act as a useful passive or recipient object, fulfilling this role as the classic figure of vulnerability (Revillard, 2018; Satz, 2014). Working with disabled people thus also becomes a question of charity, rather than rights.

Many participants described charitable approaches which do not constitute disabled people as active agents. Many non-disabled participants spoke about 'helping' disabled people. Many family members of disabled people emphasised too that, if they did not help, no one else would. For example, Aleksandra said, 'I understand that, other than me, no one else is going to come for them.'[xlvii] They also emphasised that disabled persons themselves were not in a position to act to resolve particular issues. When participants spoke about this further, they associated this with the need to spend relatively more energy on daily tasks, because of both constructed exclusion and impairment effects. They also associated disabled people's difficulty in resolving issues with the lack of access to adapted information, communication channels, and respect. Civil society actors felt that others, including state actors, perceived these boundaries as a function of the personal deficit or global incapacity they incorrectly impute to disabled people, rather than obstacles created by the environment. This perception meant again that disabled people were often naturalised as unable to be agentic and viewed as targets of charity, rather than themselves active claimants entitled to rights.

These framings of disabled people were also instrumentalised, particularly to fundraise. For example, Artyom describes his CSO as presenting disabled people as victims:

> There is some opposition [to my methods], for example [from] the fundraising and PR department, because very often their economic strategies, which allow us with that money [to do our work] do not at all coincide with the social model of people with disabilities. When you say that you shouldn't victimise people, they say that then no one will give us money.[xlviii]

Above, I cited Artyom referring to working with disabled people as a performance of 'goodness' and 'social responsibility.' Here, the act of donating in response to such victimising images centres on the person 'helping', who performs their 'goodness' and 'social responsibility' through giving to the passive disabled person. In situating disabled people as deserving recipients of charity, potential donors are focused on and positioned as the active parties. Others in the CSO justify this approach as a strategic choice, allowing them to raise more money to enable the CSO to continue its work. These actors maintained that charitable, victim-based framing was more resonant with their audience and more likely to elicit donations. The framing, however, does not challenge dominant views of disability, but rather reinforces them as a basis for raising money.

While Artyom was highly critical of this approach, some other actors describe disability as in fact a social or medical issue, objectively removed from politics. For example, Vera said, 'the grief and illness of a child, it's probably its only plus, doesn't have an ethnicity (*national'nost'*), doesn't have religion, it doesn't have anything, it's higher than politics.'[xlix] Through focusing on grief or pain (*gore*) and illness or disease (*bolezn'*), disability is reduced to a medical, physical problem consonant with a personal tragedy model of disability (M. Oliver, 1990). It is this personal tragedy, concretised in pain and illness, which is then capable of uniting people. Its opposition to such factors as religion, ethnicity, or politics suggests that they, conversely, divide people. Here again, disability acts as a trump card which erases other aspects of identity.

I do not question that pain, grief, and illness can all be parts of experiences of disability. As discussed in my theoretical framework (Chapter 3), this is the dangerous recognition of physicality and illness which many have criticised disability studies as silencing in its efforts to avoid the reductive equation of disability with these aspects alone. The danger is that vulnerability be misidentified as inherent to disability, rather than constructed and selectively imposed. In Vera's description, disability is reduced to suffering and illness which erases or renders unimportant other aspects of identity. In Artyom and Vera's words, disability is conflated with charity, medical problems, tragedy, and pain. Either critically (Artyom) or with claimed objectivity (Vera), they represent disability as detached from ethnicity, migration status, religion, and sexuality and gender identity. Disability is thus disassociated from factors which actors present as more politically risky.

Some people work against these perceptions. For instance, Vladimir and Igor, both quoted below, discuss how passivity is created by others' relationships to disabled people. They see their work as drawing disabled people out from such overprotective, passive relationships and giving them the tools and confidence to be more independent. For example, Vladimir, a disabled man who has founded an NGO, said:

> …when people relate to them like that, when even their close relatives bring them up like that […], they firstly stop believing in themselves and they believe that they are disabled (*invalidy*), that means those who can't do anything by themselves, and, if they can't do anything physically, then that means they can't do anything at all in principle. They can't work, they can't have a family because no one will love them like they are, they can't have friends either. […] And then they don't believe in anything and they really become these kinds of dependent people

> (*izhdiventsy*) who are used to getting given things (*kotorye privykli poluchat'*). They don't understand that they can give back (*otdavat'*) and that basically you need to give back to society. And how can a person really be fully-fledged individual (*lichnost'*) when they believe that everyone around them owes them something.[l]

Igor, a disabled man involved with an informal organisation, commented similarly on the goal of one project:

> [The goal is] that a person, basically, when he is sitting in the children's home (*detskii dom*) and not doing anything, when they limit him and all that overprotectiveness (*chrezmernaia opeka*). [The goal is] to save him from that overprotectiveness, to show that he, basically, is a relatively independent person. […] Here we decided to create this kind of story [*Igor refers to the project*], also to teach children to give back, that is, they should not just demand, [the aim is] to widen that circle a bit, that outlook, [to show them] that they can, that they have possibilities.[li]

Igor then describes a project where the disabled children were the ones to make and give presents to non-disabled adults, seeking to flip the script from disabled children as recipients to active givers, or themselves donors. The project aimed primarily to demonstrate to the disabled children that they can give, as well as to challenge others' assumptions that they could not.

As in Igor and Vladimir's examples, in aiming to build disabled people's sense of their own capacity, the change sought by disability CSOs often turns towards the individual, rather than their environment. In the previous chapter, I offered the examples of Marina and Ekaterina, who observe that they would prefer to work with individual cases and oppose such an approach to a 'political' approach, which they associated with working on a more structural level. Here too, Igor and Vladimir suggest working on the individual's self-perception. While self-transformation and 'alternative modes of self-making' (Lilja & Vinthagen, 2014, p. 118) are forms of resistance, they are forms of resistance which may be less likely to demand structural challenges. This individualisation makes such resistance less likely to be perceived as threatening to state. This reinforces the perception that CSO work on disability is apolitical and safe.

While Igor and Vladimir's approach differs from the trope of passive victimhood actively advanced by other CSOS, their words also suggest that perceptions of passivity and victimhood are so socio-culturally dominant as to associate working with disabled people with

charity. The entrenched nature of passivity and victimhood framings is demonstrated by the primacy which other civil society actors gave to the need to develop self-confidence, self-help, and self-advocacy, and to move away from the idea of receiving help. The minimised perception of agency similarly decreases associations with potential threat, as did avoiding framing disabled people as rights-claiming citizens. A charitable framing, legitimised for civil society action, thus dovetails neatly with dominant representations of disability. These framings are, of course, not consistently used in all organising around disability; here I rather identify both the common availability of a victim discourse which may be used by CSOs to facilitate their action, and how this discourse fits with legitimised, charitable, non-politically threatening action.

2.2.2. Perpetual infancy

Disabled people are often misrecognised as subject to 'perpetual infancy' (Battalova, 2019, p. 907). This intersects with the above discourse of passivity, again constituting disabled people as non-agentic and not politically threatening. Infantilising disabled people also distances them from sexual agency. This disassociates them from politicised sexual identities which are not a legitimised sphere of civil society action, as Artyom suggests above ('they don't work with [people who are] LGBT'). In the disability organising sphere, dominant perceptions of infantilisation are supported by the number of CSOs which are founded and run by mothers. This is particularly the case of CSOs which organise around a specific diagnosis, often founded by mothers following their child's diagnosis. The ecosystem of disability CSO may thus be constituted as reflecting a dominant, maternalist image where the mother sacrifices to support her child and help others in a similar position.

The prominence of mothers in disability organising may perpetuate external misrecognition of the disabled person as infant. Simultaneously, it positions women running the CSOs in an accepted, caring, maternal role. In a context where the state strongly proposes pronatalist discourses (Sperling, 2014) and motherhood is an important, desirable social role (Battalova, 2019), the use of this discursive frame may also be legitimising. This operates through the association of the mother-child relationship with the private sphere, misrecognised as apolitical. Caring labour is also depoliticised through association with the private sphere. This neither threatens dominant understandings of motherhood, nor those of a heteronormative family. Thus, not only is the disabled person desexualised by their association with perpetual

infancy, but the mother's position also remains within the boundaries of an accepted, heteronormative family.

Women perceived their identity as a mother as both legitimised and supporting action. Aleksandra, for example, felt that she could use her position as a 'mother of a disabled child' ('*mama rebionka-invalida*') to quicken judicial proceedings. She observed that, although there are often delays, there are not so many with her as there are with a professional lawyer. In her eyes, this is because she can claim that she is the mother of a disabled child and must therefore get back to them to fulfil caring responsibilities. She can thus put pressure on the court to 'somehow wrap things [i.e., judicial proceedings] up.' Aleksandra mobilises the expectation that a mother must be in the home, performing caring responsibilities, to expedite proceedings and decrease the length of time for which she must be away. This plays both on the disabled person as a dependent, perpetual infant, and the framing of domestic, caring responsibilities as naturally those of the mother.

The 'family' nature of their CSOs was also prized by many mothers. Themselves often unpaid, many actors expressed distrust in those without a family connection to disability who are active in disability CSOs, as well as distrust in larger, highly professionalised CSOs which they saw as focused on money and self-PR and not acting in the best interests of their children.[33] The claims made by parents' organisations are largely framed in terms of social welfare (*sotsialka*) and medical support. They situate the mothers are protective of the family, including their disabled child. Again, the child is positioned as a perpetual infant and related to through their family, most commonly through their mother. This framing also aligns both with the restriction of the disabled person to the domestic sphere, which is depoliticised and, thus, more legitimised for civil society organising.

Where protest occurs, it is then often characterised as 'shouting', evoking female hysteria rather than political threat. Thus, parents' organisations, chiefly run by mothers, are often criticised as frustrating the state with their lack of professionalism. However, this lack of professionalism is not understood as politically threatening. For example, Oleg exemplifies this criticism in describing how, 'parent groups, they are very loud, but they cannot formulate

[33]This returns to the importance of my family connection to disability in some interviews; in the eyes of many participants, this family connection acted to justify my interest in their work. I have discussed this in more detail in Chapter 2, where I present my methodology.

what they want. And they don't know the limitations. So, they come up, start shouting, and actually the government officials get irritated, and this does not lead to a solution.'[lii] While the forms of action used by some parent-led CSO were sometimes criticised as undesired and not fitting with that of 'good partners' of state, they are made less threatening by the legitimised, social discourses in which demands are framed and the domestic, familial roles which they reproduce for both mothers and disabled 'children.'

2.2.3. Forced positivity

The final discourse of apoliticism is what I term 'forced positivity'. Discourses of forced positivity entail producing positive narratives, avoiding negative images, and distancing from association with other stigmatised, and indeed politicised, behaviours or identities to redress a stigmatised identity. By producing positive narratives and avoiding negative images, I refer to producing narratives which are aligned with traits or characteristics rewarded by socially dominant norms. I call this positivity 'forced' as it occurs to counter dominant negative stereotypes around disability, including global incapacity and pathologized dependence. It is 'forced' as civil society actors identify disability as so stigmatised that they hold fewer possibilities of publicly producing negative discourses.

Above, I gave an example of in-group interaction building resources and the belief that 'living is possible' (Aleksandra). Outside of the public sphere, there is indeed space for open discussion of experiences, including negative ones. In public space too, such accounts are present; there are many open letters, petitions, blog posts, online and offline media articles discussing the difficult situation of disabled people in Russia. In one example, the online campaign group *Invalidy Intergratsiia* (Disabled People Integration), which campaigns for the increase of the amount of money given in benefits for those people engaged in the care (*ukhod*) of disabled people from the first group (*invalidy pervoi gruppy*),[34] released an online book entitled 'The Book of Pain and Shame' (*Kniga boli i pozora*) (2020). The book brings together 158 accounts from disabled people about their difficulties in affording necessities for daily life and living independently due to financial hardship.

[34]Discussed in Chapter 3, people are registered as disabled into one of four overall groups. Firstly, there is the group for children. On reaching adulthood, there are three groups into which people are categorised. These groups follow a largely medical-productivist understanding (Phillips, 2009) and categorise people from most severe impairment (group one) to least severe impairment (group three).

However, these accounts are often frowned upon by formal CSOs as not constructive. This is linked to the idea of the disabled person as feeling entitled and enacting the role of the permanent recipient or, in Vladimir's words, 'dependent people (*izhdiventsy*) who are used to getting given things (*kotorye privykli poluchat'*).'[liii] This dominant stereotype around disabled people creates discourse which may be used to dismiss accounts of problems as simply disabled people 'complaining', 'not being constructive', or malingering. Thus, any complaints are misrecognised as unfounded and typical of people who just want to receive from the state, without contributing. This builds on dominant discourses of the disability fraud, which stigmatises dependence (Hartblay, 2014a; Mladenov, 2016) and suggests that the disabled person is faking their disability to unjustly claim various benefits and services (Dorfman, 2019).

Using negative discourses to dismiss an act of resistance has been theorised by Toole (n.d., forthcoming) as misrecognising an act of resistance by taking it to confirm a negative stereotype about a particular group. This undermines the resistant force of the action, at least among those outside of the group engaged in that act of resistance. For Toole (ibid.), this is an act of epistemic oppression which denies resistance where it is present. I add that I see the very potential of this manoeuvre as having a further effect on CSO actors. They are both aware of the presence of these dominant stereotypes around disability and conscious of the potential for their communication to be taken as confirming these stereotypes. They therefore pre-emptively shift their communication, thus enacting forced positivity.

In doing so, actors self-censor, neutering their own complaints and prioritising accounts which are in line with dominant norms and produce positive discourses. They describe avoiding complaining or making certain requests, unless the situation was critical, out of fear of fulfilling negative stereotypes of disabled people as pathologically dependent and/or malingering. In doing so, they simultaneously enact compliant behaviour in an environment where public negativity and 'complaining' are dismissed as non-constructive and even associated with delegitimised human rights organisations.

In the previous chapter, I demonstrated that avoiding complaining behaviours and embracing a discourse of positivity is particularly common among more professionalised CSOs, who described avoiding scandals and sharing negative stories only as a last resort. Compliant behaviour implies drawing contention out of public space, moderating requests to match the

state, and using state channels. Some actors described criticism and complaining as typical of non-constructive behaviour and not characteristic of good partners of state. Thus, where CSOs avoid complaining to avoid reinforcing negative stereotypes about malingering or dependent disabled people, they also act as a better partner of state. Others associate negativity and complaining with human rights organisations, whose activity is delegitimised.

Eva's words make clearest the interactions between 'complaining', delegitimised human rights organising, dominant constructions of disability, and organising around disability:

> The human rights groups were just negative, they were very negative and all they were doing was criticising, and so we were like saying no, this doesn't work, but we were trying to do it in a most positive way and a more constructive way and saying let's do this, well, why don't we do this, we can do some training here, right. So, […] like when we, you talk about the human rights groups, we don't really put ourselves in that category, although we're definitely doing rights work. Definitely. But, and even when I'm at meeting with the human rights groups, I can't even begin to tell you how, I'll go to a meeting [*laughs*], and then they speak, and then by the end of the meeting I'm so depressed that I can hardly open my mouth, because they talk about all the horrible things that are happening, and there are a lot of horrible things that are happening, and I'm thinking, oh my God, and now I'm going to talk about some of these things that are happening, but I think, it's in part, it's our mindset, that we've had to, I mean, from the start, we've had a different kind of mindset, maybe it's because, it's because, maybe it has something to do with the fact that it's people with disabilities driving the work we're doing, and parents, it's about changing attitudes, and it's hard to change attitudes when you're really negative. You have to show positive images. I mean, that's another thing, showing positive images, showing positive change, because then people believe it. And then people can imitate it, they can start doing it, right. And so we had to be an example for other people.[liv]

A key difference through which Eva disassociates with human rights organisations is their negativity. Given that a key aim of her CSO is de-stigmatisation, she perceives negativity as counter to their goal. Rather, their role means 'ha[ving] to be a [positive] example' and to represent disabled people positively. In Eva and other actors' talk, complaining and being negative are delegitimised as non-constructive, overly conflictual, and associated with human rights groups. Actors saw this behaviour as in conflict with CSOs' legitimised role as partners of state, who take into account the state's point of view and its competing, and even conflicting, priorities. Again, the need to be positive to drive change around disability fits with CSOs' perceived need to be positive, constructive, and not overly critical in their relationship with state.

Aleksei gives a related example. When asked whether the CSO in which they work uses personal stories to draw attention to systematic problems and seek their resolution, he said:

> …it's not a practice of ours to tell some kind of stories under certain people's names exactly and bring them to a very high level [of state], because that's wrong, actually, I think. Of course, there are some kind of particular situations, as a rule positive situations, where a [disabled; here Aleksei specifies the impairment] person has achieved really successful results in sport, culture, the creative field, then – yes, then we actually do try to show [the story], including trying to get some kind of state prizes presented for it, so that attention is paid to the story. We also try to tell the world, society more about positive heroes of ours, about our good results.[lv]

Aleksei emphasises particularly the need to promote positive stories. Doing otherwise would not be a correct use of their position and relationship with organs of state. This ties the idea of being a constructive partner of state with the perceived need to spread positive representations of disabled people. Aleksei and Eva are not alone in emphasising positive images and narratives; many people spoke about the need to demonstrate the capabilities of disabled people to a wider world which assumed them to lack capability.

CSOs feel that they must propose positive discourses and narratives about disabled people to challenge dominant perceptions of disabled people as passive victims. This aligns with modes of organising which are perceived as less threatening and more constructive in relationship to state. It differentiates them from human rights organisations, who are seen as both too political and too negative and critical. Moreover, it differentiates these CSOs from many of the parent-led CSOs, described above, who are characterised as shouting and complaining. Their form of negativity is seen as more irritating than politically threatening, through its association with motherhood rather than with human rights organising. However, it is nonetheless again criticised and avoided by CSOs who want to enact compliance and be seen as constructive and good partners of the State.

3. Instrumentalising Apoliticism

Above, I analysed how disability organising is discursively naturalised as a legitimate area for civil society organising. This naturalisation operates through the interaction of characterisations of legitimised action for civil society with the misrecognition and restrictive construction of disability. According to these discourses, disability is recognised as an apolitical, charitable, medical issue, and disabled people are passive and, often, infantilised.

Moreover, a discourse of forced positivity moderates the tone, narratives, and images used to refer to disabled people. Finally, disabled people are excluded from the politicised public space both materially, through its physically inaccessibility and the stigmatisation perpetuated by people within these spaces, and through their discursive construction as perpetual infants, related to their mothers and the domestic sphere. This misrecognition aligns with social, depoliticised, and therefore legitimised areas for civil society action, position disabled people, where so misrecognised, as worthy recipients of charity.

Disability organising is perceived as less threatening than other areas of civil society organising. This perception is based on the naturalised vulnerability of disabled people. However, if we see this vulnerability as constructed and therefore able to be instrumentalised, we might also see disability organising as an area where misrecognition may be mobilised as a strategy of power. The distinction between these two positions is suggested by the examples of Artyom and Vera, cited above. Artyom was critical of the use of discourses which victimised disabled people and used disability as a safe image for abled people's performances of goodness and social responsibility. Meanwhile, Vera equated disability with 'grief and illness' and referred to disability as erasing other identifies ('[it] doesn't have an ethnicity (*national'nost'*), doesn't have religion, it doesn't have anything, it's higher than politics').[lvi] While Artyom sees depoliticising, victimising framings as a misunderstanding of disability which is used by others, Vera suggests that it is an objective description of the nature of disability.

These viewpoints do not both allow entry into claimed vulnerability as strategy. Butler, Gambetti, and Sabsay (2016) specify that strategies which use vulnerability to gain power are intentional and deliberate. Yet in instances, such as Vera's, where actors perceive vulnerability as objective and naturalised, they are not using vulnerability in the agentic strategy which Butler, Gambetti, and Sabsay describe. On the other hand, where actors recognise vulnerability as constructed and contingent, as in Artyom's case, this opens space to instrumentalise that vulnerability as a route to power. In both cases, claiming vulnerability or tragedy creates space for continued action in an environment where politicisation means delegitimization. However, only in Artyom's case can we identify it as a potentially resistant strategy, where others' imputations of naturalised vulnerability may be capitalised on to continue action.

Some actors strategically benefit from the naturalised apoliticism of disability organising. A clear example of this is those actors who deliberately moved into disability action from more politicised, and thus delegitimised, spheres as a way of continuing resistant action. These actors instrumentalise the relative legitimacy, and thus lesser restriction, of disability organising as opposed to, for example, feminist, LGBTQ+, or environmental organising or that against corruption and electoral fraud. They do so to engage in action which they define as resistant and, in some cases, political, in line with their own convictions.

While these modes of action and meaning-making are not the most common among civil society actors whom I interviewed, they are nonetheless an important phenomenon for two reasons. Firstly, they demonstrate the strategic awareness of disability as naturalised as a legitimate area for organising and how that is instrumentalised. Secondly, in doing so, they give an empirical example of how assumed vulnerability may be a source of agency and resistance. In exploring these examples, I show where and how actors continue to engage in resistant action which they themselves claim as political or rights-based.

The strategic awareness which actors demonstrate around disability action is contextualised by the wider binary that actors identify between 'social' and 'political' action (Chapter 5). Liza discussed how the founder of her CSO had moved into social, charitable action after becoming disillusioned with the lack of efficacy of public protest at achieving political change after what the founder perceived as the failure and repression of protests in 2011-2013. These protests took place following the presidential elections at which Putin was re-elected president. They were triggered by the re-election and by allegations of fraud in the voting process. Liza situated the founder's disillusionment as part of a bigger movement around that time:

> It was 2012, it was quite a strange year – political protests, new re-elections (*pereizbranie*), and there was some kind of rise in protest movements, opposition, and so on. We somehow thought it was possible to change something by participating in political activity (*politicheskaia deiatel'nost'*) – that was the general mood, at least with a middle class of people who live in the big, million-inhabitant cities. There was this kind of dynamite, and then it passed and faded away after political conservation. Many people went into social work. Many of those who were then doing political activity went into direct help (*priamaia pomoshch'*) or into charity.[lvii]

Liza presents the movement into 'direct help' or 'charity' as a response to disillusionment with the idea that it was 'possible to change something by participation in political activity.'

While not explicitly, 'political activity' is again opposed to movement into charitable and direct help. This direct help may fill gaps in state provision, but, in Liza's phrasing and at this moment of transition, this gap filling is not done as an explicit criticism of state failure and with the aim for political change. Liza continued to say that the founder phrased the shift in strategy by saying that 'he understood that politics divides people, while volunteering and helping people unites people'[lviii] This statement recalls Vera, who describes disability as higher than politics. However, not all actors proclaimed such distance from politics. In fact, the naturalised understandings of the social sphere as removed from politics, indicated by Liza and Vera, gave activists some latitude for continued organising.

While Liza referred more generally to a movement into the social sphere as shift away from politics, other actors used a similar logic of 'moving into social action' as a deliberate and strategic method to continue political action. For example, Artyom said:

> Our path into [working in] residential institutions [PNI] is also an attempt, in the first place, to politicise our own practice as cultural professionals. […] As a consequence, I got a job in an NGO as a [position] because I felt, again, that in that position I could do more. I can influence decision making and I have more levers, again, to change something. […] For me, my activism, I mean this museum-based pedagogy, linked with inclusion in museums, now doesn't work, because there aren't the right conditions there. I took those museum methods, brought them over into a completely different soil in residential institutions, and in my opinion that's where they started to work and were in demand. So, I mean, in [doing] that was some kind of activist position of mine within art. […] I mean, for me studying the transformation of the norm and ableism [*eiblizm*], discrimination in art was very important.[lix]

Maksim spoke about moving into a new type of organising following state repression of the wave of protests happening in 2011-2013. In the face of the heavy sanctions, including custodial prison sentences which some activists received following these protests, the movement group with which Maksim was previously involved collapsed. In discussing what he calls the 'community or movement' (*soobshchestvo ili dvizhenie*) with which he is now active, he said:

> Well, you know, about [our community or movement], at first, I was thinking, in some kind of very long-term perspective, that it could be a new political figure. Because you never know what will work here. And we started to do this [i.e., organise as this community or movement] already after the repressions which followed the mass protests. And I thought about how to continue engaging in politics [*zanimat'sia politikoi*]. And why not try to work from the face of people

> who are so excluded, like, well, so harshly excluded, yes. Why not try that figure, well, of the madman (*bezumitsa*), right, as a political one? Why not think about it [that figure] like that?[lx]

Both Maksim and Artyom discuss moving into disability action as a strategic manner of continuing political work in a difficult or repressive environment. While their intent differs from Liza's, a commonality links all three actors. Liza, Maksim, and Artyom all suggest disillusionment with and exit from formal political channels, overtly political campaigning, state institutions, and, often, direct, public, street protest. They do not believe in the possibility of achieving a change in political regime via such protest and find refuge in the perceived apolitical and safer spaces of social action offered by disability organising. Where they exit to and how they understand their work differs; Liza and Artyom turn to work with a formal, registered NGO, and Maksim to engagement in a prefigurative social movement. However, in each case there is nonetheless an element of working directly with concrete people or individualisation of action. The initial difference lies in whether actors do (Artyom, Maksim), or do not (Liza), frame this direct involvement in terms of political action or criticism of the state failure which has resulted in the need for individual or CSO intervention. As I discuss further in looking at different forms of ambiguous and hidden resistance (Chapter 7), this commonality also offers an example of the different meaning-making which actors bring to seemingly similar actions.

In the case of moving into disability action as a mode to 'politicise […] practice' or to 'continue engaging in politics,' disability organising appears a sort of abeyance structure. Some actors move into the disability sphere as organising which is judged to be overtly political faces state repression. This movement demonstrates the commonly held perception that disability organising is legitimate and relatively unthreatening. As I discussed, disability organising is allowed its space under conditions of misrecognition. Actors' intent to deliberately subvert this apparently legitimised space to continue organising is a resistant form of action, which instrumentalises the misrecognition of disability as apolitical. This space accepts challenges to that misrecognition which are indirect, ambiguous, and potentially multiply legible to different audiences, but these actions do not rule out less challenging interpretations. Indeed, the rights-based action which continues in this sphere was often described as indirect and dissimulated (Chapter 7).

4. Conclusion

In this chapter, I demonstrated how disability organising is dominantly identified as apolitical, and thus legitimised. I examined discourses which misrecognise disability itself and civil society actors' responses to these misrecognitions. I showed how discourses and some responses of civil society actors to them draw disability in line with compliant, legitimised behaviour for CSOs. They construct the disabled person as a positive, non-threatening, passive, child-like or infantilised victim, who is thus a worthy recipient of charity. All CSOs are navigating the complex and unpredictable landscape, which often compels them to adopt compliant behaviours to survive in and negotiate the unpredictable environment. However, disability CSOs' actions and perceptions of their actions are also shaped by dominant misrecognitions of disability.

The deliberate use of this misrecognition identifies space for the instrumentalization of vulnerability as a source of power. To explore this, I present actors who chose to move into disability organising with the perception that it offered greater room for contentious, rights-driven organising. This shows one effect of perhaps paradoxical effect of disability organising's overt depoliticization, as the vulnerability and apoliticism imputed to disabled people is mobilised to strategically continue action. This supports the reassessment of vulnerability. The instrumentalization of misrecognitions challenges the presupposition that 'paternalism is the site of agency, and vulnerability, understood only as victimisation and passivity, invariably the site of inaction' (Butler et al., 2016, p. 1). Instead, where the presence of resistance is a condition of power (Foucault, 1982), vulnerability too can be re-imagined as 'one of the conditions of the very possibility of resistance' (Butler et al., 2016, p. 1). Here, the assumed vulnerability present in the dominant ascription to disabled people of passivity, victimhood, and infancy, is leveraged to continue to resist. Resistance from this position thus demonstrates the instrumentalization of constructed vulnerability as a source of agency.

However, as I demonstrate in the next chapter (Chapter 7), this resistance often remains individualised and ambiguous, permitting multiple readings and meanings. Above, we saw through Artyom's example that, even where individual actors are critical of the naturalisation of victimhood and passivity in association with disability, their CSO may nonetheless externally present their work in such a way to remain legitimised and unthreatening, or

benefit from the perceived financial incentives to reproduce disempowering discourses. The strategy walks a tightrope. Aiming to minimise risk and safeguard the continuation of CSO action, it both permits some people to create their own resistant meanings around their action and leaves some power relationships untouched. In the final empirical chapter (Chapter 8), I identify some exclusions of such ambiguous strategies and how some actors respond to these exclusions.

Chapter Seven

Everyday Resistance, Ambiguity, and Difficulties in Challenging Power Relations

RQ.3&4: How do actors enact resistance while remaining apparently compliant? How does strategically ambiguous resistance relate to existing power relationships?

1. Introduction

Thus far, I have identified how actors identify and perform compliance as a strategic choice which prioritises the continuation of CSO action over taking risks around the boundaries of legitimised action for civil society. I have demonstrated how performances of compliance overlap with how disability is dominantly misrecognised. Finally, I have shown how legitimacy based on misrecognition may be strategically mobilised to continue to resist in a restrictive environment. This legitimacy is based on dominant assumptions of passivity and victimhood, as well as charitable responses to disability. Resistance from this position firstly demonstrates the instrumentalization of constructed vulnerability as a source of agency. Secondly, it suggests that certain forms of resistance go unrecognised, and thus remain legitimised to external perception. This second point is my focus in this chapter.

Here, I focus on performances of resistance by specifically exploring the unseen, compliantly framed ways in which actors describe themselves working for rights, resisting, or engaging in politics. This analysis is significant as it explores the nuances of identifying resistance in a restrictive environment, where actors' resistance strategically seeks to evade the eye of the dominator. Legitimacy is constructed through apparent compliance with the misrecognition of disability and resistance, in action which is therefore not identified as political (Chapter 6). Civil society actors' performance of compliance thus challenges research not to replicate their strategic erasure of resistance. In this chapter, I therefore aim to recognise and critically explore the forms of resistance which continue.

As discussed in Chapter 3, infra-political action, or the daily actions of resistance which are 'beyond the visible end of the spectrum' (Scott, 1990, p. 182), is encouraged by restrictive environments where actors are highly aware of power imbalance and potential sanction. This awareness is reflected in actors' ambivalent, liminal resistance, which may be perceived differently by different audiences. Exploring these forms of action demonstrates how actors continue to resist. I present actors' understandings of their continued work for rights in a context where rights-based discourses are largely delegitimised and often publicly disavowed. In looking at resistance, including rights-work, I identify strategies of individualisation, ambiguity, and curating meaning and access to that meaning.

I do so by paying attention to how actors make sense of their action. These forms of resistance often use prefigurative strategies to remain non-apparent. Yates defines prefigurative politics as characterised by 'collective experimentation, the imagining, production and circulation of political meanings, [and] the creating of new and future-oriented social norms or "conduct", their consolidation in movement infrastructure, and the diffusion and contamination of ideas, messages and goals to wider networks and constituencies' (2015b, p. 1). Here, however, I identify prefigurative strategies which are not necessarily used within a movement or even collectively. They are neither necessarily consolidated in movement infrastructure, nor aim for wider diffusion. Rather, they are strategies which create new meanings and norms within closed groups, or even to individuals. Wider diffusion is deliberately controlled in an environment where actors perceive that addressing a broader audience could incur sanction. Identifying these strategies extends the repertoires of action recognised as resistance. I also question how these strategies interact with power relations and social norms. I show that these strategies of dissimulated, or non-apparent, resistance both create space for resistance and struggle to escape or redress dominant power relationships.

The chapter is organised as follows. Firstly, I outline how civil society actors seek to work for rights while avoiding identification as doing so. Strategically distancing themselves from both direct confrontation and politicised framings, they reclaim rights in an abstract sense which understands rights as overriding values concretised in daily action, volunteering, or other work with people whose rights are not respected. Secondly, I look at three modes of maintaining the ambiguity of protest: (1) how actors identify resistance in everyday action under the conditions of disability; (2) how actors restrict who has access to their meaning-

making; and (3) how actors turn inwards and create separate, more closed spaces and events. Over these three modes of resistance, I discuss the temporality of resistance in how and when actors perceive it becoming resistance, and how and when that identification is shared. Thirdly, I look at some of the different meanings which actors ascribe to the same actions and how these meanings may reflect the re-inscription of power inequalities.

2. Understanding and Dissimulating Rights

I have demonstrated that civil society actors perceived rights work as often delegitimised, and therefore often avoided framing their work in terms of rights (Chapter 5). However, many actors nonetheless described their intent to defend rights, while approaching this in a dissimulated manner which obscured their intentions to avoid being identified as engaging in rights-based work. For example, Galina spoke about how she did not 'feel like a classic rights defender (*pravozashchitnik*)'[lxi] and tried to avoid being seen as a 'rights defender' (*pravozashchitnik*). Galina did, however, identify her work as defending rights, if indirectly. Here, I look further at how actors understand their actions as working for rights and resisting, even where compliantly framed.

Exploring how actors like Galina refer to rights demonstrates understandings of rights which do not necessarily refer to individualised social rights or realising existing entitlements under law as putatively more legitimised rights. Rather, they advanced an understanding of rights which related to a more global sense of justice and an approach which operated through volunteering and direct action. In this sense, their work is prefigurative in that it aims to implement new norms of behaviour and respect in their immediate environment. Actors identified rights work in their activities as volunteers, leading group sessions including art, life skills, sport, and other activities. Rather than more specific entitlements, they discussed this as ensuring or contributing to people's rights to self-expression, respect, freedom, and a decent life. For example, Tatiana described her perceptions of her own motivations and the role of her volunteering:

> Actually no one is guaranteed (*zastrakhovan*, lit. 'insured') not to [end up in a residential institution], and that's one of the reasons why this topic really sticks to me because, in that way [by volunteering] I am fighting a bit for myself, too. […] Maybe we do social welfare work (*sotsialka*), but again it's difficult for me to divide those concepts, because each person, in my opinion, has a right to freedom and a decent (*dostoinaia*) life, and, in that sense, we partially do rights defence

> work too. […] It's really hard for me to divide them because I in some away ended up at volunteer at [CSO] for ideological reasons. I believe that in that way I at least somehow am making up the gap between what a person is worthy of in life and what they actually have. Even just three hours in my life I can give to these concrete people to somehow make their lives a little better.[lxii]

Tatiana is motivated by ideological reasons concerning people's 'right to freedom and a decent life,' which she responds to on an individual level by volunteering. She describes her volunteering as simultaneously defending herself and building a more just society in general, through compliantly framed, individualised action. Similarly, Galina saw her work as part of an informal art group as promoting rights indirectly. She specifies that, compared to more direct action, 'we as artists have more possibilities to go there and do something.'[lxiii] This might be counterintuitive, with the long history of art taking on a radical, confrontational role which extends into the present day (e.g., Nelson, 2018; Smola & Lipovetsky, 2018). However, their art groups are potentially also depoliticised by their contact with disabled people, who are themselves naturalised as apolitical through the dominant discourses including associations with social welfare, passive victimhood and charity, and permanent infancy (Chapter 6). Here, art activities are also subsumed under social, volunteer signifiers, distanced from any rights-based, political descriptions. Civil society actors used the depoliticization of volunteering as an opportunity to promote rights. In this case, rights-based work was understood as a general attitude or beliefs. This work is prefigurative in that it primarily addresses the actors themselves, representing the manifestation of their moral or ideological viewpoint, and group participants.

In some cases, this work for rights did also turn outside the group to address others or seek to shift institutional practices. This approach was suggested by Maksim, as he discussed building a relationship with state residential institutions for disabled people within the framework of 'volunteering'. As outlined previously (Chapter 3), the state is currently encouraging the development of volunteering as a national project to serve the country, as with civil society more generally. Volunteering may thus be used as a kind of Trojan horse which allows activists to interact with residential institutions (PNI). Rethinking volunteering and social work as both political and rights-based, Maksim proposes, is also an important part of activists' knowledge production. He defined their goal to:

> …somehow shift (*dvigat'*) the situation in PNI, because that's not as impossible as it seems and now actually the situation is more positive because those people are

> looking for volunteers and I know that they are actually ready to communicate (*nastroeny na kommunikatsiiu*). They aren't thinking about hiding, they are ready for some kind of cooperation with wider society. They perceive it in the framework of volunteering, they just don't have any other thought categories (*myslennye kategorii*) for that, or practices, or habits. And that's exactly why I think that it's actually some kind of intellectual work which is important to activism because we need to widen the horizons. Widen the horizons of practical involvement, widen the horizons for practical interventions. And that practice in fact intensifies thoughts, [intensifies] some kind of intellectual search. And well, one enriches the other.[lxiv]

Maksim explicitly proposing that social movements engage in *intellectual* work by identifying their practical involvement as activism and politics, and thus encouraging activists to develop their involvement in such volunteering. Notably, it seems that the intellectual work which resituates volunteering as activism is not to be diffused beyond the movement. While Maksim aimed to shift practices within institutions, activists' engagement in and knowledge production around volunteering as political address movement participants. Otherwise, they would disrupt the depoliticised cover upon which their smooth participation in volunteering within an institution depends. Maksim thus seeks to diffuse practices more widely, but manage the diffusion of activist knowledge production to contain it within the group. Below, I will discuss how actors aim to manage the diffusion and reception of their work (Section 4). Here, I note that Maksim identifies this practical, direct action as activism. Maksim is exceptional in explicitly proposing intellectual work to redefine volunteering as rights work. However, as I have demonstrated through the example of Galina and Tatiana, many other actors do identify direct involvement as work for rights. I identify this work as resistant as actors intentionally use it to address and enact an alternative to a situation or dominant norm which they identify as unjust.

Maksim describes himself as part of an informal 'society or movement' (*soobshestvo ili dvizhenie*), Galina organises her own informal volunteering group, and Tatiana volunteers through a formal, registered CSO. Some actors who volunteered or worked with both formal CSOs and GONGOs disagreed with aspects of their approach and the CSO policy of remaining apparently compliant with state. However, they described seeking to use the CSO or GONGO as a 'loudspeaker' (*rupor*) or as an instrument to allow them to access more 'levers' (*rychagi*) of change. Often conducted through direct action, such as running activity groups, actors saw themselves as working for rights in a more abstract, ideological sense. Some, like Maksim,

spoke of aiming to diffuse practices to institutions or the CSO more widely, as in his aim to 'shift (*dvigat'*) the situation in PNI'.[lxv] Others spoke about aiming to start conversations and inform people about injustices; this again suggests an attempt to diffuse values and opinion, if not specific claims. In any case, the rights which they claimed were either typically compliantly framed or ambiguous and abstract enough not to attract attention, particularly when working within a formal CSO or GONGO. Below, I discuss how actors aim to manage the diffusion and reception of their work. In the next chapter, I discuss the exclusions of these apparently compliantly strategies which aim to work for rights.

3. Everyday Action as Resistance

Some civil society actors give new meanings to everyday actions to identify them as a form of resistance. Crucially, this meaning-making is often not open or legible to all actors. Rather, meanings or interpretations are managed or curated to reach a limited, in-group of actors. I argue that these forms of ambiguous or non-apparent action are significant precisely because recognising them as resistance counters the epistemological oppression of denying both action which operates outside the public sphere (i.e., the misrecognition of forms of resistance) and the potentially less apparent action in which disabled people may sometimes engage, due to how disabled people are socially excluded.

Maksim, quoted above, proposed a conscious phrasing knowledge production as a goal of activism ('some kind of intellectual work […] is important to activism').[lxvi] However, such meaning-making also occurs without being phrased as an act of new knowledge production by the actors themselves. For example, some actors identify resistance through the meanings that apparently non-confrontational actions assume under the exclusionary conditions which construct disability. For example, Kristina describes organising an excursion:

> We took a route […] in the centre, the very centre […], so that people saw that, like, people with disabilities can also go on excursions, want to go on excursions, and so on. I mean, there was kind of a little bit of defiance in it […]. It wasn't initially positioned as a protest (*aktsiia*). That more came in the process of doing it and now I look at it, looking back, and I think that it was also important for that reason [as an *aktsiia*]. Because people really looked at us, when we were going along all as a crowd like that. […] And it was such a huge, varied group of people in the very centre. […] And yes, of course people turned around to look at us, well it was just obvious that they were all shocked, and when you see that reaction, you actually want to go further – let them watch.[lxvii]

Kristina speaks about how the excursion *became* an act of protest when already in process based on other people's reactions to them. Her own reframing of the excursion as an act of protest responds to her perception of friction and judgement from others as a diverse group of disabled people moved through public space. In moving through the centre of town, Kristina saw the excursion as claiming a right to public space, as well as demonstrating a capacity ('people with disabilities *can* also go on excursions') and agency ('… *want* to go on excursions') on the part of disabled people. Kristina phrases these claims as something that passers-by could see by looking at their group, without, for example, any banners or signs necessary. She thus implicitly suggests that their presence itself was shocking; that disabled people should be publicly present in town and demonstrating their agency in participation in a cultural event is enough to break dominant invisibility of disabled people, and assumptions of their passivity. Her words suggest the defiance of the staree ('let them watch', cf. Renwick et al., 2016) who continues regardless and claims their right to the space in protest.

Many other participants also spoke about the invisibility of disabled people in public spaces and experiences of being verbally or otherwise harassed while present in cafes, shopping centres, or other places. The built inaccessibility of material space was also a point of consensus throughout interviews. Be it because of other people present, the built environment, or an interaction between this and other factors, public space here forms an ableist space in which disabled people 'misfit' and move with friction (Garland-Thomson, 2011b). Disabled peoples' presence may not only trigger stares and discomfort in onlookers (cf. Dohmen, 2016), but is also an unusual occurrence which thus makes visible the ableist, exclusive nature of the space not typically inhabited by disabled people. Iarskaia-Smirnova and Verbilovich have built on McRuer (2006) to observe that in Russia, too, the 'appearance of a "crip" in public provokes and actively works to undo ableism' (2020, p. 432). The excursion is therefore an example of defiant disabled presence as an act of resistance.

However, Kristina's excursion was not identifiably confrontational. The movement of a group through a public place under the form of an excursion, rather than a protest march, benefits from the ambiguity distancing it from the political. The lack of slogans, signs, and clear demands protects the excursion from being 'identifiably political.' However, Kristina nonetheless experienced it as an act of protest. The temporality of when, how, and for whom an action becomes protest recalls Oksana's art protest action (*aktsiia*), described in Chapter

5. Oksana said that her action 'became political from the moment I was getting ready to leave home. […] It went from personal to political as I started to get my things together in my rucksack, thinking that they could arrest me.'[lxviii] The naming of an action as 'political' or 'protest' emerges, for the actor, when the action is beginning (i.e., as Oksana left home) or ongoing (i.e., as Kristina moved with the excursion group through the centre of the city). While the action is, to a degree, already planned, its meaning is not. Meaning-making is more fluid and shifts as the actor perceives moments of friction.

Moving through public space in Russia, without publicly stated claims, has previously been identified as a form of infra-politics. For example, in their discussion of performances of resistance, Jacobsson and Fröhlich (2019) describe protest groups instrumentalising 'public walks' with deputies of city and federal parliaments to themselves gather and communicate about their grievances. They thus deliberately benefit from deputies' 'right and possibility to meet their constituency in public' to legally gather without having to go through any official registration of a protest march (ibid., p.1157). However, Kristina and Oksana's examples develop the application of this theoretical description further in two ways. Firstly, as I discuss above, they identify challenge through the very appearance of a disabled person in public. Secondly, they widen the temporal element of understanding and identifying resistance. The walks which Jacobsson and Fröhlich describe are characterised as premeditated acts of resistance and protest, demonstrating intent to circumnavigate the laws on public assembly. In contrast, the excursion which Kristina organised was not premeditated with such intent.

Furthermore, no degree of sharing of this meaning among all participants in the action is assumed; the others participating in the excursion may not have identified it as an act of protest and re-claiming public space. They may not have identified their presence as an act of defiance, but simply as engagement in a leisure activity. This latter point raises the issue of equality and power relationships within a movement or movement community, where different actors may ascribe different meanings to an action. Below (Section 4), I discuss how power inflects which movement members can define and communicate actions' meanings, and how this reflects unequal power distribution. Here, the ambiguity of the message of the excursion may in fact serve to mitigate potential power imbalances by not clearly claiming and projecting a single, monolithic meaning to everyone's action. This also removes a boundary to participation in an action, as participants do not have to align themselves with a

clear message or demand to take part. However, again, not all actors are taking place with the same motivations or goals. Given the importance of intent to defining resistance (cf. Bayat, 2013; Hollander & Einwohner, 2004; Scott, 1985), not all people in the excursion or gathering may be engaged in resistance. Some people may be being used by others to produce meaning and enact resistance. This indicates the need to remain aware of power relationships in how resistance is individually and collectively enacted.

These examples also nuance how we think about resistance. Scott, for example, influentially distinguishes between 'real resistance' and 'token resistance' (1985). According to this distinction, 'real resistance' is 'organised, systematic, pre-planned or selfless practices with revolutionary consequences' (Scott, 1985, p. 292). On the other hand, 'token resistance' is made up of unorganised, small-scale acts 'without any revolutionary consequences, and which are accommodated in the power structure' (Bayat, 2013, p. 43). Scott emphasises that both types are nonetheless 'real', despite their names (ibid.). His definitions thus do not remove the possibility of defining Kristina's excursion as resistance. However, actions and meaning-making like those of Kristina, Oksana, Maksim, and Artyom also nuance these definitions of resistance.

Firstly, looking more widely to the strategies and ambiguous framings of all four actors suggests that a degree of 'accommodation in the power structure' is itself strategic, and thus more agentic than 'unorganised' might suggest. Secondly, the temporality of their meaning-making challenges that ascribed to 'real resistance' as 'pre-planned' or 'organised'. How meaning emerges both over the course of the action and subsequently suggests crip time, or a bending of time and planning (Kafer, 2013; Samuels, 2017). This shows how the conditions of disability call attention to limitations in how resistance is dominantly defined, and therefore shift understandings. Furthermore, these actions challenge how we evaluate the consequences of action. They may be immediately intangible and immediately accommodated in a power structure, but may still create more long-run, cultural change (cf. Polletta, 1997). They may be 'revolutionary' for some individuals, if not for society. Finally, they suggest caution over emphasising tangible impacts to the exclusion of other forms of outcome, just as caution is needed around emphasising street-based, highly visible protest while not recognising other forms of protest. I discuss this further below, as further empirical examples extend discussion the strategic uses of ambiguity, turning inwards, and

prefiguration which indeed 'hold the potential to nudge established patterns of control and authority' (Staeheli et al., 2012, p. 630).

4. Controlling Meaning Diffusion

Ambiguity is further guarded by restricting with whom and how information is shared, splitting actions between different times and spaces, and leaning on prefigurative action, which directs its demands towards those involved in a particular action. As the excursion became protest for Kristina without signs or clear, directly formulated demands, Oksana restricted access to her reasoning around the political nature of her street action (*aktsiia*) by not making it apparent in the moment of her presence in public space. Rather, she wrote a monologue about her feelings and describing the protest as political. This was then shared with a more limited audience after the fact. The new meaning of the action was not legible to any observer present in the moment at which it took place; it was present only to Oksana. She only drew out the political meaning of her action later, in a text written to make legible her reflection to others. Dividing the action into multiple time periods splits its meanings and curates who may access which parts of that meaning. While one action took place in a public street, the text was shared in less public fora, including on her personal social media page and at small events only advertised within close networks. The deliberately staggered curation of meaning over different time periods, spaces, and in relationship to different audiences, seen in Oksana's action, thus forms a dissimulated, liminal practice of resistance.

Other public action goes unannounced or not clearly signposted. Elena described how various spaces refused to allow her grassroots group to hold lectures or other events. Finally, they held events outside. Facing growing difficulties in finding shelter while being outside, they also held public lectures in cafés, without informing the cafés of their purpose and simply gathering there:

> People refuse to let us use event space (*ploshchadki*), so we started to run lectures outside. [Me: Why do they refuse?] Because you just say you're doing a lecture about feminism – "No, we won't have that." […] We can't pay for event space, and free spaces – either it's some kind of friendly spaces like a café, but with them you have to have a good relationship (*kontakt*), have trust, or [otherwise] it's state spaces (*gosudarstvennye ploshchadki*). The state has a clear relationship to those questions, […] to feminism, of course. Anything that smells of protests, more likely than not, it'll be refused. […] That's why we were refused and refused, and then we thought, "OK then, we'll do it so that we organise lectures outside, [it'll be]

> our own thing." Well, and most importantly, it's fun, it's interesting. It's also this kind of research on the city (*gorodskoe issledovanie*), how can we use this or that city space in a different way? That's why I think our project is political. […] I always have this kind of small paranoid thought, like what if someone says something. For example, there's this [cultural centre] and we decided to organise a lecture there about protests, without agreeing anything at all [about running it there]. There's a café there, and we decided just to go there and do our event, because that was also a political gesture (*politicheskii zhest*). […] We decided that we'd run it all without permission (*bez soglasovaniia*, without agreeing it). We got there and, really, no one chucked us out. There were a lot of us, around 30. We got there, took up the whole café, rearranged the tables, and I was afraid. There was this girl on the bar and at some point she kept going off somewhere, really for a long while each time. I thought, maybe she's gone for security, but actually, no. […] There really is this instability, because of the fact that you think that they could chuck you out, because of the weather not being right [to hold events outside], and simply because some event spaces agree [to hosting an event] and then refuse at the last minute, and then you need to look for a new space.[lxix]

Finding it impossible to run events in state-owned or run spaces, Elena indicates the use of trust and friendships to gain access to event spaces in private event spaces for free. Without those connections, her group uses other spaces without agreement with anyone responsible for the space and without signalling intent. Elena identifies the group's actions as political ('that was also a political gesture'), and indeed bases this identification in part on their intention to investigate how city spaces can be used differently. However, there is no evident sign or identification of this meaning from outside the group. Meaning is largely addressed towards group participants. Maksim also addresses turning inwards. He makes clear the links between control over public space, the risks involved with publicity, and a move towards working with like-minded people who move in the same circles as him ('*dlia svoikh'*), as opposed to a wider audience:

> When we tried to announce the event, when we made an agreement with the event space (*ploshchadka*), they started to put pressure on them (*davit'*, lit. to press, crush, squash). And actually, […] this is not the kind of event, you know, that, well, how to say, this is not actually some kind of protest or revolution, so it's, like, kind of strange to, I dunno, end up in prison for this kind of event, right. Well, we're just not ready for that. There. And so, we, like, try not to go for it head-on (*idti na prolom*), because we're weak enough as it is, so a full-frontal opposition (*frontal'noe protvostavlenie*) in this situation, well, it's just not at all going to… It's impossible. And that's why we were trying to somehow run that [event] in a hidden way and this time we didn't announce the event because we understood that, if we announce the event in advance, then maybe that [event space] will run into some problems, more even than us. Because people who provide us with event space tend to run into problems. […] Basically, I just want to say that actually

> with being public (*publichnost'*) – well, [our event] was already more underground (*podpol'nyi*), more for our own people (*dlia svoikh*). And problems about being public are quite big here because, they're trying to clean everything. I think precisely because they think that it's really important to control this spectacle of publicness, which they want to stage (*rezhissirovat'*, direct, produce). It's important for them to show who are our enemies, and who are our friends, like, where we're going and so on, to decide that single-handedly. And so, they really just don't want anyone to interfere (*meshat'*). That some kind of unknown actors appear, run out onto stage, shout, protest, they don't need any of that.[lxx]

Maksim clearly lays out the power imbalance, which he perceives as clearly skewed towards unspecified state actors. He thus indicates two important aspects of the organising context. Firstly, the facelessness and namelessness of state power, which I discussed in Chapter 5. Secondly, how his keen awareness of the power imbalance and potential for sanction influences the action which he undertakes (cf. Greene, 2014, discussed in Chapter 3). Here, it results in Maksim moving away from direct confrontation and towards a more 'underground' ('*podpol'nyi*') form of activism. In the interview, Maksim also speaks of links with feminist movement groups and other like-minded communities and how these links are used to pass information about events, without sharing information directly in entirely open fora. This mode of action is motivated by a wish to avoid creating problems for others, as well as with the assessment that it is not worth ending up in prison for the kind of smaller events which he participates in organising. Being public is therefore avoided both by communicating among and towards like-minded, in-group audiences, and by ensuring that public action is not apparently identifiable to outsiders as political or resistant.

5. Creating New Spaces

I identify the ambiguous, less visible action described in Kristina's excursion, Oksana's street protest, and Elena and Maksim's unannounced or semi-private events as forms of infra-politics (Scott, 1990, p. 182). These actions are non-apparent, daily activities which resist by shifting how space is used or producing different meanings around an action or space. As I have demonstrated above, these actors refer to their work as political (e.g., Elena), a form of politicised practice (e.g., Maksim), protest (e.g., Kristina and Oksana), and about rights (e.g., Tatiana and Galina). Maksim was unusual in that he explicitly conceptualises his work as micro-political; I take his use of the term to be comparable in meaning to infra-politics, in that it suggests everyday, non-apparent actions which are nonetheless politicised by their

enactors. Above, I discussed other examples of infra-politics to show how these actions take place in daily life or, unannounced, in public spaces, thus creating new possibilities within that public space (e.g., Elena, Oksana, Kristina). However, in contrast, Maksim's example demonstrates how new, communal, and more private spaces are created outside of the everyday. While actions may remain everyday, the space is removed from the everyday:

> It was a kind of kitchen politics again. We even specially themed it that way because we […] prepared food together […]. And made presentations at the same time. I mean, it was this kind of kitchen-, well, we, like, tried to call attention to this new form of realising politics (*osushchestvlenie politiki*), and in fact re-think (*pereomyslit'*) kitchen politics as maybe something important because how we prepare food together, how we, I don't know, share our space, how we live in kommunalkas and solve problems, that's all micro-politics (*mikropolitika*). And those are all, like, really important questions for the anarchist movement. […] Well and basically, it's a political question. We tried to look at it in that way. [lxxi]

Maksim's strategic assessment of risk motivates his movement towards to prefigurative action, developed through the 'kitchen politics' and communal living experiments. Similarly, other actors organise peer-support groups and work to build inclusive, while fairly closed, communities which are largely based on existing friendship ties. This action moves away from infra-political action in daily life and creates spaces which are set apart, either reoccurring on a weekly basis as a volunteer group or support group meets, or running for a period of months or weeks, as with small-scale communal living experiments like those in which Maksim is involved. This action is prefigurative in that it is characterised by 'collective experimentation, the imagining, production and circulation of political meanings, [and] the creating of new and future-oriented social norms or "conduct"' (Yates, 2015b, p. 1). We have seen above how Maksim reflects this characterisation by imagining and experimenting with new 'political figures' and calling for the movement to be involved in 'intellectual work' to produce new meanings. Here, we also see how he engages with creating and aiming to consolidate new social norms. Maksim discussed how their group aimed to create new possibilities and equalised relationships between people:

> And you see this environment kind of full of friendly,- of some kind of closeness, these unofficial links, the patients immersed themselves in it, let's say, and some of them were saying to us that it was really valuable to them in itself because it widened their social circle (*krug obshcheniia*). The thing is that often these people don't have friends, or work, no one but their parents. […] And, so, it was a kind of valuable way out beyond the bounds of that closed circle. And one girl could leave the home for the first time. Because before that she had nowhere to go. And she

> […] for the first time was able to leave the house and even for the first time prepared herself food. Before that her mother had always done it. I mean, [even though] she is completely capable of doing it herself. […] I think that it's important to create the kind of environment which washes borders away, which allows, which gives space to creativity and some kind of informal connections. […] And this environment is needed so that, well, so that people feel that they are each other's equals. And, at the same time, it's important so that all of the participants of this society, how to put it, so that they could contemplate true self-realisation, not within the framework of art therapy or something, right, because it seems to me that it [art therapy] also often limits people.[lxxii]

Here Maksim sees their work as creating an environment which challenges and reconfigures power relationships and boundaries between different members of the movement. Although the space which Maksim is involved in creating is outside of the typical public sphere and the movement clearly manages who can access it, he nonetheless emphasises that their living experiment is in fact a way of exceeding and expanding 'the bounds of [participants'] closed circle.' The space is separated from the wider public sphere and clearly proposes different rules, as an environment which 'washes borders away' and attempts to equalise power relationships.

In doing so, Maksim differentiates himself from other forms of action, here exemplified by art therapy, by stressing the goal of 'true self-realisation' outside of a limiting, top-down framework for action. Maksim thus proposes living together and cooking together are a more all-encompassing way of creating change. In these spaces, the collectives aimed to create new possibilities for action and self-understanding (e.g., 'for the first time [she] was able to leave the house and even for the first time prepared herself food […] this environment is needed so that […] people feel that they are others' equals'),[lxxiii] by creating a space where those who are typically excluded by wider society are included as equals. The demands largely fall on the collective members, who are all responsible for creating such a space. That this work occurs among the collective is a strategic choice which largely, although not entirely, prioritises turning inwards over diffusing ideas and norms beyond the group.

While Maksim indicated the collective's caution in how they advertise and address their events and living experiments, he also sees these new, future-oriented ways of living as addressed to specific wider audiences. Thus, their work aims for some careful diffusion of ideas, in this case towards residential institutions. Certain ideas have indeed already experienced diffusion, as Maksim himself moved into disability organising from a social

movement protesting the political regime, bringing with him horizontal decision-making processes and assemblies. This kind of action again aims for a kind of long-run change which is not entirely 'accommodated in the power structure' (Bayat, 2013, p. 43), but rather may shift existing power relationships (Staeheli et al., 2012, p. 630). He describes their strategy of building, and diffusing, a new culture of relationships through how daily activities are conducted together:

> We, let's say, create the kind of environment where all these rules, entry points, taking into account the opinion of each person, they are thoroughly developed, articulated, and brought into a whole culture. And with the help of such an environment, which is thoroughly inclusive, right, we contact the PNI [psycho-neurological residential institutions] and kind of spread this relationship, outside of personnel, outside of patients [i.e., a strict division between the two roles]. They [patients] have understood that there is this kind of relationship, and there is another kind. They already see the difference [between these approaches]. The personnel also can see the difference, we come with our kind of thing to the administration [of the PNI], some of the people in the administration, let's say, are open, there are people like that now, and they adopt (*perenimat'*) our kind of thinking, we just create some kind of discussion. And that's how we foster this culture inside an institution, I see it like that. […] More concretely, we've understood that we're interested in this kind of micro-politics, which is about the politics of relationships, the politics of decision-making, for example, all of our meetings are organised like assemblies […] But all the same all of our activity was directly towards destigmatisation. And I've already spoken a lot about how our aims were the creation of an environment. […] But the big picture was just to make public discussion of this problem. And not in the context of help, we, for us it's quite important to tear apart this idea of help. Because it's the most repressive and limiting. Well, it limits, like, right, or imposes things on people, well, hierarchizes, like, makes a hierarchy. Unlike that, for us it was important to create the kind of environment […], which adds something to the horizon of possibilities of people who have ended up in front of the problem […]. And also we wanted to make the discussion of these problems more, more free. I mean, open that discussion. Make it more habitual (*privychnyi*, in sense: normal, typical).[lxxiv]

Maksim uses consciously politicising framings of 'micro-politics' and brings different techniques into his work from involvement with anti-government protest groups. Excepting this, people working in art groups in fact often described their organising in similar ways. Without using language of assemblies and micro-politics, Galina, Tatiana, and Artyom also emphasise creating comfortable spaces which sees new norms of behaviour and horizontal, non-hierarchical relationships. They aim to create, at least within their group, new modes of relating to each other. In some cases, they also mentioned that via public-facing activity, such as public discussions and exhibitions, they aimed to diffuse new modes of relating to disabled

people and understanding disability to a wider public. I therefore also identify their action as having prefigurative intent, in that they seek to develop new social norms which resist the current situation of stigmatisation.

6. Differential Meanings and Existing Power Relations

In attempting to build new norms which challenge the constructed exclusion of disabled people, civil society actors recognise the complexity of challenging existing power relations and the tendency to in fact replicate power inequalities. In this section, I discuss how power inequalities are replicated particularly at the level of actors' meaning-making, and diffusion or projection of that meaning. This is important particularly as I have thus far proposed that this meaning-making, and thus intent, is central to the identification of resistance. For example, I identify resistance where actors have identified a discursive norm and intend to work against it. Similarly, using vulnerability as a resistant strategy is also dependent on actors holding a subversive intention in instrumentally claiming that vulnerability to enable continued action.

However, actors have varied understandings of the nature of vulnerability as associated with disability, with some seeing vulnerability as an inherent characteristic of disability, while others claim it strategically. Furthermore, the different experiences, backgrounds, and identities of the various people involved in a group or movement result in great variance in any desire to challenge, expand, or protest socially dominant norms. We have seen one example of this in actors' production of discourses of enforced positivity (Chapter 6), which operates by alignment with characteristics or achievements which are dominantly understood as positive. Certain actors described wanting to show positive images to regain status lost through association with disability; these positive images present disabled people as attaining normatively successful achievements or objectives. Here, I demonstrate how the tension between resisting and attaining certain norms plays out in liminal resistance, which often is both defined by and leaves space for individual meaning-making.

A clear example of the tension in the different meanings of a single project to different actors is given by Artyom, who described a project organised by another registered CSO:

> There was this very telling situation when that director said, "look, in this project we are deconstructing the norm, we are looking for something new. But when the

> people who were participating themselves started to speak, it was, "well, we really like working with intelligent, educated people, with people from the art world." So, I mean, on a rhetorical level that director from the art world is deconstructing a norm, but the people he invites [to participate], they are, for example, concerned with the opposite, with getting into that norm (*popadanie v normu*; matching up with the norm). And so it happens that, because of this lack of critical thinking, these people have completely parallel existences in this project. I mean, one side is deconstructing something, and the second is constructing something.[lxxv]

Artyom describes how two different groups use the project in two different ways. The disabled participants saw it as a tool to increase their own status by working with 'intelligent, educated people […] from the art world.' On the other hand, Artyom related how the director described the action as deconstructing a norm. I previously also mentioned the possibility of parallel existences within Kristina's excursion (cf. p.186), in as much as not all the people who walked with her through the centre of town may have identified their walk as a protest march. In that case, Kristina's meaning-making around the excursion as resistance and as protest was not displayed and was shared only with me after the fact. Still, this claim comes from a position of someone who identifies as non-disabled. Kristina claims resistance while she herself is not disabled, and therefore not herself producing the friction at the root of her own meaning-making around resistance. Others who are immediately perceived as disabled may experience the stares differently. Kristina may be stigmatised while moving as part of the group of people who are identified by others as disabled. However, she does not provoke that response by herself.

In contrast, we have the example of Aleksandra, a mother of a disabled child, who described their retreat to private spaces in response to the constant weight of stares, points, and comments (Chapter 6). Aleksandra's experience of visibility was one without recognition, where the heightened visibility of disability 'produces […] social invisibility' (Siebers, 2004). She is simultaneously 'on display' and 'politically and socially erased' (Garland-Thomson, 2005, n.p.). This is not to deny the agency of the 'staree' (Renwick et al., 2016) and the recognition claims which Kristina, and others, see public presence as making in potentially demonstrating existence, capacity, and will in response to stares. However, like the director described by Artyom, Kristina's privilege to choose when she wants to break a certain norm may support her wish to do so.

Actors' relative positions related to the norm influence their understanding of actions and relationship with the norm. Those who might typically be perceived as fitting with the norm or inhabiting a more powerful social position were more ready to challenge the norm, perhaps even gaining power through doing so. This, for example, could be the case of the director who uses the art project to develop his own professional work. On the other hand, other participants might wish to gain power through fitting in with the exact norm which the director proposes the project as challenging. In describing her participation in a theatre play, Sandahl criticises how her 'impairment was […] put to use to create meaning, meaning over which I had little control' (2005, p. 620). Equally, in Artyom and Kristina's cases, participants might also be being used to create meaning with which they themselves do not agree.

The ambiguity of certain forms of resistance shapes their relationship with existing power relations. In the example of the excursion, the ambiguity of its identification as protest supports its existence and the very possibility of that protest. This functions on the basis that the image projected by the excursion is one of apparent compliance with norms around protest, if not norms around who occupies the public sphere. In challenging the latter norm around the use of public space, Kristina identifies protest. However, the fact that her interpretation was not shared with other group members or diffused more widely (beyond the interview) perhaps protects participants from the feeling of being used to create meaning which Sandahl describes (2005). A strength of ambiguous action is thus that it is ambiguous not only towards the state. It also maintains this ambiguity towards participants, allowing them to bring their own meanings to action. Within Kristina's excursion, there is room for multiple appreciations of the act of moving through the town, from a leisure activity to one of protest.

However, the lack of open discussion within the group around these questions also limits the degree to which such power dynamics may be elucidated, recognised, and challenged. Where groups do not work to directly address these power dynamics, existing power relationships may be reinscribed. Maksim attempts to challenge power relationships in having discussions about how their informal group will act and the meanings of their actions. Still, there are disagreements:

> And so, we organised the process [like assemblies] so that everyone could express themselves (*vyskazat'sia*). And so that everyone can take part in discussions and

> so on, and of course questions of power were really hotly discussed at times. For reasons including because some people weren't at home with (*nositeli*, lit. carriers) this democratic culture.[lxxvi]

In this example, certain power dynamics are recognised through discussion. Maksim aims to work against these parallel existences within a project by aiming to flatten the distinction between participants who are residents of state institutions and those who are not. He also does so by actively building horizontal spaces for discussion, with the goal that each person can express themselves, be heard, and build more collaborative meaning, unlike the working process of the director.

However, these discussions may not be participated in equally, and may exacerbate power inequalities as more powerful voices erase others. Other research has shown that purportedly horizontal, prefigurative movements nonetheless reinscribe existing dominant power relationships (Ishkanian & Peña Saavedra, 2019). We might identify indications of this Maksim's example, too, as he implicitly suggests that those who are not used to democratic culture and horizontal discussion processes need to learn and adapt to those group norms. He frames these people as causing disagreement, and thus implicitly suggests that they might be target for the diffusion of the norms which he proposes. Reflecting further on the differences in backgrounds, statuses, and power, Sonia discusses working with PNI residents as a non-resident:

> Because what happens to people in institutions (*internat*) doesn't only deprive them of identity, but also all the situations and the whole system, the one that's organised for them, where they live in rooms [Sonia refers to either large, dormitory-style rooms or cramped shared-rooms typical in PNI], all that says to them, you don't need any kind of identity at all. You don't have one – and that's fine, you're not worthy of one or you wouldn't be able to handle one. […] It's this kind of really absolute thing, of course. And here [I'm speaking about] many different identities, from human, civil to mental. Me going to an institution was also about my identity because I'm, like, cut into two halves. There was one world and another one, which I was trying to unite. It was all about the fact that people at the institutions, when we communicated for a long time, saw me as an absolute god (*bozhestvo*) from the point of view that I have freedom, I have choice. I can do whatever I want, but they can't, and that automatically means that [they think] "I'm bad, I'm ugly, I'm this and that," while any person who comes from freedom [i.e., the outside world], "they're all-powerful, they are different, they are" – all that.[lxxvii]

Sonia's view of how strongly PNI residents perceived the differences and lack of equality between her and them indicates difficulties in rebalancing and equalising relationships, as both her and Maksim aim to do. It suggests the likelihood that some PNI residents may enjoy working with Sonia specifically for the status they might gain from it, differentiating themselves from other residents and associating themselves with Sonia's 'freedom' and perceived ability to choose for herself.

Institutionalisation, as Sonia suggests, and the regulation of legal capacity further skews the power balance. Artyom continues to talk about this imbalance as he compares his project with in which he identified 'parallel existences':

> And I said, "OK, we in the cultural sphere talk about inclusion, but how many people have you hired to work, for example, in your fund? Or how many people have you paid? Did you pay the director, the author of the project? And what about the other people [who participated]?" That's, for example, what we're working for now [at Artyom's registered CSO], so that for all our exhibitions the artists are paid and have contracts. It's hard, for example, to do that with people who don't have legal capacity (*nedeesposobnii*), because there legally isn't a type of agreement [which they can contract], but we come to an agreement, and I give them their money all the same.[lxxviii]

Here we clearly see differentiation by whose labour is renumerated and whose is not. Artyom's example also demonstrates how this inequality is structurally created; as many of the disabled participants in his project have been stripped of legal capacity, there is no form of contract which they can legally enter. He tries to circumnavigate this inequality by drawing up an agreement and paying them, even if this agreement is technically not legally binding. He is critical of those actors in cultural organisations and CSOs who do not renumerate or hire disabled people. Inequity is reinscribed by who is paid for their labour in a project and who is meant to be rewarded by their participation alone, without payment. The lack of equal recognition of labour propagates differentiation in the power relations, disempowering disabled people. The lack of financial remuneration shifts how they understand both the action itself and their relationship to it. This thus underwrites multiple, parallel existences in a project.

Laying aside the question of whether Maksim, Artyom, and others succeed in equalising power relationships in any way, these examples highlight the possibility of parallel existences within projects. Thus, I note Maksim's example as both an instance of an attempt to address

power relationships, which may nonetheless elucidate certain power inequalities left undiscussed in other examples, and evidence of different attitudes and opinions within a movement. My point here is that these parallel existences potentially become more problematic in the absence of any discussion and where meaning is more loudly claimed, and thus people with less power are more evidently instrumentalised for others' aims.

In decreasing ambiguity by concretising and diffusing meaning, actors run the risk of foregrounding more powerful voices, like that of the director whom Artyom mentions, and erasing those of others. In communicating to a wider public, the non-disabled director's understandings of the group's work could efface those of the disabled participants in the group. The potential strength of ambiguity in allowing multiple meanings and existences within a project is then limited. In acting as a loudspeaker for more powerful participants, Artyom's description of the project clearly demonstrates the problems which occur when these parallel existences replicate pre-existing power structures. The director, who has the power of social worth in line with certain norms (e.g., being part of the art world, not being an institution resident, having a formal educational background) is willing to claim that he is giving up power and deconstructing a norm. However, the people with whom he works are in fact more interested in gaining power through their association with people such as him, who, by extension, they see as part of the normatively valued group.

In describing these power relationships, I do not intend to naturalise disabled people as inherently in a position of lesser power. I also do not intend to suggest that disabled people uniformly seek to gain status through conforming to an ableist norm. Firstly, we see clearly how lesser access to power is constructed in many ways, including, for example, the structural impossibility of entering legal contracts and legally receiving pay for those without legal capacity and segregation and exclusion in PNI. Secondly, there are disabled people who clearly work to challenge that norm and to cultivate pride in a disability identity. Here, my point is rather to explore, within ambiguous, everyday action for resistance, the difficulties which actors face in disrupting and counterbalancing existing power inequalities. This same difficulty is, of course, present in this research. Where whose meaning-making we register around any action is also an operation of power relationships, I may easily amplify inequalities by who I speak and do not speak with and through at interview and in analysis. It is therefore all the more important to pay attention to those moments, implicit or explicit, where multiple

meanings are reported or suggested. Ambiguity of meaning has a complex quality here. It allows continued resistance and permits people to bring their own meaning to actions. However, it can also mean that power inequalities go unrecognised and unchallenged. By the same token, where ambiguity is lost, the people who formalise and diffuse any specified meaning are often those who hold comparatively greater power.

7. Conclusion

In this chapter, I have explored actors' intent and meaning-making around ambiguous, multiply legible actions to show that they identify these actions as forms of resistance. This contributes to undoing the epistemological violence of failing to recognise certain forms of resistance. Actors strategically chose not to present their actions as rights-based or resistant to a wider audience. However, research does not have to replicate this projection. Exploring intent and experiences of action demonstrates the importance of attending to resistance which occurs through presence, without clear demands, or without pre-planning or immediate outcomes beyond a narrow audience. Here, I demonstrate how rights are reclaimed through direct action. I show how actors identify an action as resistant as it is in process, expanding the temporality of resistance to move away from an emphasis on pre-planned action. I also look to how actors divided the meaning of an action and how that meaning is shared over different time periods and audiences to minimise risk.

I have shown how these actions can reinforce existing power imbalances, particularly where they aim to deconstruct norms or shift relationships. This is a complex picture. One strength of ambiguous action (e.g., Kristina's excursion) conversely remains its strategic ambiguity vis-à-vis the state, which also allows ambiguity among participants too. This makes space for participants to bring their own meanings to action, unlike organising when meanings are more clearly projected and formalised (e.g., the project which Artyom describes). However, actors' strategic choices can also create clear exclusions, intended or otherwise. Another violence is thus present in these ambiguous, multiply legible, and inward-facing actions; they signal the perceived need for erasure and misrecognition to ensure continued action, responding to state rhetoric, discourse, policy, and legislation. Remaining ambiguous and apparently non-confrontational means strategically observing certain limitations, which themselves reinforce inequalities. While micro-politics and ambiguous action may build

fulfilling communities, these responses also structure intersectional inequality as people find that certain aspects of their identity may not be openly responded to, particularly within formal, registered CSOs involved in disability organising.

Actors' use of ambiguous, dissimulated resistance thus leads to my final set of questions, which examine which identities exceed the boundaries of legitimacy and how actors negotiate the resultant exclusions. Here I look at the experience within disability organising of both people who identify as LGBTQ+ and disabled, and people who identify as LGBTQ+ but not as disabled. CSO compliance creates as legitimate a desexualised, non-agentic view of disabled people and the disability organising space. LGBTQ+ and disabled people are thus produced as delegitimate actors, negotiating a complex interplay between legislative and discursive discrimination. In my final empirical chapter, I explore how they negotiate (self-)erasure and exit from disability spaces, create new communities of inclusion, and differentiate their expectations for disability and LGBTQ+ organising.

Chapter Eight

Disability and LGBTQ+ Intersections and Exclusions

RQ.5: How do ambiguous, non-overt strategies of resistance and enacting legitimacy exclude LGBTQ+ people? How do they negotiate their exclusion?

1. Introduction

Building on my analysis of how disability action is dominantly discursively legitimised and of the ambiguous, infra-political forms of resistance which continue within disability organising, I here look at LGBTQ+[35] identities in their intersection with disability and disability organising. Previously, I have looked at how scope for infra-political action is created by the normative discourses associated with disability. The evasion of recognition of disability resistance is supported by a presumed lack of agency and depoliticization, concretised in the exclusion of disabled people from much of material public space, an enforced discursive mode of positivity, and discourses of victimhood and infancy. In contrast, LGBTQ+ identities are normatively constructed as agentic and highly politicised. Where associated with disability, the recognition of LGBTQ+ identity disrupts the dominant reading of a disabled person as a worthy recipient of charity.

Dominant assumptions about LGBTQ+ organising differ from those around disability organising. While the former is seen as threatening and delegitimised (Buyantueva, 2018; Stella, 2013), the latter is legitimised through the alignment between misrecognised disability and legitimised civil society organising. Direct expression of LGBTQ+ identity thus exceeds the bounds of legitimised action for civil society, as well as those legitimised for performances of disability. While disability, misrecognised, is normatively legitimised, apparent identification as LGBTQ+ means exclusion from legitimacy. Therefore, when performing compliance and

[35]A note on language: most participants typically said 'LGBT.' However, some switched between 'LGBT' and 'LGBTQ+' (*LGBT Kvir Plius*), or only used the latter. To both reflect and encompass all participants' language, I here use LGBTQ+. In the specific citations used in this section, it is largely 'LGBT' which appears. However, these same people cited often also used other expressions, including LGBTQ+ and Queer, in other parts of the interviews.

containing resistance, certain identities are erased or excluded as inherently delegitimised and threatening. I therefore question one of the exclusions of how disability organising enacts compliance. I ask how it shapes disability organising and is negotiated by LGBTQ+ disabled people and LGBTQ+ people working with disability CSOs.

As I focus on sexual and gender orientations and identities, I am aware of the existing criticism of 'disproportionate' focus on such LGBTQ+ organising, often by Global North/Western researchers, and to the exclusion of the 'majority' of 'other', social CSOs (e.g., Salamon et al., 2020). This criticism could itself be made with more care, given its potential alignment with dominant state rhetoric which frames being LGBTQ+ as something foreign, alien, and threatening. A focus on politicised and contentious LGBTQ+ organising has been criticised as leading to unbalanced characterisation of Russian civil society and its capacities (e.g., Cheskin & March, 2015; Javeline & Lindemann-Komarova, 2010). There are, of course, multiple other intersecting identities. However, the focus on the intersections between LGBTQ+ and disability identities and organising is important here for three key reasons.

Firstly, actors' discussion of LGBTQ+ visibility and space for organising was tightly linked not only to the creation of taboos and rhetorical delegitimization, but also to the thicker, weightier power of state. Actors referred to the Federal Law No.135-FZ 'For the Purpose of Protecting Children from Information Advocating for a Denial of Traditional Family Values' (2013), commonly known as the 'Gay Propaganda Law'. This law makes it illegal to discuss or share information about non-heterosexual relationships or orientations with people under the age of 18. Examining the intersections between LGBTQ+ and disability organising thus allows exploration of legislative control in interaction with dominant discursive control and misrecognitions. I have previously demonstrated that the latter align disability organising with legitimised civil society organising; LGBTQ+ identities disrupt this alignment. Taking 'intimacy politics' as a master key in analysing power relations (Swader & Obelene, 2015), this focus makes visible the structural creation of exclusion, particularly from formal, registered CSOs' spaces, and actors' negotiations of these exclusions, erasures, and silences.

Secondly, far from being over-represented, this focus in fact responds to an area of research which calls for further development. Literature on Russian civil society has mainly focused on LGBTQ+ identities specifically through LGBTQ+ organising. There is little research on how those people who identify as LGBTQ+ experience organising in 'other' thematic areas. This is

despite these thematic areas never being truly 'other', or detached from LGBTQ+ people, given the presence of LGBTQ+ people throughout organising. Furthermore, disabled people's diverse experiences of sexuality in Russia remain under-researched (for important exceptions, see: Iarskaia-Smirnova & Verbilovich, 2020; Klepikova, 2018; Kondakov, 2018). In the wider post-Soviet space, there is limited further research focusing on disabled people's sexualities. A key example is Sumskiene and Orlova's work (2015) on experiences of disabled women in residential institutions in Lithuania. However, the introduction to the Special Issue on Post-Soviet Intimacies (Swader & Obelene, 2015), of which Sumskiene and Orlova's article is both part and the only contribution concerning disability, makes clear the relative scarcity of work in the field of intimacy and sexualities in general, as well as its overwhelming focus on European post-Soviet societies. The scarcity of research is even more marked when we look at that bringing together sexualities, gender identities, *and* disability. Meanwhile, there is a rich literature on LGBTQ+ advocacy, resistance, and organising. However, it mainly remains silent about disability. Literature on disability organising in Russia too has largely not brought such investigation of sexualities into dialogue with social movement and civil society literature.

Thirdly, LGBTQ+ movements and organising were mentioned by some participants in this research. Among grassroots, movement, and formal NGO participants, as well as those active in multiple such spaces, I began to note the citation of LGBTQ+ organising as an example and model for disability organising. These mentions came particularly from actors interested in developing a more rights-based approach. These relatively few actors raise an important question for investigating the break-down of legitimacy as it is built around disability as a sphere for civil society action. Here, I use a few key informants to demonstrate this tension and how it is negotiated.

Thus, in this chapter, I look at the example of LGBTQ+ disabled people and LGBTQ+ people working and volunteering in different forms of disability organising. Looking at this particular intersection allows investigation of how a delegitimised, politicised (LGBTQ+) and legitimised, depoliticised (disabled) identity interact, and how this is negotiated in organising. While previously, I have thought particularly about forms of organising and action which remain ambiguous, here I bring back the link to recognition and identity and one way in which is it limited by remaining apparently legitimised. I look at the influence of the legislative

environment, particularly vis-à-vis the so-called 'Gay Propaganda Law', in institutionalising inequality of recognition. This inequality of recognition was previously discussed as enforced through the pressure to align disability organising with legitimised civil society organising, often through alignment with dominant discourses of disabled people as passive, child-like, etc. Here, this is extended and considered in relationship to the context specifically concerning sexual and gender identities.

I begin by presenting how participants referred to LGBTQ+ organising as a model for disability organising. These references also demonstrated the differences which they identified between the areas for organising. These differences are found in terms of how legitimised they are and their consequent capacity to have a relationship with state, as well as to make certain more contentious, recognition-based demands. I then look at the ways in which LGBTQ+ people in disability spaces negotiate their exclusions through self-censorship, exit, building new spaces and hidden collaborations, and differentiating their expectations for different organising spaces. As well as a limitation in the recognition possible from within formal disability organising spaces, this demonstrates pragmatic responses and understandings of the capacities of various spaces in a context where maintaining a relationship with state requires performances of compliance.

2. Disability and/versus LGBTQ+ Organising

Civil society actors referred to LGBTQ+ organising as an example for disability organising in three main ways. Discussing LGBTQ+ organising as a normatively positive model, these actors identified it as: presenting an overtly rights-based position; working for de-stigmatisation and pride in identity; and in modelling inclusion which names and responds to at various structures of oppression. Actors also contrasted LGBTQ+ and disability organising. These contrasts demonstrated the discursive delegitimization of certain framings and identities which LGBTQ+ organising clearly promotes. Comparisons with LGBTQ+ organising, and the presence of LGBTQ+ people withing disability organising, therefore demonstrate both one limit of identity-based legitimacy and a tension in disability organising. Disability organising's relationship with state is predicated on a limited recognition of disabled people, which excludes LGBTQ+ identities. Compliance both offers disability organising certain opportunities which LGBTQ+ organising cannot access and depends on the exclusion and self-censorship of

LGBTQ+ identities. In this section, I present LGBTQ+ organising as a model for disability organising. I then discuss how disability organising is shaped by compliance and the need to maintain a relationship with state.

Some participants identified LGBTQ+ organising as presenting an overtly rights-based position using discourses of equality and citizenship. This position was notably different from the ambiguous, hidden rights work, and dissimulated resistance of much formal disability organising which I discussed in previous chapters. As a disabled person involved in both disability and LGBTQ+ organising, as well as in an intersectional organising group, Fyodor was a key informant in this area. He observed that:

> The LGBT community is very strongly woven together in principle with the civil movement (*grazhdanskoe dvizhenie*), which already exists in Russian now. […] When we talk about the *inva* community (*inva soobshchestvo*, disability community), it's not…,- disability (*inva*) activists, most of them don't see themselves as some kind of general civic activists, like, the disability (*inva*) agenda is kind of separate. And disability (*inva*) organisations don't reflect at all on the topic of freedom of speech, or on the topic of-, nothing. There's some kind of separate disability (*inva*) world.[lxxix]

Participants also referred to LGBTQ+ organising as a model for inclusion. Fyodor also spoke of the LGBTQ+ movement as claiming to be inclusive when 'they've actually got that inclusion.'[lxxx] He differentiated this from disability organising, which he perceived as promoting a caveated inclusion in fact excluding LGBTQ+ people. Sasha felt similarly that LGBTQ+ organising had more strongly developed intersectional, non-discriminatory modes of organising:

> Also, I feel that in general in the Queer culture of NGOs and LGBT organisations, who, maybe have some kind of intersectional approach, you can say that it's basically common practice (*priniato*) to think more about how accessible events are for different people. Not only about LGBT, but it's also generally in principle common practice to think about different kinds of discrimination. […] In LGBT spaces I have often come across this practice, that there it's not only homophobia, biphobia, transphobia that aren't allowed, but also sexism, racism, ableism, and so on. […] [But] the other way round works worse. Yes, because, generally, communities of people with disability, in the first place, are quite closed. […] Among them there are LGBT people and then, yes, these people somehow cross over (*peresekaiutsia*, intersect), but in general there isn't usually discourse about LGBT just like that in disability spaces.[lxxxi]

Participants also referred to LBGTQ+ organising as a model for how to de-stigmatise certain identities and work to claim pride in them. The metaphor of 'coming out' and becoming visible was used by some participants to describe the process of positively presenting their own identity as a source of strength, rather than of shame. In reference to de-stigmatisation and pride, Boris said:

> Then, it was at the end of 2015, I said that [the movement he participates in] has to learn from the LGBT movement on some methods and rules. […] Look, I believe that the LGBT movement in Russia is the biggest movement playing a big role in the de-stigmatisation of certain topics. […] That's why I believe that the LGBT-movement […] plays a big role in the issues which aren't discussed in society, but which nonetheless very important for society. […] One of the lessons is that, possibly, if people don't hide their diagnoses, then what's the meaning of pride (*praid*), it's not just demanding rights, it's also demonstrating your sexual orientation or your gender identity.[lxxxii]

However, while actors identified LBGTQ+ organising as an example for disability organising, they also differentiated between the two. They spoke about how assumptions around disability differ to those around LGBTQ+ identities, and why disability organising does not operate in the same way as LGBTQ+ organising. Looking further at these assumptions demonstrates the argument identifying alignment between dominant discourses around disability and legitimised action for civil society (Chapter 6). Fyodor exemplifies some key parts of this argument in describing the work of his intersectional grassroots 'initiative group' (*initiavtivnaia gruppa*), which works around sexuality, gender identity, and disability:

> When you start to tell people that actually there are situations where one thing is laid on top of the other, then people's mind starts to give out because that already kind of breaks the stereotype (*shablon*, mould), right? Because we understand that Russia's an Orthodox country and generally many people have this kind of thought that people with disabilities, basically, you need to help them, let's say for example, it's charity or even not charity, it's this kind of thought, like, you just have to do it. Well, it's some kind of church (*tserkovnyi*) perception, right. That's one relationship to a person. And if at the same time as that he's, for example, gay, and the television is telling you 24 hours a day that gay people are the henchmen of the West sent to destroy, I don't know, our spiritual, great-power, moral everything everything everything, then you've already got a different kind of relationship to that person. And if it's all intertwined in one person, then a person […] doesn't understand how to relate to them. And that's the moment when some social clichés (*sotsial'nye shtampy*) start collapsing slowly, right, and then you can talk about some wider topics, about how, basically, we all have rights.[lxxxiii]

Fyodor refers to the perception that non-disabled people have an obligation to help disabled people. At this point of the interview, he relates this primarily to a church-related perception (*tserkovnoe vospriiatie*). Later in the interview, he discusses it as part of dominant discourses around disability, also present in disability organising itself, which emphasise charity and does not recognise the rights-based claims of disabled people. The trope of non-disabled people helping passive disabled people out of charity (cf. Chapter 6), is foundational to how disability action is naturalised as overlapping with social welfare, charitable, legitimised action for civil society. Here, Fyodor says that this mould is broken when a disabled person is understood not only as disabled, but also as gay.

Precisely how this mould is broken delegitimises this sphere for civil society action. In Fyodor's phrasing, being 'gay' is equated with being 'henchmen of the West' who are 'sent to destroy' Russia. In terms of the discursive and legal regulation of civil society, this phrasing reflects a mode of delegitimising civil society action which operates by 'render[ing it] as influenced by outside forces intending to harm Russia and its people' (Fröhlich & Jacobsson, 2019, p. 1153). Fyodor suggests that this point of view is supported by dominant religious ideas and the television. Although not explicit, this also suggests a link with state rhetoric, as much of the television is recognised as state-aligned (Hutchings & Tolz, 2016). Thus, when a disabled person is out as gay, they disrupt dominantly translated expectations that they are a deserving, passive recipient of charity. In doing so, they also disrupt their intersection with a legitimised form of civil society action.

In Chapter 6, we have seen mothers performing a gendered, caring role which positions disabled people as children. These mothers face criticisms, may be seen by the state and other CSOs as shouting and irritating, and have to perform the role of the 'good mother' in order to redress some stigma and blame which they may face as mothers of disabled children (Iarskaia-Smirnova et al., 2015). However, they are both tolerated and not delegitimised as politically threatening. Furthermore, their presence may legitimise organising, both through associating the disabled person with the role of a child and by suggesting 'hysteria', rather than threat. In contrast, claiming an LGBTQ+ identity disassociates the disabled person from that legitimised position as a child and occupies a position which has been delegitimised as politically threatening (Kondakov, 2014, 2018).

The inherently delegitimised nature of LGBTQ+ organising was itself a difference from how disability organising is dominantly perceived. Actors suggested that, because LGBTQ+ organising was so delegitimised and could not have any relationship with state, it had in fact gained greater freedom and strength than disability organising. They felt that the latter was hampered by its strategic decision to maintain a certain relationship with state. Disability organising was thus seen as more cautious and restricted. For example, Fyodor said:

> If the organisation receives money directly from the state, then it's clearly not going to put forward any,- well, I mean to say, it's not going to do any protest activity (*protestnaia aktivnost'*). You won't have any positional demands (*pozitsionnye trebovaniia*). Just because it's the hand that feeds. […] There are organisations which depend directly on the state and then, well, who pays the piper calls the tune. That's the first thing. Second, even if an organisation is actually independent, right, it's still going to think a few times, "will I get hit on the head if someone wants to hit me on the head [for this]." And so that really slows things down. […] Why is the LGBT community (*soobshchestvo*) so strong and politically active and, well, basically does a whole load of stuff? – in their activity there has not been any involvement of the state. I mean, everything that they've done, they've done in spite of state action. In the inva-sector (*inva-sektor*, disability section), it's all exactly the other way around. I mean, there's a huge amount of attention from the state, attention exclusively from their own position (*vnimanie s svoei kolokol'ni*), with their kind of worldview and it really slows things down, because again there's a lot of containment in that kind of action, so I mean instead of organising an 1000-person meeting of wheelchair users (*koliasochniki*) with the demand that the metro is made accessible, for example, what actually happens is the opposite that some kind of pro-governmental organisation, [brings together a group of wheelchairs users to check the accessibility of a museum, and then uses that to show that] in the country work is ongoing in order to ensure accessibility. So, it works out that the state is substituting itself in for the private (*chastnyi*) third NGO sector, and in fact by doing so is sabotaging its [i.e., the NGO sector's] whole work.[lxxxiv]

Fyodor thinks that the state influences CSOs, even when they are not directly financially dependent on the state. He suggests that registered CSOs think twice before engaging in activity critical of state positions. Whether they receive funding from the state or not, registered CSOs may be subject to administrative restrictions or other sanctions. Unregistered CSOs perhaps have more latitude here as they are not necessarily made visible to state via their registration. Nonetheless, the individuals within them may still be subject to sanction. Fyodor mentions the possibility of negative consequences which state actors could set in motion 'if someone wants to.' This echoes my previous discussions of the context for civil society organising, including the interplay between the facelessness of power, the possibilities

of instrumentalising legal mechanisms to restrict CSO action, and an awareness of the rules of the game which produce self-censorship and compliant behaviours. Fyodor believes that the need for CSOs to cooperate with the state to achieve certain goals has shifted the development of formalised disability organising towards less confrontational lines. As I discuss below, the shift towards action which is not overtly confrontational is part of excluding or causing, directly or indirectly, the (self-)censorship of LGBTQ+ people.

What Fyodor identifies as a weakness of disability organising could also be seen as a strength. Unlike LGBTQ+ organising, some parts of disability organising have the option of working with the state, while other actors within the disability organising space take on more contentious roles. This could be a strategic division of labour which allows a wider range of organising and campaigning to co-exist. However, LGBTQ+ identities are widely delegitimised and struggle to co-exist with the consensus of a wider disability organising sphere. In some cases, failure to engage with LGBTQ+ identities stems from discrimination, rather than a strategic choice to maintain a wider range of action across a range of differentiated actors. While some saw LGBTQ+ organising as a model in developing a broader identity and recognition claims, others rejected LGBTQ+ organising entirely. These views may interweave with and be legitimised by state-led delegitimization discourses. Fyodor comments:

> Part of those people, even those who are themselves activists, they are still homophobic, I mean, they are still going to have been only just telling you about how, like, equal rights, all that, right? And then you start talking with them a little bit about gay people and they say, "No, gay people, gross. Stop." Not everyone, not everyone, but part of them. Another part, they understand on an intellectual level what you're saying to them, right, so like, equal rights, all that, a common agenda, the intersection of some of our spheres of action, that actually cooperation would be objectively in the interests of both sides, right, because, well, all the same you always need allies. And there you'll see that it's already a kind of different level, but all the same you understand that [it's a] no, because of the state, no, because of fear, no, like, I don't know, because tomorrow they'll come with some kind of inspection and shut us down.[lxxxv]

Fyodor and Artyom describe registered CSOs as unwilling or afraid to collaborate with or openly support LGBTQ+ organising. While some make this choice based on values, some have fears which are driven by their concern to be able to continue immediate, concrete, and often urgent action. As I have demonstrated previously, actors avoid politicised action to protect the individuals with whom they work and ensure that their CSO may continue action (Chapter

5). The possibility of sanction makes CSO actors risk averse, particularly where it concerns public action on the part of a CSO. Fyodor continues:

> I have good relationships with people who work there [in a registered CSO] and, like, with their management and, again, on the level of our values (*na tsennostnom urovnem*), we understand each other. But it doesn't go any further because, we, you can explain it in different ways, but the heart of it is that, like, "We don't want to take a risk because it's not something that exactly on our agenda." The reasoning goes that "we do a lot for people with disabilities (*liudi s invalidnost'iu*) and that's our main task. Well, if we turn around and start with all that, it jeopardises (*stavit pod udar*) all that good work that we are doing. It's a kind of moral choice. […] And here, [as an CSO] all the same you have to be in the same room as [members of government] because, like, even with all that, even though these are far from being the nicest individuals, all the same they do something, sometimes they are your tactical allies. And that's an awful feeling and very many people who work in the non-commercial sector,- no matter what they do, everyone who, for example, helps children who urgently need some kind of operation,- they very often have to work with these kind of people. And that's really hard because you know what kind of people they are. You know where that money's from. It's morally flawed, but at the same time you know that if right now you don't work with them, then a concrete child is going to die or a concrete ramp is not going to get built. Basically, you won't have anything at all.[lxxxvi]

Previously, CSOs' prioritisation of urgent service delivery and medical care has been associated with the absence or irrelevance of rights-based approaches (cf. Rasell & Iarskaia-Smirnova, 2014; Thomson, 2002). However, as I have demonstrated in the previous chapter, this equation does not necessarily hold up. Within formal CSOs and other spaces, there are people who view their work as rights-based, even if they strategically do not overtly frame it as such. Furthermore, an action may still promote a certain right or rights, even where it is neither understood, nor framed in that way by its actors. Nonetheless, the choices made by formal CSOs demonstrates how a hierarchy of exclusions is created in an environment in which actors perceive it necessary to make a choice between, on one hand, maintaining a relationship with state to deliver certain services and, on the other, making wider claims about disability rights and identities. Fyodor describes actors as thinking of work for LGBTQ+ rights as peripheral to the main work, which cannot be sacrificed. In Fyodor's telling, these pressures result in a disability sector which is largely case-based and uses charitable approaches:

> [Disability CSOs take] this case-by-case approach going by concrete cases, not big campaigns, constantly being cautious about the state, using this rhetoric of downtrodden (*ritorika ugnetennykh*) slash charity, that all creates…- It helps for

> some things. Tactically maybe it helps a concrete boy get a concrete wheelchair. But it doesn't solve big problems. […] So [disability CSOs work with] some specific concrete cases. Again, in that all, there is a very strong flavour of the concept of charity. Because, when you do something for people with disabilities, and this is in the position of the state, the rhetoric you hear on TV, and, unfortunately, what representatives of the disability community (*predstaviteli inva-soobshchestva*) say too, all the same you have the rhetoric not of "let's get this boy an electric wheelchair because it's written in the constitution that everyone has the right to move around freely and la la la," no. It sounds like this: "Look what a wonderful little boy, he's having such a bad time without this wheelchair, but we're all good people, you should share what you have, and, anyway, this [needing to use a wheelchair] could happen to anyone."[lxxxvii]

Fyodor identifies the use of discourses of charity and, just prior to this moment in the interview, describes CSOs who use images of disabled people as 'pure souls' and 'heavenly angels.' While not all CSOs take such an approach, these dominant discourses around disability nonetheless remain present and support the charitable logic which legitimises disability organising in Russia. However, as Fyodor himself recognises, the charitable approach 'helps for some things.' This aligns with my suggestion that apparently legitimised framings may be tactically chosen both to dissimulate actors' strategies of resistance and to achieve certain goals (Chapter 7). Moreover, this also suggests an avenue for the division of labour among a wider sphere of disability organising and different viewpoint of that organising. It is not necessary for there to be consensus from all parts of disability organising spaces those groups like Fyodor's to recognise the utility of other CSOs' case-by-case, service provision work and to perhaps perceive it as allowing them to engage in other, more contentious work. However, this is made difficult precisely as the discursive choices which these CSOs make, however strategically, in their public framing of action in fact exclude many disabled LGBTQ+ people. As I show below, this can make it harder for them to access CSO services. The perpetuation of images of charity and disabled people as infantilised, 'heavenly angels' also reinforces the patronising and objectivising modes of interaction which disabled people reported commonly experiencing.

Fyodor's grappling with the nature of disability organising and its differences in comparison to LGBTQ+ organising suggests the strategic limits of identifiably contentious work for disability organising in Russia, where the latter seeks to maintain a relationship with the state and to avoid sanction. The choices which CSOs make in response to their environment create exclusions. The state-led rhetorical environment and legislation thus both structure the

misrecognition and exclusion of aspects of disabled people's experiences. Where a disabled person claims sexual agency and a sexual identity, they break the stereotypical understanding of a passive disabled person deserving of charity. They leave the realms of 'heavenly angels' and become people who are 'unworthy' or delegitimised, both as recipients of civil society support and participants in civil society organising. In the next section, I explore how LGBTQ+ people negotiate these exclusions.

3. LGBTQ+ and Disabled: Negotiating Exclusions

I previously quoted Artyom saying that working with disabled people is 'a kind of politically comfortable image in Russia to show how good we are, [to show] that there is some kind of social responsibility in the country.'[lxxxviii] Immediately after this, he continued:

> We're again trying to take into account that, the thing is, we've got many LGBT people, including among [PNI] residents [with whom Artyom works], and I'm also from the LGBT community too. [Artyom refers to the LGBTQ+ events he has worked on.] I have serious problems that I can, for example, speak about a person with disabilities, but I can't speak about a person with LGBT disability (*o cheloveke s LGBT invalidnost'iu*). Our organisation doesn't know how to work with that, they're afraid of it and don't want to.[lxxxix]

LGBTQ+ people are, of course, present throughout disability organising. However, their presence often remains silenced. As Kir said, 'You end up with the impression that it's an entirely cis-gender, heterosexual community,'[xc] although this is not the case. Artyom discusses LGBTQ+ presence in the formal CSO for which he works:

> The organisation takes the position that we have many employees, many LGBT employees, for example, many people who go to protest marches, for example. But we are banned, I mean, we go there not as representatives of the organisation, but just as individuals. When I participate in LGBT events, it's "take part, but don't mention [the CSO]". There was a round table about LGBT and disability a year ago, which [a grassroots informal organisation] organised. And it was so stupid, because all our colleagues came, all these faces we know, but I wasn't allowed to write [the name of the CSO], with everyone knowing each other, but, for example, it's not written on my badge. And the whole time you are saying, "now I work for a big charity organisation in [city]." It's just the pits (*marazm*). But that's the reality. Because there are Orthodox grants, because the organisation actively cooperates with the church.[xci]

Artyom's description identifies several points which I explore further in this section, focusing on how actors negotiate and respond to them. LGBTQ+ experience within disability organising (including disabled people who identify as LGBTQ+ and non-disabled people who identify as

LGBTQ+) is not discussed and often deliberately silenced out of concern for organisational survival. This is based on the fears of sanctions or negative impact on receiving funding. Here Artyom relates this to Orthodox grants and cooperation; elsewhere, actors continue this link with Orthodoxy to draw a line to the state's generally conservative rhetoric. They reference laws on publicly offending religious beliefs and against 'Gay propaganda' as having a restrictive effect on formal CSO organising. I have introduced the latter law above. The former refers to Article 148 of the Russian Criminal Code, which declares it a federal crime to publicly conduct actions with the express purpose of insulting religious beliefs. The article was adopted in 2013 in the wake of the Pussy Riot case, brought against the protest group for staging a performance inside the Cathedral of Christ the Saviour in Moscow in 2012.

In response, LGBTQ+ people hide aspects of their identity within disability organising spaces, exit these spaces, and create their own spaces. Building on differences in expectations and possibilities for disability versus LGBTQ+ spaces, some activists also differentiate their expectations for both; they in fact expected more work to support disabled people to come from LGBTQ+ spaces, rather than disability organising to support LGBTQ+ disabled people. This was based on the logic that LGBTQ+ organising is anyway delegitimised and by definition cannot currently have a collaborative relationship with state. Thus, they have no reputation to build or maintain with the state, unlike disability CSOs.

3.1. Exit and (Self-)Erasure

People who identify as LGBTQ+ commonly described having to hide their sexual orientation and/or gender identities. In some cases, participants did not feel comfortable being out in the CSO in which they worked or volunteered. However, actors also were directly requested to hide their identity by other members of the CSO. For example, Daria discussed her experiences across two formal CSOs and a grassroots initiative (*nizovaia initsiativa*) at a state school:

> They asked me there not to talk about that, at [formal CSO], not to show in anyway my close relationship with my girlfriend, who was working alongside me [i.e., on the same project at the same formal CSO], and not at all to talk about those topics with the [people using the CSO's services]. It was already a bit late, because there had already been some moments when someone had asked me, "Do you have a boyfriend?" And I said, "No, I have a girlfriend." And people went away, thinking about it. Nothing bad happened, plus we didn't break the law, there everyone was

> older than 18, but, anyway, that happened. Then I worked [at a grassroots initiative (*nizovaia initsiativa*) in a state school]. […] But there were the same limitations there. They also said to me before hiring me, "Please delete from your social media all the information linked to LGBT-politics and stuff like that, because you know that we've got all kinds of Orthodox extremists here, and if they find out about us, they'll turn us in (*nastuchat*) and our whole project will get shut down." I actually found a way out because I realised I couldn't delete all that information, because there was a whole load of it, [so] I just changed my name on all my social media, so that it was harder to match them [i.e., my social media accounts] up with me. […] So, works out that those [grassroots] initiatives have their own limitations too when they're working with state structures.[xcii]

Although Daria works with adults only, who, as she notes, are not subject to the so-called Gay Propaganda Law, she has been told to hide her sexual orientation. As with the Foreign Agents Law, the weight of the Gay Propaganda Law is felt also outside of its remit as technically written on paper. It still causes concern on the part of CSO leadership that their CSO could have the law turned against them and lose their project. This was also the case for the grassroots initiative, which Daria linked to its operation within a state school. This equation was again common, where proximity to state or working within state structures meant that the CSO had to engage in reputational work and compromise to ensure that they may continue action. It also demonstrates the fear, uncertainty, and concern to maintain projects, which generally cause people to make highly strategic choices to protect CSO action (Chapter 5). Here we see how these choices shape the lack of open recognition of LGBTQ+ people in the disability organising sphere.

In negotiating how she responded to the request to hide her support for LGBTQ+ rights and own identity, Daria demonstrates resistance in her compliance. It was important to her that she was out and open about her relationship; she mentioned it casually when asked, rather than hiding it. When asked to remove material from her social media, she rather changed her name. Practically, of course, she suggests that it would have been hard to remove all the material she had online. However, she also discussed in the interview how having such material on her social media pages was an important part of other forms of activism in which she is involved and personally important to her to keep. While resistant, her response demonstrates another retreat towards the ambiguity which is so commonly mobilised to permit continued action.

While Daria was directly requested to hide her orientation and negotiated her compliance so as not to entirely erase her identity and activism, Kir described a different situation. They have generally left disability organising, as they do not feel welcome there. However, they still occasionally find themselves forced to interact with certain CSOs and online resource groups to access advice or services which are more impairment specific and not otherwise available. In online activism and commentary, Kir actively manages who they may be identified by; they do not wish to be openly identifiable to everyone as a trans activist. Talking about one article in which they described themselves as such, they said:

> If I'm honest, I was even afraid of putting my name out there because I was afraid that acquaintances of my acquaintances could come across the article, people I really don't want to inform about who I am. […] Now I'm more careful and sometimes when I write some material linked with LGBT and disability, particularly in some very public places, I sometimes am afraid of putting my name out there. The people who know me as an activist will recognise me. And the people who don't know me, what difference does it make [if I'm named or not]?[xciii]

Here again is the strategy of turning inwards and curating who has access to which information ('people who know me as an activist will recognise me'). Information is available to those who are already in the know through other channels. Otherwise, Kir suggests that their individual identification is not important and potentially risky. Generally, Kir self-censors and erases aspects of their identity within both disability and public-facing forums. They described largely removing themselves from disability spaces based on the impossibility of being open about their identity there, despite, as we will see below, the fact that they would have been interested in being involved with formal disability organising.

Asked about accessing advice or services within disability spaces, Kir said that doing so would meaning having to self-censor, erasing the fact that they identify as 'non-binary, trans, [and] pansexual.'[xciv] Although not directly asked to do so, their expectations and perceptions of disability organising spaces mean that they do not believe that they would be accepted there if they were out and open. Kir says:

> Really, there are actually complications with that because I can come to the LGBT community [as opposed to the disability community and CSOs] and say, "guys, I have [this disability]." Of course, they'll need to get used to me, but generally no one will give a damn about it, really. […] But it's a been a really long while that I

> don't speak to the so-called All-Russian Organisation [Kir specifies which one],[36] because that's really difficult. I don't go there because I wouldn't be able to be there. I could be there as a disability activist (*inva-aktivist*), that's not a problem. They, maybe, would even be happy to have me as I'm quite a young, proactive person, to the extent of, as it were, my capabilities. But I will not be able to come out there as LGBT because they'll chase me out of there with a yard broom (*pogoniat menya "poganoj metloj"*),[37] as it were, and I won't even try. No, I'd find it interesting and, maybe, important to go to them [the GONGO], do something myself, ask for support from them. But I'm afraid that that's not possible.[xcv]

Later in the interview, we spoke about CSO services which Kir felt they might need, for example to finish their studies and find employment. Despite recognising their need for certain services, they felt blocked particularly from accessing in-person CSO services, as accessing them would mean having to hide that they were trans. Kir said, 'I think that I would hide [being trans]. […] So, going there as a trans person (*trans-chelovek*) is just really dangerous, I think. Like hell anyone there needs me.'[xcvi]

Kir nonetheless describes certain services as necessary, for example advice on certain disability entitlements or assistive technology. They negotiated this by, where necessary, mainly accessing services online. Online, asynchronous, informal supports, like forums and social media groups were particularly useful. Kir explained that using these forums and groups made it easier both to mask their identities and to disassociate from how they were forced to refer to themselves online. Kir described that using the incorrect pronouns to refer to themselves was easier when they could shut the laptop and go away from the space whenever they needed to take a break, unlike in offline, synchronous, in-person situations. Where possible, they also sought such advice among informal groups of disabled people who were often also LGBTQ+ and with whom they felt more comfortable (Section 3.2.).

There are clear consequences to how difficult it is to access services from within disability spaces. Often, these services are not replicated outside of disability organising. Therefore, people experience a choice between foregoing services or censoring delegitimised aspects of

[36]There are only three 'All-Russian Organisations' and they have some division by disability (namely: All-Russian Organisation for Deaf People; All-Russian Organisation for Blind People; All-Russian Organisation for Disabled People). As described in presenting my methodology (Chapter 2), I have therefore redacted the exact organisation to which Kir refers to better maintain anonymity.

[37]In Russian, '*poganaia metla*' refers to the unclean broom used to sweep out the outhouse. Kir suggests that they are considered so unclean that, beyond just being chased away with a household broom, they would be chased away with the dirty outhouse broom, so as not to spoil the normal one.

identity to safeguard their access. Exit from disability spaces and the creation of new spaces may importantly offer community and support which LGBTQ+ disabled people otherwise lack (Section 3.2.). However, the LGBTQ+ sphere does not respond to the full range of disabled people's needs. The LGBTQ+ sphere may support recognition claims, build community, and be in many ways transformative for those within it. Still, it does not, and indeed cannot, engage in the direct service provision which is currently conducted by disability CSOs. LGBTQ+ disabled people's need to self-censor to access necessary services from disability CSOs demonstrates that this is not experienced as a simple division of labour among spaces which all people access with equal comfort. Rather, where it is impossible to exist comfortably within disability spaces, actors both exit towards other spaces and create new spaces and communities where they can feel accepted and comfortable, even at the loss of certain specialised services provided only by disability CSOs. Misrecognition operates unequally and is structurally underwritten to disproportionately exclude those whom dominant discourses and, particularly, legislative and policy conditions remove from legitimacy. This misrecognition negatively affects redistribution, where the latter is understood as that accessed through LGBTQ+ actors' engagement with CSO services.

3.2. Ground-Up Initiatives and Dissimulated Collaboration

In response to the failure of disability spaces to openly accept and welcome LGBTQ+ identities, actors create or engage in grassroots initiatives and dissimulated collaborations. Some actors create or join intersectional movements which are organised around recognising LGBTQ+ disabled people. Actors also move into LGBTQ+ spaces, finding it easier to be included and accepted there than in disability spaces. Actors interact with formal CSOs in individualised and fragmented ways, often through informal, intersectional disability movements. Through these dissimulated collaborations, they try to influence formal CSOs through their individual members and aiming at longer-term change within the sector. Identifying movement between different spaces and dissimulated collaborations responds to weaknesses in accounts which have not recognised or 'downplayed' connections between individuals and social movements (Yates, 2015a, p. 241) and between formal, registered CSOs and movements (cf. Glasius & Ishkanian, 2015).

The lack of recognition of LGBTQ+ people from within disability organising motivated the initiation of the intersectional movement in which Fyodor participates:

> He [i.e., the initiator of the group] spent a lot of time working with people with disabilities, […] and at the same time he's gay and a significant part of his work is linked to LGBT activism. And so, he kind of was telling me that one day he realised that what was going on with him was kind of strange, that his life is like divided into two parts, that there's like LGBT people, gay people over there, and some kind of movement around that, and then over here there are disabled people and they're kind of separate. But, actually, there are people who are really in both categories.[xcvii]

Experiences like those outlined above from Daria and Kir demonstrate that it is difficult to respond overtly to these categorical divisions from within formal disability organising spaces. In the case that Fyodor describes, the inability to do so from within the disability space led to the founding of a small grassroots movement and community which focuses particularly on rights of disabled, LGBTQ+ people. As well as the building of new initiatives, some actors' exit from disability organising spaces results in movement to existing LGBTQ+ spaces and community building within those spaces. Kir describes their experience of beginning to join the LGBTQ+ community:

> When I came as an activist to the LGBT community, to the Queer community, I realised that here the situation is even more interesting. On one hand, it's all a lot better because in the LGBTQ community you meet people with different identities and it's hard to surprise a lot of them. But on the other hand, it's all a little more complicated because it's kind of unusual that I'm a [disabled], non-binary, trans, pansexual person. It's a very interesting combo and people are surprised that I can have other identities aside from being [disabled], that I'm not part of the cis or heterosexual community. I don't even know why, in principle, [they think that] I couldn't have some kind of gender identity or sexual orientation.[xcviii]

As Kir says, movement into LGBTQ+ organising spaces as a disabled person was not entirely smooth; stereotypes and lack of awareness around experiences of disability also exist there. They reference the assumption that disabled people are asexual ('[they think that] I couldn't have some kind of gender identity or sexual orientation'), reflecting dominant discourses by which I previously discuss as legitimising disability by disassociating it from the political realm by infantilisation and desexualisation. Still, they found it possible to be open within the LGBTQ+ community about aspects of their identities and experiences which they felt forced to occlude within disability CSOs. Furthermore, they described how they were quickly welcomed and included with LGBTQ+ spaces. They identified their work to facilitate this acceptance as activism; Kir made various interventions, both in person and online, to inform and educate about disability. They described how these interventions were shared and

amplified by key members of various LGBTQ+ spaces, supporting their inclusion. These LGBTQ+ community members also saw the development of inclusive access measures within LGBTQ+ spaces as a strength which increased the reach of their events. Some disabled people attended LGBTQ+ events despite no prior interest in LGBTQ+ culture and driven only by the availability of access. For example, Sasha commented:

> There are so few places with visual description (*tiflokommentirovanie*, audible narration of visual elements) that even people who don't identify as LGBT and just generally maybe don't really even have much interest in Queer culture, they still came to our event to hear how it was commented for them, because there's this kind of demand (*potrebnost'*, need) for it. And on the whole the reaction [to them bringing in further accessibility measures] was very positive.[xcix]

Kir found their online activism important not only in building their relationship with the LGBTQ+ communities with whom they also interact offline, but also with LGBTQ+ disabled people both online and offline. Kir explains:

> When I came out [online] and changed the pronouns I use to write about myself, I also started publicising some LGBT events, organisations I went to, and suddenly people started to come to me [online], some of them staying anonymous, but some completely openly coming to me, people who are themselves LGBT with disabilities (*LGBT s invalidnost'iu*). We spoke about how it's really important for us, having community solidarity is really important, when we meet, and when for us there are certain intersections in our identities (*peresecheniia v identichnostiakh*). For example, one person came, they wanted to stay anonymous. Of course, I didn't force them to speak with me and didn't try to deanonymize them. They just wrote that it was really important for them to read my posts. Another person came to me, a blind (*nezriachaia*, non-sighted, lit.: non-seeing) homosexual woman (*gomoseksual'naia zhenshchina*). We wrote to each other directly, […] for her it was important to speak with me because few people know about the fact that she is homosexual, and she knows that I will get her because we can have similar difficulties. We can ask each other some technical questions, some legal questions, all those kind of things. There was another person too, we're still in touch […]. We started to speak and she had a similar difficulty to me: she was an active, public figure, she [had won prizes in competitions run within disability spaces] and everything was very cool, but she couldn't come out as LGBT. […] You constantly speak with a whole load of people, but you can't say that you've got a girlfriend, because you can't say you've got a girlfriend. It works out as if you don't have any kind of personal life, although you do. […] When people with disabilities who also relate to the LGBT community started coming to me, for me it became a really important motivating factor, first of all because they show me that we aren't alone, and also because I, with my activism and what I write, show them that we aren't alone.[c]

Kir identifies as activism the act of publishing material online on LGBT events and coming out themselves as trans. This aligns with the resistance paradigm (Chapter 3), which identifies as a form of resistance such actions where intended as such by an actor and where they interact with stigmatisation and exclusion. Stating that they are trans allows others know that they are 'not alone', even in cases where people may read the site without leaving any comments or leave comments anonymously. I would extend the concept of the passive network of recognition (Chapter 3, cf. Bayat, 2013) to include that which may be brought into being by online posts such as that of Kir. These passive networks create the possibility for imagined solidarity and fragmented action conducted by an atomised group which is perhaps smaller than those to which Bayat (2013) applied the concept (e.g., people living in material poverty, women). This possibility is particularly important under conditions of constructed vulnerability where actors perceive visibility to be potentially dangerous. Here, Kir's actions are an example of creating a space for existence and breathing room for people who may not wish to publicly identify themselves. Online space is able to bring together, asynchronously and across material space, a fragmented, smaller group whose members need another person to show them that they are not alone. It simultaneously enables people to maintain their anonymity, if they want to do so.

The online platform does not only act to discuss questions relating directly to identity. Rather, Kir suggests that it also becomes a comfortable place where people feel they can get answers about 'technical' and 'legal questions' relating to disability. As I showed above (Section 3.1.), Kir felt discomfort turning to disability CSOs who could answer these questions, but which were hostile to their identities. In contrast, by building an online space, they in fact develop a space of mutual support where such questions can be answered without any conditions around a disabled person's identity.

Online space is also important in challenging another form of difference identified between LGBTQ+ and disability organising. Some actors also mentioned that, unlike LGBTQ+ events and protests, disabled people could often not gather both because of the inaccessibility of material space and because of the resources and energy taken to manage physical embodiments of disability. For example, Sasha said that activism was harder because the world is 'adapted' (*prisposoblen*, physically set-up) for abled people. They gave the example of another intersectional disability collective: 'they have really far more problems [than

LGBTQ+ organisers often have] to find a place, for example, which could be accessible for people with different kinds of disability.'[ci]

Previously (Chapter 6), we saw how disabled people are excluded from material public sphere by both material inaccessibility and stigmatising interactions with others. The use of online spaces thus responds to several issues. In this case, some users find the anonymity of the platform important as allowing them to safely discuss their experiences as LGBTQ+ disabled people. However, as well as that, online platforms allow disability activists and community members to gather in a way which material, public space does not. Online space provides another mode to claim the right to presence, existence, and protest. They thus allow disabled people to challenge the perception that they do not exist, as Kir themselves notes ('they show me that we aren't alone, and […] I […] show them that we aren't alone').[cii]

Kir's current work is largely turned towards LGBTQ+ and disability communities and nonmovements, centring around creating inhabitable worlds for themselves and others through claiming existence and creating spaces where they could be accepted as themselves. However, online activism addresses multiple audiences. In Kir's case, they initially turned to online activism because they were tired of the questions which they constantly received or heard as they moved around in public spaces. Kir therefore used online spaces to create a platform where they could respond to, challenge, and educate on those questions, with the goal of shifting their experience in the offline world.

Other intersectional organising groups turned more towards dissimulated collaborations with formal disability CSOs. I have quoted Marina, who works for a registered CSO and said, 'We have to think about our reputation a lot, who we can be linked with, who we can't, who we can openly enter into a coalition with, who we can help but clearly not, well let's say, be seen out together.'[ciii] Above, I cited Artyom describing how CSO employees may go to events around LGBTQ+ and disability intersectionality, but only in their individual capacity and without mentioning the name of the CSO where they work. Social movements and communities sought to mobilise these possibilities for hidden collaboration and interaction, moving out of the formal disability CSO space. However, these actors still felt that they were limited by the need of involved CSOs' employees or volunteers' to maintain caution and ambiguity. Fyodor described how they worked with formal CSOs:

> When we started some kind of cooperation (*vzajmodeistvie*) with [formal CSO], then initially it was like, "yes, let's, we're working [with you]. But we, like, don't do it publicly." And basically, on those conditions they were ready to work. And we did some things together, I mean, people from them came to some of our events and, I mean, there was not some kind of ban from their side, like, no, don't go, that wasn't the case. And again, it was this kind of undercover collaboration (*podkoviornoe sotrudnichestvo*), but all the same it had some fruit of its own. Because some disability (*inva*) representatives, now they have a little more of a broader view on the overall civic agenda (*obshchaia grazhdanskaia povestka*). And, like, that's always a positive. […] But that's just a grain of sand in comparison to the absolute carte blanche that LGBT organisations give us, who say, OK then, like, guys, let's do inclusion and shout from every corner that now we're inclusive. Unlike state organisations, they shout about having inclusion and they've actually got inclusion.[civ]

This 'undercover collaboration' is an example of 'the boundaries between the formal NGOs and informal groups of activists [being] blurred' and the unseen 'cross-over and collaboration' between them, as theorised by Glasius and Ishkanian (2015, p. 2622). Glasius and Ishkanian focus on 'two types of resources that were most often mentioned by activists [in their interviews, as accessed through formal CSOs]: the provision of meeting space, and the provision of expertise, including substantive expertise, campaigning know-how and legal aid' (2015, p. 2632). Here, activists largely mentioned other forms of collaboration. In their cases, formal CSOs did not act as 'resource centres' for grassroots activists. Rather, grassroots activists attempted to attract individual employees or collaborators from formal CSOs to offer them training. This training aimed to introduce knowledge which goes beyond the limits of what CSOs identify as permitted topics of discussion and organising, and therefore cannot be introduced in those formal CSO spaces. In Fyodor's example, the group sought to build informal, unseen ties in the hope of thus securing non-immediate change within formal CSOs themselves by influencing those who might later take up positions of power. Fyodor describes positive results as their potential, indirect, and hidden influence:

> There are people all the same who now know a little about that [intersections of LGBTQ+ and disability identities], considering that these are quite talented people, right, that all the same working in disability (*inva*), they already have a slightly different vision. And, as a consequence, if later in 10 years or so they become leading, I don't know, players in the arena of the disability (*inva*) movement for the rights of people with disabilities, they will already be more open and prepared than the people who are there right now [in leadership positions].[cv]

Again, this action works through individualisation, as the CSO is fragmented and disappears into the individual actors employed here who attends the training. Moreover, the temporal division of outcome reoccurs here as it did with Oksana, who staggered when she released different information about her public action, making political claims only after leaving the street and to a limited group of people with whom she largely had prior connections (cf. Chapter 7). Temporally staggering information and outcome thus becomes a technique to strategically obscure meaning, and thus to continue action. Individualised and ambiguous action may aim for both immediate change in building prefigurative communities and longer-run change. With their action, as in the case of Kir, actors also aim to claim agency around how they express their identities and challenge exclusion.

These forms of 'undercover collaboration' also are an instance of grassroots actors engaging actors from formal CSOs who were not necessarily previously involved in grassroots activism. We have seen this happening in the other direction, as in the example of Artyom, who moved into 'a job in an NGO […] because [he] felt, again, that in that position [he] could do more'[cvi] (Chapter 6). These actors do so to increase their possibilities of action in terms of links with government or access to state residential institutions, just as others found CSOs to gain legitimacy and increase possibilities of formal collaboration with state organs. Glasius and Ishkanian (2015, p. 2623) also demonstrate that civil society actors sometimes experience working in formal CSOs as constraining. This holds true here. For example, Artyom also commented that:

> I came [to the CSO] with different hopes, and I have to say that most of them turned out to be false. […] NGOs now are set up for survival, for management, for economics, and to a lesser extent are about politicisation, about analysis of the current situation, and about really involving people with disabilities. They all speak for people, but they find it really hard to work together with people with disabilities. They are all based on the exploitation of that image of the victim without their own will (*bezvol'naia zhertva*), [on] paternalism.[cvii]

However, as well as seeing actors in formal CSOs consequently seeking other outlets for activism, outside of formal CSOs, we also see activists from outside formal disability CSOs driving this movement. Thus, grassroots activists aimed to address individuals from formal CSOs who are not necessarily prepared to engage in longer-term or regular activism outside of the formal CSO, but who might be accessed through punctual training or events. This

demonstrates extended, multi-directional forms of movement and fluidity occurring between different organising spaces.

3.3. Differentiated Expectations

Movement between spaces also tells us about the differing expectations actors had for different organising spaces. Above (Section 2), I discussed how Fyodor grapples with his criticisms of disability organising's proximity and need for compromise with the state. He saw this as slowing down progress on change to dominant understandings of disability. However, he also recognised that charitable, case-based approaches do have a certain, limited purposes. As I discussed in Chapter 5, numerous actors spoke about how they were careful not to spoil their relationship with the state to be able to continue action and help the people with whom their CSO works. Maintaining this balance is recognised, and even instrumentalised, by actors across a spectrum of organising activities as allowing continued action (Chapter 6). However, activists differed about how permissible they found both compromise and the exclusions which it created.

Fyodor organised largely in a grassroots social movement and saw LGBTQ+ formal CSOs as far more open and ready to collaborate than disability CSOs. In their turn, Kir had turned away from disability organising and largely was active in creating their own spaces within and beyond LGBTQ+ movements and communities. In contrast, Artyom largely organised in a formal disability CSO, attending other protests and demonstrations in his own individual capacity. While Fyodor and Kir were both critical of disability CSOS, Artyom felt that it was LGBTQ+ CSOs and the wider LGBTQ+ community which did not do enough to support disability organising. While some people struggled to accept the compromises which disability organising, especially that in contact with state institutions and bodies, makes, Artyom understood their compromises. As Artyom felt that LGBTQ+ organising had less to lose and was already separate from state, he had higher expectations for that space. This co-existed with his frustration, discussed above, with the working methods and images used by many disability CSOs. Artyom explained:

> Personally, like, I'm fundamentally scared of being separated from [the CSO's] wards (*rasstat'sia s podopechnymi*), because these things are really close to me, and we're actually scared and what I really want is rather support from LGBT organisations and not them throwing it back in our faces, like, "what are you afraid

> of?" Yes, I mean at [that event] I didn't hear any concrete approaches for how we can cooperate. I mean, there were some kind of mutual reproaches, but that there was someone who proposed some kind of model… And then, they work kind of strangely, so, they invited us, but not heads of organizations, so I mean – [they invited] people who don't actually decided anything in the organisation. I said, "OK, if you want to come to [where Artyom works] and work with the people there, I can introduce you to everyone", but I can't, like, answer for the position of the organization, I just don't have those powers. I mean so the problem was like the position of those activists, the problem was how the event was organised, the problem was that there were no concrete models proposed.[cviii]

The fear and uncertainty which mark the experiences of actors and strategic calculations with which their negotiate their environments return here; Artyom is afraid of being forced to stop working with the people with whom he works. Appreciating the care which disability CSOs have to take to be able to continue action, he rather wants to see more concrete, direct action from LGBTQ+ groups. An irony is that the approach which Fyodor described using above also seems to have been experienced by Artyom here; the leadership of Artyom's CSO were not invited to the discussion, while he was. However, Artyom did not understand the organisers' choice, as he felt like he had little power to control the position of the CSO and therefore that it was not useful to invite him to the event. While Fyodor presented this choice as a strategy to enable longer-run change, Artyom did not recognise the same. Rather, he complained of not seeing any concrete strategies at all. However, given the fear and uncertainty of formal CSOs, approaches to their leadership may have been rejected. Furthermore, any strategies, including 'concrete' ones, may have to remain similarly indirect and surreptitious to achieve buy-in and participation from many members, employees, or volunteers of formal CSOs.

Actors are clearly aware that different organising spaces have different capacities. However, they disagree over ideology and approach, even within these bounds. These disagreements, the fears and need to compromise of formal CSOs, and the continued discrimination from actors within disability organising makes it difficult for formal CSOs and grassroots groups, social movements, and social movement communities both to build links amongst themselves and to see themselves as part of any single wider movement, using their different capacities to address and move forward different aspects of any broader common issue. Furthermore, different groups also campaign and operate in opposing ways. For example, the paternalistic, victim-based framing which Artyom identifies his CSO as using stands counter to other actors' goals.

4. Conclusion

In this chapter, I have demonstrated how disability CSOs' performances of compliance cause exclusion and (self-)censorship of LGBTQ+ people. LGBTQ+ organising is naturalised as highly politicised and contentious. This stands it in stark contrast to disability organising, which is naturalised as apolitical and compliant. Looking at how politicised LGBTQ+ identities interact with depoliticised disability identities demonstrates how enacting compliance creates a space for organising within which LGBTQ+ people feel required to erase their sexuality and/or gender identity. Remaining legitimised as a CSO actor requires perpetuating the misrecognition of disability, by removing it from association with sexual and gender identities which fall outside the dominantly translated norm. These aspects of identity exceed the boundaries of religious, charitable, and passive images of disabled people and are delegitimised areas for civil society organising. In this chapter, I have both identified these exclusions and demonstrated some ways in which they are negotiated.

Firstly, I identified differences between LGBTQ+ and disability organising through the comparisons which actors drew. Certain disability actors saw LGBTQ+ organising as an example for disability organising. They perceived the LGBTQ+ movement as more politically engaged, inclusive, and working for greater ideological change. In contrast, civil society actors saw disability organising's proximity to state as weakening it and maintaining a strategically depoliticised, case-by-case, individual approach. The strategic compliance of CSOs who seek to maintain a relationship with state institutions and bodies creates exclusions for people whose identities are delegitimised by the current legislative and discursive environment. While these exclusions are necessary to access certain levers of state power and to continue CSO work, they demonstrate how the environment creates a hierarchy of needs. In putting these often individualised and redistributive claims first, LGBTQ+ disabled people find themselves not recognised within disability organising.

Secondly, I examined LGBTQ+ actors' responses to these exclusions. Previously, I have demonstrated that actors use ambiguity strategically to continue resistant action. Here too, individualisation and ambiguity of action remain part of response strategies by LGBTQ+ people. Thus, they leave disability spaces or self-censor regarding their sexuality and/or gender identity when within them. They found their own intersectional initiatives, build their

own communities online, and develop inclusion within LGBTQ+ spaces. Finally, they dissimulate action through individualisation to work with formal CSOs, while bearing in mind the latter's constraints given their proximity to state. Regardless of the agentic forms of resistance with which actors respond to their exclusion from or to their perception of their need to self-censor within disability organising spaces, a tension remains. The restrictive context for organising legitimises certain expressions of disability, while delegitimising others. This legitimacy is central to be able to continue action, including those which LGBTQ+ people also need to access. However, accepting to perform legitimacy in this way creates a hierarchy of needs and perceived urgency with marginalises LGBTQ+ people and makes their access to certain services more difficult.

Chapter Nine

Conclusion

1. Introduction

I began this thesis by questioning why civil society engaged in social action is often characterised as depoliticised. I suggested that this characterisation is based on the misperception of social action. I also proposed that this misperception can be used as a strategy of power. This proposition is based on the understanding that power is fluid, contextualised, and inevitably characterised by the presence of resistance. Using it to look at disability, I identified how disability is constructed as extra-political, removed from power, and non-threatening. Rather than naturalising these legitimising myths (Toole, 2019, p. 612), I proposed to investigate how they operate, how actors negotiate them, and how this shapes disability organising, exploring the experiences of a range of civil society actors on a granular level.

In the first empirical chapter, I presented a bottom-up characterisation of this distinction between social and political action, where the latter is delegitimised and identification as a political actor strongly associated with sanction. Many actors understand this distinction as in itself fluid and able to be instrumentally applied to control CSOs. However, they also associate being political with certain forms of action, relationships to the state, and discursive modes in presenting their work. Despite their perception of rules as poorly institutionalised, they have distilled certain modes of behaviour which aim to manage risk of sanction. I thus demonstrated that apparently social actors are highly aware of power relationships in their environment, and how these power relationships shape action.

In the second empirical chapter, I looked at how disability organising is constructed as social. Having demonstrated the incentive to be identified as non-political, I asked why disability organising may credibly claim a social identity. Understanding disability as an identity and contingent power relationship requires that we ask this question, as this understanding of disability means that we cannot simply naturalise as fact that disability is depoliticised and, for example, feminism or LGBTQ+ rights are not. I answered this question through examining the dominant discourses around disability in interaction with those which characterise social

action. These create the opportunity for disability action to be understood as legitimised. However, this legitimacy is dependent on discourses which misrecognise disability as medical deficit, primarily eliciting individualised, charitable responses. This shapes disability organising, creating both opportunity and threat. I closed the second empirical chapter by identifying a first opportunity: instrumentalising assumptions of vulnerability and depoliticization, some actors move into disability organising as a manner of continuing action which they identify as resistant. This suggests how vulnerability may be used as a source of power and agency.

The third empirical chapter developed reflection on the opportunity for infra-political action, looking at how actors understand their work as resistant, although it may not be perceived as such by others. It also questioned some of the difficulties which ambiguous action faces in challenging existing power relationships, discussing particularly how actors' perception that resistance must remain ambiguous and not disturb legitimacy creates tensions and exclusions. As disability organising has the opportunity to maintain a relationship with state on the basis of acting as a legitimate partner, CSOs which seek to maintain that relationship struggle to exceed the bounds of discursive legitimacy.

In the fourth empirical chapter, an interaction between LGBTQ+ and disability identities and organising demonstrated this. Being LGBTQ+ disrupts the image of the disabled person as passive, infantilised, and vulnerable. Rather, it has been associated with discourses of politicised agency. Disability CSOs are therefore hesitant to recognise LGBTQ+ disabled people, or LGBTQ+ people within their organisations. This perpetuates a narrow misrecognition of disabled people and demonstrates the contingency of their legitimacy.

In the remainder of the conclusion, I first outline the overall contributions which follow from these empirical chapters. I then outline some untold parts of the empirical research, as part of my commitment to the research participants and to highlighting the necessarily partial nature of the thesis. Finally, I conclude by suggesting some future directions for research.

2. Contributions

I have explored how assumptions of depoliticization operate in relationship to constructions of disability. I have examined how this creates both opportunities and weaknesses for organising. This has implications for both research on (the resistance of) civil society and

disability organising, as well as for CSO actors themselves engaged in organising. As such, my contributions address a few different, although sometimes overlapping, audiences. Here, I present these contributions through their empirical, theoretical, and practical findings and implications. These intertwine; I take the position that 'theories are perspectives that make different aspects of the social world visible' (Fuhse, 2022, p. 100). However, for clarity I seek here to pull them apart a little. First, I outline how my empirical findings contribute to knowledge of the operation of disability organising. Second, I present the wider theoretical implications of these findings for understanding resistance. Finally, I suggest the significance of my contributions in terms of some challenges and calls for practices of organising and research.

My empirical work has nuanced understandings of present-day organising around disability in Russia. Organising which is dominantly understood as social, and thus non-contentious, is less researched. In response, I analysed how actors working in disability organising, itself dominantly understood as social, perceive their environment and how this shapes their action. Importantly, I showed that these actors nonetheless see their organising as subject to threat and dependent on enacting compliance with state. I also presented actors' perceptions of legitimised action to show a shift in understandings of rights and political action. State-led delegitimization of political action is strongly associated with human rights groups and overt protest. Therefore, many actors appeared to understand rights as delegitimised in general. They suggest a restricted notion which characterises civil and political rights as 'proper rights' and does not see social rights as 'rights.'

I identify this context as conducive to infra-political action. A few factors suggest this. These factors combine those which incentivise infra-political behaviour, and those which build scope for its enactment. The first group, incentivising infra-political behaviour, is composed by actors' perceptions of an unpredictable environment, an imbalance of power skewed towards the state, threat, and the potential for sanction. The second, building scope for infra-political action, lies in a restricted understanding of rights and contention. Infra-political action, by definition, avoids perception according to dominant understandings. These dominant discourses allow other forms of enacting rights and resistance not to be identified as such, and thus to evade perception. The association of disability with legitimised social, charitable action also builds potential for disability organising to be normatively

(mis)recognised as extra-political and, consequently, for infra-political action to evade identification. I demonstrated how this operates by identifying key discourses characterising disability and how they overlap with those characterising legitimised, social action. Identifying these key discourses also allows me to identify where and how disability organising might become delegitimised by exceeding their boundaries.

My final empirical contributions are then to demonstrate that apparent compliance is itself an agentic choice and that resistant, infra-political action does indeed occur in this context. I do so by exploring actors' meaning-making and intent, showing also that resistance is not necessarily pre-planned but also emerges on actors' identification of moments of friction. I identify resistance in actions which are ambiguous and multiply legible. I introduce resistant strategies such as individualisation, curating the diffusion of meaning through turning inwards and temporally splitting its sharing, and meaning-making and renewed knowledge production around everyday action. I show how these modes of resistance struggle to escape existing power relationships. To do so, I considered an identity which is removed from the space for apparently compliant, infra-political action by exploring the experience of LGBTQ+ actors within the disability sphere. I explored how LGBTQ+ actors negotiate differential recognition, as well as some of implications of their exclusion from or erasure with disability organising. Underpinned by the Gay Propaganda law, I demonstrated the structural creation of inequalities of recognition for disabled people.

These empirical findings are founded on a particular theoretical approach. This lens both uncovered the contributions made and identifies a path forward for subsequent research. My first engagement was to bring together literature from (critical) disability studies with studies of civil society and social movements. I also owe much to gender studies and Black feminist thought, both implicitly as they have influenced critical disability studies and explicitly as I signal in my direct citations. These citations are an acknowledgement of debt (Ahmed, 2017), and include work on discursive control, vulnerability as agentic, and presence as resistance.[38]

[38]Finally uncited in this thesis, but nonetheless supporting my thinking on presence as resistance is also Elijah Anderson's work on white space (2015). Anderson observes that, 'White people typically avoid black space, but black people are required to navigate the white space as a condition of their existence' (2015, p. 10). White space is ableist space, and systems of white supremacy and ableism are deeply intertwined (Chris Bell, 2010; Hartblay, 2020). Disabled people are also required to navigate 'white space' which are not conceived as theirs. Building on Garland-Thompson (2011b), and Butler et al. (2016), and McRuer (2006), I spoke of actors' identification and meaning-making around friction and misfitting in space as

Bringing these fields together allowed me firstly to argue from the standpoint of the transformation of expectations and assumptions, which disability studies proposes as central to what disability is and does (Hartblay, 2020; McRuer, 2006; Price & Kerschbaum, 2016; Sandahl, 2003). Holding this against dominant criteria for investigating action and recognising resistance (Véron, 2016) argues both for extending recognition of resistance, and for the failure to do so as a matter of epistemic injustice.

I thus contribute to theoretical debates around the nature of 'social' civil society action, vulnerability, infra-political action, and legitimacy. These areas all contribute to thinking about resistance. Firstly, I have argued that we cannot normatively assume that social action is depoliticised, or excluded from the realm of 'contestation and agonistic engagement' (Swyngedouw & Wilson, 2014, p. 6). Rather, apparent compliance may be strategic choice to enable continued action and possibilities of action which are predicated on partnership with state.

Secondly, I suggest that assumptions of vulnerability are discursively linked with extra-political framings. In a context where these framings are legitimised, dominant misrecognition of a group as inherently vulnerable may legitimise action. Explored through disability organising, I argue that this legitimacy can be instrumentalised in agentic strategies of infra-politics. These strategies evade perception by remaining under the cover of apparent compliance. Assumed vulnerability and depoliticization are thus a source of power. Instrumentalising this is a case of actors 'taking up of the tools where they lie, when the very "taking up" is enabled by the tools lying there' (Butler, 1990, p. 145).

Thirdly, I argue that exploring what occurs beyond the eye of the dominator transforms and extends range of resistance. Investigating this relies on criteria of actors' own intent and meaning-making, which may be neither loudly projected, nor evident when read according to normative discourses. Actors resist through ambiguous and prefigurative enactment of claims for dignity. These forms of action often turn away from collective meaning-making and deliberately manage the diffusion of meaning. The management of who is allowed access to which aspects of meaning is a technique to avoid control and sanction. Evading the perception

creating resistance. Anderson's telling of the discomfort in accessing such spaces and the different ways in which the same spaces are perceived by Black and white people also reflects some of the experience of disabled people discussed in Chapter 6.

of the dominator does not only rely on the ambiguity of the action in any single moment. Rather, actors stagger the release of meaning to produce and direct different messages to differentiated audiences. As well as this staggered production of meaning, I have also argued that the temporality of how resistance is experienced and identified by actors means that prior planning is not a criterion necessary to recognise resistance. Rather, where actors encounter or reflect on moments of friction, they (may) identify resistance. This causes them to reframe the experience and meaning of everyday actions.

Fourthly, I suggest that the limits of this legitimacy may also indicate the limits of the use of infra-political action to resist. Where the limits of legitimacy are exceeded, action becomes visible to the dominator. This may be of less concern to organising and communities which remain otherwise less legible to state, indeed often through using forms of resistance which focus on inward-turning community building. However, here some actors, particularly those working through formal, registered CSOs, again face strategic choices about their management of risk to maintain CSO action. While creating opportunities for resistance, I suggest that apparent alignment with legitimising discourses perpetuates misrecognition. Importantly, enactments of legitimacy operate unequally to reinforce existing areas of exclusion. In the case explored here, this results in a formal disability organising sector which remains hostile to LGBTQ+ people. More widely, this suggests differences in ease of accessing CSO services, problematic particularly where those may be an important part of meeting need.

Finally, I argue that these forms of resistance may be hugely important to the actors themselves. Actors understand them as making sense of and responding to an injustice in a direct way. Ambiguous, liminal resistance is often experienced as fulfilling a need for community, shifting self-knowledge, or making a difference to identity and everyday life. In cases of exclusion and hostility, it acts to claim and mutually recognise existence and build supportive communities. To be inward-looking should, therefore, not necessarily be characterised as a weakness or limitation, but investigated as a potentially rich, transformative resource for those involved.

Therefore, it is important to both recognise this resistance and to remain critical concerning how actors negotiate certain boundaries and where they may reinforce existing power relationships. This is a call to both civil society organising and research. To research on civil

society organising, I suggest that failing to recognise these forms of ambiguous resistance is a form of epistemological violence, which silences the possibility of resistance from certain positions. We would also do this violence were we to characterise these forms of resistance as unimportant or marginal. To do so suggests a normative ranking of resistance which prizes overt resistance and resultant change which is externally apparent and measurable. Accessing or achieving such forms of change is a function of power. To not recognise other forms of change, including individualised resistance to disciplinary power, is to fail to engage with a whole range of action. This action is not ignored at random, but is elided again precisely as a function of a power relationship; it is this action which is open to those facing oppression and excluded from formal, institutionalised channels of power. Critiques of action as parochial or inward-facing elide the value, and indeed protective characteristics, which turning inwards may hold for excluded groups. Research should rather be wary of reinforcing erasures and hierarchies of resistance, excluding certain people from capacity to resist, and making assumptions around depoliticization. Where apparent resistance is penalised and structures inequity, it is necessary to investigate what stands behind the strategic enactment of compliance. In doing so, adhering to criteria of intent and meaning-making, rather than necessarily form of action, uncovers resistance which other analytical frameworks erase or minimise.

To those involved in civil society organising, a challenge of this environment is how it fragments the sphere of organising by rendering collaboration with more contentious partners risky. Disability organising is a diverse sphere, with many different actors and disagreements about strategies and goals. Here I focus on the difficulty of cooperation based solely on degree of legitimacy and logic of appropriateness, rather than, for example, moral convictions or competition for funding (although these are doubtless linked). Formal disability CSOs do have the opportunity to work with state, based on enacting compliance. This allows opportunities for influence that they do not wish to renounce. Groups and communities without a relationship to the state operate under different constraints. Some actors clearly appreciate this, as we see in how actors move between CSOs and social movements for different actions, or propose to run unpublicised, informal training for registered CSOs. However, even where there is agreement over goals, there remains animosity. Actors involved in social movements and associated communities, as well as individual actors,

criticise CSOs for their fear and avoidance of risk. Equally, actors who are more involved in CSOs as well as in social movements criticise those in social movements for their lack of understanding. These different standpoints interrupt solidarity. They are a factor in disrupting the capacity of disability organising to develop a strategy which takes advantage of what solidarity is present to divide labour among organising spaces and create further collaborations. Where there is willing among actors, the challenge for civil society actors is firstly to be aware of how their compliance risks misrecognising and excluding certain people. Secondly, it is to build collaborations, however dissimulated, which respond to those exclusions.

3. Untold Stories

Here, I suggest some other directions which this thesis could have taken. I have reflected (Chapter 2) on the uncomfortable partiality and permanently unfinished nature of any thesis, particularly as it seeks to present a single overarching story or argument. I also mentioned that there were various aspects of people's accounts in interviews that I was not able to pursue in the thesis. Here, I return to this thought by indicating a few alternatives which I did not write. This also suggests areas for research which build from the silences of this thesis, rather than from its direct contributions. I discuss the latter in Section 4.

I did not, for example, spend much time with discussion of the experiences of organising for women and, particularly, mothers. I gave some indication of this in referring to one pathway of legitimacy for disability organising as its association with motherhood and care, as mothers dominate parent-led organising. However, I did not focus on the varied ways in which mothers navigate disability organising and its relationships with their child or children. Mothers were strongly represented within organising, seeing it as an extension and professionalisation of their role in caring for their children. Some discussed forming organisations to help others, having struggled themselves. Others discussed registering a CSO to give themselves access to further levers of control and be able to speak to state representatives with a higher, official status. Their movement into organising and how its nature shifts over time is another question, as is children's relationship to their parents' organising.

I have also not focused thematically on the different campaigns which are present within disability organising. One in particular nuances discussion of medicalisation. Involvement with

and exposure to medicine and medical experts is one part of disabled people's experiences. I recognise this and have argued not for its omission, but against the equation of medicalisation with depoliticization. However, another point remains undiscussed. Medical experts have often been characterised as promoting or even imposing interventions which seek to rehabilitate to an external norm (Chapter 3). However, they were also characterised as allies in certain campaigns, particularly those for the registration of certain drugs in Russia and their inclusion in the state budget. They were partners in offering training and development to both parents, relatives and partners, other medical staff, and disabled people themselves. While I have often focused on relationships with state actors, relationships with doctors were also important. Exploring this side of organising could have been another route to challenging the depoliticization of medical expertise.

Finally, I did not discuss those who organised as individual activists, or in loose interest-based networks, precisely because they were against CSOs in general. There were some individuals whose organising aimed to develop others' awareness of existing state services and provisions and their abilities to access them. This action was also undertaken by some CSOs. However, these people deliberately did not form CSOs and strongly criticised them; they saw CSOs as privatising services which should be offered by the state, and thus in fact restricting access to those services. They strongly mistrusted CSOs and were sceptical of their work, accusing them of profiting from the services they offer and not having the proper expertise to respond to people's needs. They did not believe that the state should partner with and fund CSOs, but rather that the state itself should itself develop and deliver social services. This set of stories questions the purpose of CSOs themselves and their relationship with the communities for which they aim to provide services.

These are some stories which were in the interviews for this research, but I did not finally write. Also present are the stories which were not in the interviews, due to how I constructed the research. For example, research on disability organising in Russia remains largely restricted to majoritarily Orthodox, white, European, urban Russia. I was no exception here. Investigating these experiences is also a necessary future direction of research. To conclude in the next section, I look further at those directions of research which I identify based on the current contributions of this thesis.

4. Future Directions

In this thesis, I have tried to demonstrate the construction of depoliticization and how it shapes disability organising. I have demonstrated the presence of strategic resistance which instrumentalises and subverts the assumptions of depoliticised vulnerability. I began to reflect on the limitations of these strategies. Future research could further investigate if and how actors may challenge dominant discourses when their activism uses these same discourses as to strategically dissimulate resistance. While I have looked at this through disability organising, investigating this in relationship to other identities which are also contingently assumed to be vulnerable (e.g., being a child or elderly) would reveal further contours to this strategy. Unlike the case I have explored through LGBTQ+ identities, there is no legislative control of discussion of childhood or old age; it would thus also be interesting to explore the operation of the limits of legitimacy in these cases. Claiming vulnerability where it is not already dominantly imputed to an identity would also nuance investigation of how this strategy operates.

This research also suggested the importance of investigating how disillusionment with political action shifts over time. Some participants spoke about a move into social action as a response to their disillusionment with political campaigning. Where that sphere was restricted and had not given them the results they wanted, they felt that apparently social action was a way of making a direct change which could not be disrupted in the same way as campaigning for a shift in government could be. While my interviews looked at a specific point of time, observing via social media and general continued involvement in the field of my research, I have noticed a return to overt political campaigning even of those actors who characterised their move into social organising as a mode of disavowing politics. Here also is a story of the different meanings of political disengagement and a shift to prefigurative, direct action; for some this was claimed as a retreat from politics, for others this was claimed as a mode of 'doing politics' where other avenues result in sanction. Differences in motivation and if and how they shape organising also stand to be investigated.

Another avenue which this thesis has sought to open is that of intersectionality of disability organising in Russia. While discussions of disabled people's experiences of sexuality and sexual agency in Russia are emergent (Iarskaia-Smirnova & Verbilovich, 2020), they were yet

to be related to their experiences of disability organising. My attempt is clearly provisional and based on fewer interviews that other aspects of this thesis. It also does not deal with intersectionality generally, but rather only with some experiences of LGBTQ+ actors. A rich area of research would indeed be to develop an intersectional analysis of disabled experiences in general and of disabled people's organising in particular, including that which does not directly concern disability rights.

This relates to a final point: exploring the experience of disabled LGBTQ+ people has raised the question of activism as a response to loneliness and social dislocation. For example, Kir (from Chapter 8) also described being propelled to activism to find friends and defined achieving the goals of their activism as having built a network of friends with whom they can comfortably express themselves. Where there is a large gulf between views in activist circles and those within the wider society through which activists move, how does this affect how actors use and understand the role of these communities? Rather than seeing identity formation in activism as linear and unitary, again where there is such a gulf in the legitimacy of certain identities in different circles, where and how do people alter their performances of self?

5. Conclusion

In this thesis, I have used a framework of power and resistance to define disability and explore how it is legitimised as a field for organising. The overall theoretical framework allowed me to make visible the relationships between disability and civil society organising around disability. By doing so, it also allows me to uncover infra-political resistance which strategically evades the eye of the dominator. This operates by two theoretical moves, which I here connect to my empirical analysis. First, I see both civil society and disability as discursive 'terrains of conflict' traversed and constructed by power relationships (Steinburg, 1998, p. 853). I use this to think about how legitimacy is constructed: what do civil society actors perceive as a legitimate civil actor? What do civil society actors perceive as a legitimate performance of disability? I looked at the overlaps between legitimised characteristics in both spheres, and how that both legitimises and limits disability organising.

Second, building on the idea that power is necessarily accompanied by resistance, I looked at friction with perceived boundaries of legitimacy as characterising actors' identification of

their own resistance. This, in turn, operationalises theory which proposes to identify resistance through the intent of the actor. I have used this framework to lay aside more longitudinal concerns with campaign or other direct causal outcomes in terms of, for example, policy and legislative change. Rather, I focus on making visible resistance which strategically evades the eye of the dominator. This resistance may not be obvious or apparent. However, here I claim its recognition. In recognising strategically non-apparent resistance which aims to challenge those power relationships, even ambiguously or as concerns their relationship to self, I aim to engage in research which does not replicate the relationship of the dominator, to whom this resistance is imperceptible. This project therefore seeks to participate in and call for research which does not dominate, but rather listens to and amplifies resistance. In doing so, it also demonstrates how analysis of disability can productively question and extend how we identify resistance, the nature and instrumentalization of assumed depoliticization and vulnerability, and the limits of such strategies as they perpetuate misrecognition.

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Appendices

1. Appendix I: Research Ethics Approval

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Research Division

Ms Philippa Mullins
Department of Social Policy
P.S.Mullins@lse.ac.uk

12th April 2017

Dear Ms Mullins

Re: 'State, Civil Society, and the Realisation of Disabled People's Rights in Russia' [ref. 000569]

I refer to the above research proposal which you recently submitted for review by the Research Ethics Committee.

Having considered your ethics review application and supporting documents, I am satisfied that you have properly addressed the ethical issues raised by your proposed research. I am thus able in my capacity as Chair of the Committee to approve the application.

Please note that any significant changes to the research design must be reported to the Research Ethics Committee. Amendments to the research design that may affect participants and/or that may have ethical implications must be reviewed and approved by the Research Ethics Committee before commencement (or recommencement) of the project. The Research Ethics Committee may periodically conduct a selective audit of current research projects.

I would like to take this opportunity to wish you well with your research project.
If you have any further queries, please feel free to contact Lyn Grove, Research Division.

Yours sincerely,

Professor John Worrall
Chair of the Research Ethics Committee

cc. Lyn Grove, Research Division

2. Appendix 2: Overview of Participants

2.1. Location of Participants

This table refers to the location in which the participant currently lives and organises. However, in many cases, participants had moved to the city and/or their organising spread beyond the city itself.

Location	Number of Participants
Moscow	34
Saint Petersburg	20
Nizhny Novogorod	7
Total:	61

2.2. Other Participant Characteristics

Disability status refers to whether the participant identified themselves as disabled or not at time of interview.

	Age Bracket	Main Involvement: Gov/NGO/Informal	Gender Identity	Disability Status
1	18-25	Informal	M	D
2	18-25	Informal	F	ND
3	18-25	Informal	F	D
4	18-25	Informal	F	ND
5	18-25	Informal	M Trans	ND
6	18-25	Informal	M Trans	D
7	26-35	NGO & Informal	M	ND
8	26-35	NGO	M	ND
9	26-35	NGO	F	D
10	26-35	Informal	M	ND
11	26-35	Informal	M	D
12	26-35	NGO	F	ND
13	26-35	NGO	F	ND
14	26-35	NGO	F	ND
15	26-35	NGO	M	D
16	26-35	NGO	F	ND
17	26-35	Informal	F	ND
18	26-35	NGO	M	ND
19	26-35	NGO	F	ND
20	26-35	NGO	F	ND
21	26-35	GONGO	F	D
22	26-35	GONGO & Informal	M	D
23	26-35	Informal	F	ND
24	26-35	NGO	F	ND
25	26-35	NGO	M	ND
26	36-45	NGO	F	D
27	36-45	Informal	F	D

28	36-45	NGO	M	ND
29	36-45	NGO	F	ND
30	36-45	NGO	M	D
31	36-45	NGO	M	D
32	36-45	NGO	F	ND
33	36-45	Informal	F	ND
34	36-45	NGO	F	ND
35	36-45	NGO	F	ND
36	36-45	NGO	F	ND
37	36-45	NGO	F	ND
38	36-45	NGO & GONGO	M	D
39	36-46	NGO	F	ND
40	46-55	NGO	F	ND
41	46-55	NGO	F	ND
42	46-55	Business	F	ND
43	46-55	NGO	F	ND
44	46-55	GONGO	M	D
45	46-55	NGO	M	D
46	46-55	NGO	F	D
47	46-55	NGO	M	ND
48	46-55	NGO & Informal	M	ND
49	46-55	NGO	F	ND
50	46-55	NGO	F	ND
51	46-55	GONGO	M	D
52	46-55	NGO	F	ND
53	46-55	Informal	F	ND
54	46-55	NGO	M	D
55	46-55	Informal	M	ND
56	46-55	Informal	F	ND
57	46-55	NGO	F	ND
58	46-55	NGO	M	ND
59	56+	GONGO	F	D
60	56+	NGO	F	ND
61	56-65	Informal	F	D

3. Appendix 3: Interview Schedule

As I outline in presenting my methodology (Chapter 2), I did not use an interview schedule beyond my first meeting. I present an English version here to show my departure point at that time.

I treated each interview as a conversation and aimed to respond to what the participant was saying in that moment and to the avenues that they suggested. Thus, even in my first interview, I never followed the exact order of the questions as listed here or treated the different topic areas as discrete. Rather, I followed the flow of the conversation and looked at the schedule to check that I had covered the topic areas listed. The phrasing as written here was also for my use, to ensure that I could glance at and understand the questions. In reality, questions were phrased in more informal, conversational ways which made sense in the context of the conversation. They were also, of course, in Russian. I rewrote this schedule in Russian prior to my first interview.

I continued to develop the questions I asked by making reflective notes both immediately after each interview and on re-listening to the audio or re-reading the transcript. In particular, the schedule shared below does not reflect the depth of discussion of social and political identifiers, as well as disability identity and (mis)recognition. It also does not show the discussion of how actors strategically negotiate and problem-solve in operationalising their aims.

- **Introduction**
    - Greeting and introduction
    - Discussion of research project
    - Discussion of interview (length, discussion of audio recording, use of audio recording, use of direct quotations, anonymity and confidentiality, interest in personal opinion and experience, free to interrupt, move on to next question, not answer, stop interview, etc.)
    - Discussion of consent
    - Another time for questions
    - With consent, begin recording
- **Opening**
    - How long have you been involved with disability organising/in this CSO?
    - How did you get involved?
    - Are you involved elsewhere/in any other forms of organising?
    - Could you describe your role(s)?
- **Motivation**
    - Why would you say other people are involved?
        - In disability organising?
        - In this organisation/movement/group?
    - Why are you involved?
    - Relationship to disability: yours, others?
    - How do you think people relate to disabled people? Why?
    - Is it changing? Why (not)?
- **CSO activity**
    - How did [organisation/group/movement] begin? [Ask in turn about different forms of organising involved in]
    - Have its aims evolved since when it began? How?

  - What does it aim to do now?
  - Why do you think it has evolved in this way?
  - What does [CSO] do? What are its programmes? How would you describe them?
  - Who decides on this?
  - How/why are these decisions made?
  - [The CSO addresses a certain issue X] Why is X a problem? How can you resolve it?
  - What happens if that doesn't work, where do you go? Which mechanisms do you use?
  - Does it work?
  - How did you work out this strategy/plan?
  - Are there any mechanisms which you don't use? Why?
- **Funding**
  - How is [CSO] funded?
  - Has this changed since it has been running?
  - Why has this changed?
  - Has this changed how you fundraise?
  - Has this changed how you operate? If yes, in what ways?
- **Environment**
  - Have you seen changes in the environment that [CSO] works in over the time you've been involved with it?
    - Political?
    - Social?
    - Other?
  - (How) have these changes affected **how** you deliver services?
  - (How) have these changes affected **whom** you deliver services to?
  - (How) have these changes affected how you communicate with the public?
  - (How) have these changes affected how you communicate with state officials and institutions?
- **Relationship with other actors**
  - How does [CSO] relate to or use state services or fora (including the public chamber)?
  - Do you think that this has changed over time? How?
  - Why do you think it's changed like this?
  - How does [CSO] interact with state bodies or officials?
  - To what end does [CSO] interact with state bodies or officials?
  - Do you think that this has changed over time? How?
  - Why do you think it's changed like this?
  - Would more interaction with the state support [CSO]? How/why (not)?
  - Do you have contact with any other groups or individuals?
    - Other CSOs, grassroots groups;
    - Individuals who support the CSO (specialists or other).
  - What form does this contact take?
    - Advisory
    - Pro bono service provision etc.
    - Partners or allies
    - Adversaries
  - (How) do you interact with other organisations?
    - Formal organisations
    - Informal organisations, activists
    - Protest groups, etc.

    - What is the purpose of this interaction?
    - Why is this interaction necessary?
    - Why does it take these forms?
    - Are there organisations with which you don't (or won't) work or interact? Why (not)?
- **Closing**
    - What do you think is important about your CSO/role?
    - What does it mean to you?
    - How would you like [CSO] to develop in the future?
        - What would support this?
        - What would be an obstacle?
    - Is there anything else that you would like to add?
    - Offer overview of findings. If interested, check the participant's contact details.
    - Check they have my contact details should participant wish to follow up.
    - Thank the participant and close the interview.

4. Appendix 4: Russian Language Participant Citations

[i]‘с одной стороны, волков бояться, - в лес не ходить, а с другой стороны нарываться никто не хочет.’

[ii]‘я каждый день понимаю, что может абсолютно любое что-то может быть, и тут логики никакой нету’

[iii]‘Это как по болоту, когда идешь, тыкаешь в кочку, тыкнул... или как по минному полю. […] В гибридном постмодернистском обществе этой грани нет, законы не работают, телефонное право существует. […] Мы же живем по понятиям, мы же не живем по закону, мы же не можем с вами сказать, что вот закон исполняется так-то. Прекрасная поговорка, которая называется закон, что дышло, куда повернешь, туда и вышло.’

[iv]‘я […] пыталась понять, почему мне на столько страшно, и связан ли страх с реальным положением вещей в России, политическим, социальным, или этот страх связан больше с моей тревогой. И это вопрос, которым я вообще задаюсь на протяжении всей жизни. […] И я вот […] просто я заставляла себя расслабиться. И вот в этом заставлении себя расслабиться я увидела … какую то в принципе метафору о моей жизни в России. […] Я вообще не планировала делать этого более политической, но она стала политической с того момента, когда я стала выходить из дома. […] Она из личного перешла в политическую тогда, когда я стала собирать рюкзак, думая, что меня могут задержать. Моих многих знакомых активистов постоянно задерживали на пикетах, на мирных пикетах, на одиночных пикетах. То есть там, где их не должны были задерживать, но их задерживали. […] Просто знаю….в этом прикол, что ты живешь в месте, в котором может случиться все, что угодно. Твоя свободна может быть закрыта, ну..ущемлена в любой момент. Да, может быть на время, да тебя не посадять в тюрьму, но ты там на пару часов или там на 10 часов выпадаешь, тебя забирают, свобода перемещения нарушается.’

[v]‘Ну вот все короче, любой повод вот и поэтому, все время чувствуешь себя под топором то есть там ну как бы сегодня нас не тронули, а завтра естественно вообще без проблем закроют потому, что ну мы не собираемся например отказываться от иностранного финансирования.’

[vi]‘Ну просто ограничны серьезно, ну то есть страхом таким, ну да, то есть пониманием того, что у государства всегда есть возможность ну прекратить деятельность организации. […] Опять же если там захотят придраться, то причину найдут.’

[vii]‘оказаться иностранным агентом зависит не от того, как сформулирован закон, потому что все равно найдут способ к тебе применить, если что. Здесь если мы кому-то в какой-то момент окажемся поперек горла вдруг почему-то, это один из способов нас, ну не закрыть, но немножко отравить нам жизнь. Это далеко не единственный, можно найти массу других способов.’

[viii]‘Это неправильно, но русские вообще в России правда думают, что политика отдельно, социалка отдельно, они не понимают, что социалка это и есть политика. И это мне кажется изменить мы точно не сможем. Это ментальность.’

[ix]‘Мне кажется, что любая социальная организация все равно, в какой-то степени, политизирована, то есть редкая некоммерческая организация в России совсем не

связана с политической деятельностью. Почему? Потому что социалка - это тоже политика, и многие социальные вопросы решаются политическим путем. Разделить эти две сферы нельзя.’

[x]‘Появилось такое чудовищное сочетание словосочетание СО НКО, социально-ориентированная НКО. То есть, извините, а что есть НКО не социально-ориентированные, а какие тогда? То есть это какая-то такая чудовищная штука и в итоге многие организации совершенно ужасно попали под каток...’

[xi]‘если кто-то расценит это как раз как политическую борьбу’

[xii]‘Даже наш фестиваль, он очень мягкий по европейским меркам, это не анархисткий слет как бы, это не саммит, это черт возьми обычный какой-то культурное событие, мы там как бы просто обсуждаем что-то, экспериментируем с пространством для встреч. А все равно, все равно, для них это неприемлемо. То есть, они хотят, чтобы ничего вообще не было.’

[xiii]‘Да, кто. Кто это "они". Кто это "они". Я не знаю кто это [*смеется*], вот.’

[xiv]‘У нас политической деятельностью назвать можно что угодно. […] То есть, у нас, если хочешь придраться. […] у нас в стране если кто-то захочет кого-то посадить, закрыть, еще что-то, то придраться найдут к чему, даже если у тебя все идеально.’

[xv]‘если хочешь придраться’

[xvi]‘Это, конечно, гадкие политические подковерные игры, потому что, опять же, на детей всем наплевать. Они не были ничьей целью. Они просто пошли как побочный эффект от того, что они там бодались.’

[xvii]‘Если честно, я считаю, что у нас возможно все, после закона Димы Яковлева, который был подписан за две недели после того, как-- Через месяц после того, как было подписано российско-американское соглашение о том, что если одна из сторон захочет прекратить иностранное усыновление, она обязана известить за год. […] И ровно через месяц после этого, за две недели был подписан закон Димы Яковлева. С тех пор у меня понимание, что возможно абсолютно все, что угодно, очень реально.’

[xviii]‘в последние годы очень сместился акцент в сторону поощрения деятельностей социальных и благотворительных НКО. Государство всячески содействует их работе, пытается их поощрять, продвигать, помочь им выйти на рынок социальных услуг. Конечно, правозащитным организациям гораздо сложнее живется. Если они входят в конфликт с органами власти, то им очень трудно работать. Не все готовы постоянно в этом конфликте находиться, поэтому у нас, мне кажется, правозащитных организаций меньше стало за последние годы и менее они активны и заметны стали, зато всякие социальные, благотворительные очень активизировались, стали более заметны, видимы.’

[xix]‘Нам сначала надо выучить, как они это называют, потом понять, что они под этим имеют в виду. Они же не хотят нас понимать. Они сразу говорят: вы дураки, ничего не понимаете. […] Вот мы переродились, мы стали говорить по-другому, потому что иначе нас не слышали.’

[xx]‘Я говорю: "То, что [нам] по закону положено, сделайте". […] Я именно отстаиваю позицию государства. Потому что, это же государство законы такие приняло, соответственно. А вы - государственные чиновники, соответственно, вы должны исполнять то, что приняло государство.’

[xxi]‘Поэтому мы там слова, перестали употреблять публично слово «лоббирование», «влияние на социальную политику». […] Мы там не знаю, что пишем, «проводим мониторинг», и «делаем выводы о состоянии» там ну да, ну короче какую-то чушь там, […], но мы реально там переформулируем, вот так вот, чтобы как бы ну,- ну или там часто, ну чаще всего мы стали писать ну там про «социальную работу» понятно и плюс там как бы «защищаем права по индивидуальным случаем», ну то есть это не запрещено, там в суде представляем там ну как бы вот консультируем и ведем, сопровождаем индивидуальные случаи для защиты прав. Ну вот а то, что из сопровождения этих случаев складывается потом системная картинка и мы можем там предлагать что-то властям, это мы или полностью умалчиваем или как-нибудь так пишем, что там ну там «информируем» там, ну что-нибудь, короче, придумываем.’

[xxii]The interview was conducted in English.

[xxiii]‘Я говорю: "Знаешь, что? Нет, я, конечно, понимаю, что вы защищаете права, но вы защищаете права, в основном, политические. При этом есть социальные права, которыми занимаются инвалидные НКО: это право на образование, это право на трудоустройство, получение иных соцуслуг. Вы не считаете это правами". Для меня это очень удивительно, потому что традиционно же было такое разделение на две корзины. Советскому Союзу всегда предъявлялись претензии в том, что он не соблюдает политические права. Советский Союз все время рассказывал, что западные страны не соблюдают социальные права. […] При этом, те организации, которые называют себя правозащитными в России, они занимаются исключительно политическими правами. До них что-то постепенно доходит, что они не будут популярными, пока не займутся социальными правами, потому что это просто волнует, на самом деле, людей.’

[xxiv]‘В России и в [городе] в частности организации разделяются на те, кто занимается правозащитной деятельностью и те, кто занимается социалкой. Государство поощряет занятие социалкой и совсем не поощряет занятия правозащитной деятельностью. Поэтому прямой правозащитной деятельностью как таковой [организация] не занимается. Потому что, если мы занимаемся людьми, желательно не заниматься правозащитной деятельностью. К сожалению, это условия нашей игры. […] Прямой правозащитной деятельностью конечно мы не занимаемся, потому что, еще раз говорю, у нас очень сильно разделяется социалка и правозащитная деятельность. Потому что тогда, вплоть до того, что ты станешь иностранным агентом, если ты занимаешься правозащитной деятельностью.’

[xxv]‘Мы, конечно, социальное НКО, и часто мы очень сталкиваемся в каких-то областях с тем, что очень близко к правозащитной теме. Значит, опять же, я вижу, что [директор НКО] […], учавствуя в этих обсуждениях, все время очень боится за фонд. Когда к нам обращается кто-то с чем-то, что ставит нас под этический удар, и я следом за [директором], и [директор НКО] в первую очередь выбирает безопасность фонда, потому что мы все время помним, что за нами стоят конкретные дети, конкретные семьи, и если мы начнем очень сильно продавливать какие-то правозащитные моменты

- а права, конечно, нарушаются повсеместно и постоянно, и права пациентов, бесконечно - но мы стараемся прямо в борьбу такую сильно не лезть. Хватает борьбы по отдельным случаям, […] на другом уровне, не в политическом поле, а на социальном поле.'

[xxvi]'я не чувствую себя правозащитником классическим, то есть я [*work in the arts*], и единственное, что я могу, - это делать выставки и по своей какой-то части работать. То есть пока я могу в этой сфере что-то делать и есть поле для работы, то есть я вижу, что это тоже сопряжено с некой защитой прав. Просто правовая защита из разных состоит структур, и это не всегда в суде отстаивать нужно, иногда просто информировать и давать возможность людям высказываться - это тоже некая правозащита. У нас некий правозащитный грант, конечно, у нас такой, может быть, не совсем прямо классический правозащитный, […] но тем не менее я думаю, что у нас есть правозащитный потенциал, просто он такой косвенный, скорее, нежели прямой. […] То есть любые попытки заявить напрямую о правозащитной деятельности в интернате типа: "Я занимаюсь правозащитой" - все, как бы, до свидания. То есть там это невозможно, поэтому мы как художники имеем больше возможности туда приходить и что-то делать. Плюс мы делаем выставки, по возможности, опять же, публичного освещения и через выставки можно говорить о более проблемных вещах, нежели типа через какие-то правозащитные тексты.'

[xxvii]'Сложности возникают постоянно […]. Но с [*CSO*] как раз получается за счет репутации организации и еще то, что у нас не только правозащитная часть, юридическая помощь, но большая часть работы [*CSO*] - это как раз социальная работа.'

[xxviii]'есть, на самом деле, негативный такой эффект, потому что как раз из-за того, что, например, наша программа есть в одном из интернатов для взрослых, там часто возникает сложность именно в юридической помощи, потому что, с одной стороны, мы сотрудничаем, потому что […] наши сотрудники они приходят заниматься с теми же людьми, которые живут в интернате. [*Our programmes*] тоже полностью зависят от интерната, потому что интернат там хозяин. Они могут какие-то создать плохие условия для наших сотрудников. В конечном счете страдают, конечно, люди, которые там живут, но интернат часто это не волнует. Например, мы не можем из-за этого какие-то активные действия принимать против интерната, даже когда есть юридические основания обжаловать. Всегда мы вынуждены думать о том, не станет ли хуже нашим подопечным, и в этом тоже сложность.'

[xxix]'… петиция, скажем так, - это способ уже не заявить, а прокричать о своей проблеме, это уже по-другому. Потом петиция change.org это к сожалению не российский ресурс, это ресурс иностранный и у нас он немного не любим. Когда создается петиция, это так называемый такой молот, когда уже надо закричать, а потом уже через крик перестать кричать и начать прорабатывать все это системно. Скорее всего это так. Петиция это скорее всего для СМИ.'

[xxx]'Вот так все идет, вот в таком спокойном темпе, потому что поспешишь - людей насмешишь, ничего хорошего не сделаешь.'

[xxxi]'НКО стали понимать, и государство тоже, что надо быть партнерами государству. […] Мы знаем, что, если мы подадим в суд и суд скажет, что - да, [*this accessibility measure has to be put into place*]. Ну, хорошо, и что? Они завтра это не делают, потому что нету

ресурсов, понимаете. Государство на нас будет смотреть уже не как на друга. […] И в данном ключе очень важно сохранять баланс отношений как с государством, так и в интересах [*our target group*].'

[xxxii]This interview was conducted in English.

[xxxiii]This interview was conducted in English.

[xxxiv]'нужно каким-то образом с властью очень близко дружить'

[xxxv]'Мне пришлось стать помощницей депутата Государственной думы для того, чтобы делать запросы и давить на власть.'

[xxxvi]'Я прошу депутатские запросы: больше мне от них ничего не надо.'

[xxxvii]'У нас все-таки не верховенство закона, а верховенство личнего фактора. Верховенство человека конкретного, который вот здесь находится в этой точке, несет ответственность.'

[xxxviii]'Фактически все в ручном управлении. Необходимо искать вот эти руки, которые бы включали правильные рычаги.'

[xxxix]This interview was conducted in English.

[xl]'Этот проект вместе с депутатом [*Name*] […] он уже имея статус депутата, может рассылать запросы в местные министерства, какие-то органы. […] Обычный человек тоже может написать, но это дело висит, а когда это делается как депутатский запрос или адвокатский запрос, то это уже другого уровня, скажем, обращение. Но у нас принципиальная позиция, что он у нас представлен как частное лицо, […] у нас нет на сайте нигде, что он [*participant lists his positions in government*]. И мы очень от этого намеренно уходим, потому что на самом деле, вот со стороны какие-то организации выражают к нам недоверие просто из-за того, что у нас есть какой-то личный сервис с депутатом. […] На мой взгляд мы понесли какие-то репутационные потери из-за того, что приняли это сотрудничество и это факт.'

[xli]'нам приходится много думать о своей репутации, о том, с кем там можно дело иметь, с кем нельзя, с кем можно ну как бы открыто входить в коалицию, кому ну можно помочь, но явно не как бы не светиться условно говоря вместе, если там какие-то очень кардинально настроены люди потому, что но есть такие же совсем правозащитники, которые там,- ну нам все-таки приходится вот все время балансировать между там условно говоря партнерством с властью и нападением на власть, то есть чтобы быть достаточно хорошими, но и не стать слишком удобными. […] Да вот ну и у нас тоже есть такие условно говоря полускрытые, ну как, партнеры, не партнеры, ну по крайней мере мы с ними взаимодействуем. […] это их тоже целевая группа поэтому мы пересекаемся, что они там к нам обращаются типа, вы не могли бы там защитить там или там ну короче вот так, но мы там ну нигде активно не участвуем на прямо публичных мероприятиях и там не объединяемся с ними там в написании каких-то петиции открытых.'

[xlii]'они не работают с ЛГБТ, они не работают с мигрантами с инвалидностью, а это [he refers to a previous sentence: "…работать с инвалидами…"] такой политически удобный образ в России, чтобы показать, какие мы хорошие, что у нас какая-то социальная ответственность в стране есть.'

[xliii]‘Действительно огромное количество людей с инвалидностью элементарно не могут из дома выйти. Следовательно, что им это свобода собрания там массового, что им нарушение на митингов, если они попасть на эти митинги не могут.’

[xliv]‘Ну, поедешь ты один с расторможенным ребенком куда-то, тебе все будут делать замечания, тебя все будут выгонять. Ты же не будешь от этого счастливее, правда? И тебе не захочется, в общем-то, никуда вылезать, будешь сидеть один и горевать. А если пять таких детей, десять таких детей, то уже никто не сделает замечание и никто пальцем не покажет.’

[xlv]‘мамам иногда просто побыть вместе, просто побыть там, где ты не один и понять, что, в общем, можно жить. Для того, чтобы понять, что можно жить, надо общаться с такими.’

[xlvi]‘политически удобный образ в России, чтобы показать, какие мы хорошие’

[xlvii]‘я понимаю, что кроме меня за них прийти никому.’

[xlviii]‘есть, например, противодействия, например, отдел фандрайзинга и пиара, потому что очень часто экономические стратегии, те, которые позволяют на эти деньги они часто не совпадают вообще с социальной моделью людей с инвалидностью. Когда ты говоришь, что не надо людей виктимизировать, они говорят: а нам никто деньги не даст.’

[xlix]‘А горе и болезнь ребенка, наверное, это единственный плюс, не имеет национальности, не имеет религии, она не имеет ничего, она выше политики.’

[l]‘…когда к ним так относятся, их принципе так воспитывают даже близкие, […], они, во-первых, перестают верить в себя и они считают, что они инвалиды, это которые сами делать ничего не могут, раз ничего не могут делать физически, то значит ничего не могут делать и в принципе. Работать не могут, семьи у них быть не может, потому что их такими никто любить не будет, друзей у них тоже не может быть. […] И дальше они уже не верят ни во что, и становятся действительно такими иждивенцами, которые привыкли получать. Они не понимают, что они могут отдавать и что нужно отдавать вообще-то обществу. А как человек может действительно быть полноценной личностью, когда считает, что ему все вокруг обязаны.’

[li]‘чтобы человек, собственно говоря вот, когда он сидит в детском доме и ничего не делает, когда его ограничивают и вот эта чрезмерная опека. Чтобы его избавить от чрезмерной опеки, показать, что он, собственно говоря, относительно самостоятельной человек. […] Здесь как бы мы решили сделать вот такую историю, тоже чтобы учить детей отдавать, то есть они не должны только потреблять, чтобы немножко расширить этот круг, кругозор, что они могут, что у них есть возможности.’

[lii]This interview was conducted in English.

[liii]‘они […] становятся действительно такими иждивенцами, которые привыкли получать’

[liv]This interview was conducted in English.

[lv]‘…у нас нет практики делать какие-то именные истории и их выносить на очень высокий уровень, потому что это неправильно, на самом деле, мне кажется. Конечно бывают какие-то особые ситуации, это как правило положительные ситуации, когда [disabled*;*

here Aleksei specifies the impairment] человек добился каких-то очень высоких результатов в спорте, культуре, творчестве, тогда - да, тогда мы его историю как раз пытаемся показать и в том числе добиваемся предоставления каких-то государственных наград, чтобы обратили внимание на эту историю. Мы тоже пытаемся больше рассказать миру, обществу, о наших положительных каких-то героях, о наших каких-то результатах хороших.'

[lvi]'…не имеет национальности, не имеет религии, она не имеет ничего, она выше политики.'

[lvii]'Это был 2012 год, он был довольно странный - политические протесты, новое переизбрание и был какой-то подъем протестного движения, оппозиция и прочее. Мы как-то думали, что можно что-то изменить участием в политической деятельности - это было общее настроение, по крайней мере, у среднего класса людей, живущих в крупных городах-миллионниках. Был этот запал, потом он прошел и сошел на нет после политики консервации. Многие люди ушли в общественную работу. Многие из тех, кто занимался тогда политической деятельностью, ушли в прямую помощь или в благотворительность.'

[lviii]'Он понял, что политика разъединяет людей, а волонтерство и помощь людям объединяют людей.'

[lix]'Наша дорога в интернат - это в том числе и попытка, во-первых, политизировать свою собственную практику как культурных профессионалов. […] Я в последствии в НКО устроился работать именно [position], потому что я почувствовал опять же, что я на этой позиции могу сделать больше. Я могу влиять на принятие решений и у меня больше рычагов опять же вот, чтобы что-то менять. […] Для меня мой активизм, то есть вот эта музейная педагогика, связанная с инклюзией в музее, сейчас не работает, потому что там нет условий. Я взял вот эти музейные методы, перенес их на совершенно другую почву в интернат, вот там на мой взгляд они стали работать и были востребованы. То есть в этом была моя некая активистская позиция внутри искусства. […] То есть для меня очень важно вот это исследование трансформации темы нормы и эйблизма, дискриминации в искусстве.'

[lx]'Ну, ты знаешь, что касается [*our movement*], то исначально я думал, ну в такой очень далекой перспективе, что это могло бы быть новой политической фигурой. Потому, что никогда не знаешь, что сработает здесь. И мы начинали заниматься этим уже после репрессий, последующих за массовыми протестами. И я думал о том, как продолжить заниматься политикой. И почему бы не попробовать заниматься и от лица ну вот людей, которые настолько исключены как бы, ну, настолько жестко исключены, да. Почему бы не попробовать эту фигуру ну безумица, да, как политическую? Почему не помыслить ее так?'

[lxi]'я не чувствую себя правозащитником классическим'

[lxii]'… что никто на самом деле не застрахован от этого [i.e., *ending up in a residential institution*], и поэтому, в том числе и меня очень сильно цепляет эта тема, потому что я таким образом немножко за себя бороться, в том числе. […] Наверное, мы занимаемся социалкой, но опять же мне очень сложно эти понятия разделять, потому что право на свободу и достойную жизнь, по моему мнению, имеет каждый человек, и в этом смысле

мы отчасти занимаемся и правозащитной деятельностью тоже. […] Мне очень сложно это разделять, потому что я в некотором смысле идеологически попала волонтером в [*CSO*]. Я считаю, что я таким образом хоть как-то восполняю ту пропасть между тем, чего человек достоин в своей жизни и тем, что он имеет по факту. Хотя бы три часа в своей жизни я могу уделить этим конкретным людям, чтобы как-то сделать их жизнь чуть-чуть лучше.'

[lxiii]'мы как художники имеем больше возможности туда приходить и что-то делать'

[lxiv]'Как-то двигать ситуацию в ПНИ потому, что это не так невозможно как кажется и сейчас наоборот ситуация благоприятнее потому, что эти люди ищут волонтеров и я знаю, что на самом деле они настроены на коммуникацию. У них нет идей о скрытии, они настроены на какое-то взаимнодействие с соцумом. Они воспринимают это вот в рамках волонтерства, у них просто нет мысленных категорий других для этого, и практик, привычек. Именно поэтому, мне кажется, активизму важна как раз интеллектуальная какая-то работа потому, что надо расширить горизонты. Расширить горизонты практических вмешательства, расширить горизонты для практических интервенций. А практика наоборот интенсифирует мысли, какой-то интеллектуальный поиск. И ну это одна обогощает другую.'

[lxv]'…двигать ситуацию в ПНИ…'

[lxvi]'активизму важна как раз интеллектуальная какая-то работа'

[lxvii]'Мы взяли маршрут […] в центре, прямо самый центр […], чтобы люди видели, что, как бы, что люди с инвалидностью тоже могут ходить на экскурсии, хотят это делать и так далее. То есть немножко такой вопреки был. […] Она не позиционировалась, как акция. Это скорее всего в процессе пришло и вот сейчас я тоже смотрю на это, назад глядя, и, мне кажется, что это было важное еще и поэтому. Потому что то, как люди на нас смотрели, когда мы шли такой толпой, можно сказать. […] И вот такая огромная разная группа людей конечно в самом центре. […] И да, конечно люди на нас оборачивались, но видно было, что народ был в шоке немножко от того, что видел, и вот в этот момент было такое чувство, когда видишь эту реакцию, наоборот, что хочется идти дальше и пусть смотрят.'

[lxviii]'но она стала политической с того момента, когда я стала выходить из дома. […] Она из личного перешла в политическую тогда, когда я стала собирать рюкзак, думая, что меня могут задержать.'

[lxix]'Нам отказывают в площадках, поэтому мы стали проводить лекции на улице. [*Interviewer: Почему они отказывают?*] Потому, что просто ты говоришь, что у нас лекция про феминизм - "Нет, мы не будем делать". […] мы не можем платить за площадку, а бесплатные площадки - это или какие-то дружественные площадки типа кафе, но с ними нужно иметь хороший контакт, иметь доверие, или государственные площадки. У государства есть четкое отношение к этим вопросам, […] к феминизму, конечно. Что-то, что отдает протестом, будет скорее всего отклонено. […] Поэтому нам поотказывали-поотказывали, мы думаем: "Ладно, будем делать то, что мы на улице устраиваем лекции, своей фишечкой ". Ну, и главное, что это весело, это интересно. Это тоже такое городское исследование - как можно по-другому использовать то или иное городское пространство, поэтому я считаю наш проект политическим. […] Постоянно у

меня есть такая небольшая параноидальная мысль: а вдруг кто-нибудь, что-нибудь скажет. Например, у нас есть [*a cultural centre*], и мы решили провести там лекцию про протесты, не согласовывая вообще ничего. Там есть кафе, мы решили, что просто придем туда и проведем мероприятие, потому что это тоже был политический жест. […] Мы решили, что без согласования там все проведем. Мы пришли, и действительно нас никто не выгнал. Нас было много, человек 30. Мы пришли, заняли все кафе, переставили столы, и я боялась, там была девушка на баре и она в какой-то момент часто уходила, прямо надолго. Я думала, наверное, она пошла за охраной, на самом деле, нет. […] Реально есть нестабильность: и из-за того, что ты думаешь, что тебя могут выгнать, из-за того, что погода может быть неподходящей и просто из-за того, что какие-то площадки соглашаются, а потом отказываются в последний момент, надо искать новую.'

[lxx]'когда мы пытались анонсировать событие, когда мы договаривались с площадкой, они начали давить. И на самом деле, […] это же не такое событие, знаешь, что, ну как сказать, это же не какой-то протест, революция, это как бы ну довольно странно за такое событие, не знаю, садиться там в тюрьму, да. Ну просто мы не готовы на это. Вот. И поэтому мы как бы стараемся не идти напролом потому, что мы и так слабые, что фронтальное противоставление в данной ситуации, ну, оно просто ничего не... оно невозможно. Вот поэтому мы пытались как-то скрыто провести это и мы уже не анносировали событие потому, что мы понимали, что если мы будем заранее аносировать событие, то может быть будут проблемы у этого [*event space*], понимаешь, даже не у нас. Потому, что проблемы обычно возникают у людей, которые нам представляют площадку. Так или иначе я просто хочу сказать, что как раз с публичностью - ну, [*our event*] был уже более подпольный, более для своих. И проблемы публичности здесь довольно большие потому, что пытаются все зачистить. Я думаю именно потому, что они считают, что очень важно контролировать вот это вот спектакль публишности, который они хотят режиссировать. Им важно показать, кто наши враги, кто наши друзья, как бы, куда мы идем и прочие, единолично определять. И поэтому, они не хотят вообще, чтобы кто-то мешал. Что возникали вот какие-то неизвестные актеры, выбегали на сцену, кричали, протестовали, им все это не нужно.'

[lxxi]'Это было такая кухонная политика опять. Мы даже специально тематизировали это потому, что мы […] совместно приготовили еду […]. И параллельно читались доклады. То есть это было такая кухонная-, ну мы пытались как бы обратить внимание на эту новую форму осуществления политики, и наоборот переосмыслить кухонную политку как может быть что-то важно потому, что то, как мы готовим вместе еду, то, как мы, не знаю, делим наши пространство, то, как мы живем в коммуналках и решаем проблемы, это все микрополитика. И это все как бы очень вопросы важные для анархисткого движения. […]. Ну и вообще это политический вопрос. Мы пытались посмотреть на это таким образом.'

[lxxii]'И в эту среду вот как бы полна такой дружестких, близости какой-то, такие связи неоффициальные как бы, да, в нее как бы погрузились пациенты, скажем, и кто-то из них нам говорил, что для него это было ну просто ценно само по себе потому, что расширяло круг общения. Ведь часто у этих людей нет друзей, нет работы, никого кроме родителей. […] И поэтому это был какой-то ценный выход за пределы этого замкнутого круга. И одна девушка смогла впервые выйти из дома. Потому, что до этого ей некуда не было ходить. И она […] впервые смогла выйти из дома и впервые при этом готовила себе еду. До этого мать всегда это делала. Ну то есть она вполне способна на это. […] Я

думаю, что важно создавать такую среду, которая смывает границу, которая позволяет, дается место творчесту и каким-то неформальным связям. […] И вот эта среда она нужна ради того, чтобы ну, чтобы люди почуствовали себя на равных с другими. И в то же время она важна для того, чтобы все эти участники этого сообчества, как сказать, смогли помыслить для себя настоящую реализацию не в рамках арт-терапии там, да, потому, что мне кажется она часто тоже ограничивает людей.'

[lxxiii]'впервые смогла выйти из дома и впервые при этом готовила себе еду […] эта среда она нужна ради того, чтобы ну, чтобы люди почуствовали себя на равных с другими.'

[lxxiv]…мы, скажем, создаем такую среду, где все эти правила, вхождение, учтение мнение каждого человека, они тщательно разработаны, артикулированы, и введены в целую культуру. И с помощью такой среды, где, вот, она такая тщательная инклюсивная, да, мы входим в контакт с ПНИ и как бы распространяем вот это отношение, вне персонала, вне пациентов. Они как бы понимали, что есть вот такое отношение, и есть другое. Они уже видят различие. Персонал тоже может видеть различие, мы входим с нашим этим к администрации, какие-то люди администрации, скажем, открыты, такие сейчас есть, они перенимают какие-то размышление, мы создаем просто какую-то дискуссию. И так мы прививаем эту культуру внутри институции, я вот вижу так. […] Более конкретно, мы понимали, что нас очень интересовала […] такая микрополитика, которая касается политики отношений, политики принятия решений, например все наши встречи были организованы как ассемблеи […]. Но все же все наши деятельность более направлена на дестигматизацию. И я уже горовил много о том, что наши цели были создание среды. […] Но общий план был просто сделать публичным обсуждение этой проблемы. И не в контексте помощи, это мы, для нас было довольно важно вспарывать эту идею помощи. Потому, что она самая репрессивная и ограничивая. Ну, ограничивает, как бы, да, или кого-то навязывает, ну иеракхизирует, как бы, ставить иерархию. А то есть для нас было важно создать такую среду […], которая добавяет в горизонт возможностей людей, оказавших перед лицом проблемы […]. И так же, мы хотели сделать обсуждение этих проблем более, более свободным. То есть открыть это обсуждение. То есть делать его более привычным.

[lxxv]'там была очень показательная ситуация, когда режиссер вот этот вот говорил, что: вот мы в этом проекте деконструируем норму, мы ищем что-то новое, а когда стали люди сами говорить, которые участвовали: ну вот нам очень нравится работать с умными образованными людьми, с людьми из искусства, то есть на уровне риторики этот режиссер из искусства деконструирует норму, а люди, которых он приглашает, они, например, заинтересованы наоборот в попадании в норму. И получается, что за счет этого некритического мышления они в этом проекте существуют совершенно параллельно. То есть один что-то деконструирует, а вторые что-то конструируют.'

[lxxvi]'И так мы устраивали процесс так [*i.e., like assemblies*], чтобы каждый мог высказаться. И все могли принять участие в обсуждении и прочие, и конечно у нас вопросы власти стояли остро в каких-то моментах. В том числе потому, что кто-то вообще не был носителем этой демократической культуры.'

[lxxvii]'Потому что то, что происходит с людьми в интернате не только лишает идентичности, но и всеми ситуациями и всей вообще системой, той, которую им выстраивают, где они живут в помещениях, говорят, что тебе идентичность никакая и не

нужна. То, что у тебя нет - окей, и не надо, ты ее не достоин или ты не сможешь с ней обращаться. […] Какая-то абсолютная, конечно, вещь. Тут много разных идентичностей, от человеческой, гражданской до ментальной. Мои хождения в интернат тоже были про мою идентичность, потому что я была разрезана как бы на две половины. Был один мир и другой, который я пыталась соединить. Это все было про то, что люди в интернате, когда мы долго коммуницировали, воспринимали меня как абсолютное божество, с точки зрения того, что у меня есть свобода, у меня есть выбор. Я могу делать все, что я хочу, а они - как бы нет, и это автоматически значит, что я плохой, я некрасивый, я там такой-то и такой-то, а любой человек, который приходит со свободой, - он всемогущий, он типа другой, он - вот.'

[lxxviii]'И я сказал: окей, мы в культуре говорим про инклюзию, а сколько людей вы наняли на работу, например, в ваш фонд, например? Или: скольким людям вы заплатили? Выплатили режиссеру, автору проекта? А вы платили людям? Вот, например, чего мы добиваемся сейчас в [*CSO where he works*], чтобы за все выставки у нас художникам платили и контракты были. Это сложно, например, сделать с недееспособными людьми, потому что юридически нет формы договора [*which people without legal capacity can contract*], но мы как бы договариваемся, я все равно деньги отдаю им.'

[lxxix]'ЛГБТ сообщество очень сильно вплетено в принципе в гражданское движение, которое существует в России уже сейчас. […] Когда мы говорим про инва сообщество, оно не...,- инва активисты, большинство не воспринимает себя как какими-то общими гражданскими активистами, как бы инва повестка она как бы отдельна. И инва организации они никак не рефлексируют ни тему доступности свободы слова, ни тему- ничего. Есть некий такой отдельный инва мирок.'

[lxxx]'у них есть эта инклюзия'

[lxxxi]'И еще у меня есть ощущение, что вообще в квиркультуре НКО и каких-то ЛГБТ-организаций, которые, может быть, принимают какую-то интерсекциональную оптику, можно сказать, в принципе, принято больше задумываться о доступности мероприятий для разных людей. Не только для ЛГБТ, но и вообще в принципе про другие виды дискриминаций принято задумываться. […] В ЛГБТ-пространствах я часто встречал такую практику, что, у нас запрещены не только гомофобия, бифобия, трансфобия, но еще у нас запрещены сексизм, расизм, эйблизм и так далее. […] Обратно это работает хуже. Да, потому что, в общем-то, сообщество людей с инвалидностью, во-первых, достаточно закрытое. […] Среди них есть ЛГБТ-люди и тогда – да, это люди как-то пересекаются, но в целом какой-то дискурс об ЛГБТ просто так в [disability] пространствах обычно не поднимается.'

[lxxxii]'Тогда же, в конце 2015 года это было, я сказал, что необходимо [*for the movement he participates in*] учиться у ЛГБТ-движения некоторым методам и правилам. […] Смотрите, я считаю, что ЛГБТ-движение в России - это самое крупное движение, которое играет большую роль в дестигматизации определенных тем. […] Поэтому я посчитал, что ЛГБТ-движение […] играет большую роль в тех вопросах, которые не обсуждаются в обществе, но тем не менее очень значимы для общества. […] Один из уроков в том, что, возможно, если люди не будут скрывать свои диагнозы, то в чем смысл прайда, это не только требования прав, это еще и демонстрирование своей сексуальной ориентации, либо гендерной идентичности. '

[lxxxiii]‘А когда ты начинаешь разговаривать с людьми, что вообще есть ситуация, когда все вот это как-то накладывается одно на другое, то у людей немножко сознание начинается как бы западать потому, что это немножко уже разрывает шаблон, да? Потому, что мы понимаем, что Россия, это православная страна, и вообщем у многих есть такое, что люди с инвалидностью, вообщем, им надо помогать, скажем например, это благотворительность или даже не благотворительность, это такое типа ну вот, надо. Ну некое такое церковное какое-то восприятие, да. Это одно отношение к человеку. При этом если он к примеру гей, да, а телевизор тебе 24 часа в сутки говорит о том, что это приспешники запада посланные разрушать, не знаю, нашу духовную великодержавную нравственную всю всю всю, у тебя уже другое отношение к человеку. И если это все в одном человеке переплетено, то человек […] не понимает как к нему относиться. И вот в этот момент когда какие-то социальные штампы начинают потихонечку трещать, да, можно уже на какие-то широкие темы разговаривать, на теме того, что вообщем мы как бы все права имеем.’

[lxxxiv]‘А если организация напрямую получает деньги от государства, то понятно, что она не будет вдвигать никакие,- ну как это сказать, то есть это не будет какая-то протестная активность. Это не будет какие-то позиционные требования. Просто потому, что это рука, которая кормит. […] Есть организации, которые напрямую зависят от государства, и тогда ну кто платит, тот и музыку заказывает. Это первое. Второе, если организация все-таки независимая, да, она все равно несколько раз подумает, а не настучать ли по голове при желании настучать по голове, например. Поэтому, это очень сильно тормозит. […] Почему ЛГБТ сообщество такое сильное и политически-активное и вообще, то есть, много чего делает - в их деятельность не было никакого участия государства. То есть, все то, что они сделали, они сделали вопреки тем действием, которое проводило госурдарство. В инва секторе, все напрямую противоположно. То есть, есть огромное количество внимания государства, внимание со своей колокольни, со своим каким-то мировоззрение и это очень сильно тормозит потому, что опять таки есть много вмещения в такую деятельность, то есть вместо того, чтобы устраивать тысячный митинг колясочников на тему того, что приспособлите метрополитен, к примеру, какие-нибудь наоборот какие-нибудь прогосударственные организации [*brings together a group of wheelchairs users to check the accessibility of a museum, and then uses that to show that*] в стране ведется работа на то, чтобы все было доступно. То есть получается, государство подменяется собой частный вот этот третий НКО сектор, тем самым на самом деле саботируя всю работу.’

[lxxxv]‘Часть людей, которые даже сами являются активистами, они все равно гомофобные, то есть все равно они тебе вот только только сейчас рассказывают про то, что там тра тра тра равные права, да? Ты чуть-чуть с ними начинаешь говорить про геев и они говорят, "нет, геи, фу фу фу. Стоп." Не все, не все, часть. Другая часть, она на интеллектуальном уровне понимает о чем ты им говоришь, да, что там типа равные права тра-та-та-та-та, общая повестка, пресечение каких-то сфер деятельности, что в общем-то взаимодействие, которое выгодно объективно было бы обеим сторонам, да, потому, что ну все равно союзники всегда нужны. Там ты увидишь это как-то уже другой уровень, но все равно ты понимаешь, что нет потому, что там государства, нет потому, что страх, нет там, не знаю, завтра придут с какой-нибудь проверкой и закроют нас.’

[lxxxvi]‘у меня очень хорошие отношения с людьми, которые там работают и как бы с руководством и опять таки на ценностном уровнем мы понимаем друг друга. Но дальше

это не идет потому, что, ну это можно разными словами объяснить, но суть заключается в том, что типа "не хотим рисковать потому, что это не совсем наша повестка." Рассуждение идет таким образом, что мы много чего делаем для людей с инвалидностью и это наша основная задача. Ну, если мы вдруг начинаем это самое, то это ставит под удар всю ту хорошую большую деятельность, которую мы делаем. Это такой выбор нравственный. […] Тут все равно ты должен находиться с ними в одном помещении потому, что как бы при всем при этом при том, что это далеко не самые приятные личности, они все равно что-то делают, временами они отказываются твоими тактическими союзниками. И это ужасные ощущения и очень многие люди, которые работают в некоммерческом секторе,- неважно чем они занимаются, все, кто занимается, к примеру, помощью детям, которым экстренно нужна какая-то операция,- они вынуждены вот с такими людьми очень часто работать. И это очень тяжело потому, что ты понимаешь, что это за люди. Ты понимаешь откуда там эти деньги. Это нравственно небезупречно, но при этом ты понимаешь, что если вот сейчас ты не будешь с ними работать, то вот конкретный ребенок он просто умрет или там конкретный пандус просто не построят. Вообще ничего не будет.’

[lxxxvii]‘Но все равно вот кейсовость конкретных случаев в отличии от больших кампаний, постоянная оглядка на госурдарство, использование риторики угнетенных тире благотворительности, вот это создает... Это вообщем в чем-то помогает. Это тактически может быть помогает конкретному мальчику получить конкретную коляску. Но это не решает больших проблем. Вот [*disability CSOs work with*] какие-то конкретные случаи. Опять таки в этом еще во всем чувствуется очень сильный привкус такого понятия как благотворительность. Потому, что когда вот что-то делаешь для людей с инвалидностью, и в этом и позиция государства, риторика, которая с телевизора звучит, и то, что к сожалению говорят сами представители инва-сообщества, то все равно звучит риторика не "давайте сделаем этому мальчику электрическую коляску потому, что там в конституции написано, что все имеют права свободно передвигаться и тра та та," нет. Это звучит как "вот посмотрите какой замечательный мальчик, как ему плохо без этой коляски, а мы же тут все люди добрые, надо делиться тем, что у тебя есть, и вообще это может произойти с каждым.’

[lxxxviii]‘а это [*he refers to a previous sentence: ‘…работать с инвалидами…’*] такой политически удобный образ в России, чтобы показать, какие мы хорошие, что у нас какая-то социальная ответственность в стране есть.’

[lxxxix]‘Мы опять же пытаемся это учитывать, что: а у нас ведь много людей ЛГБТ в том числе проживающих, вот и я тоже из ЛГБТ-сообщества. [*Artyom refers to the LGBTQ+ events he has worked on.*] У меня серьезные проблемы, что я могу, например, говорить о человеке с инвалидностью, но я не могу говорить о человеке с ЛГБТ инвалидностью. Наша организация не знает, как с этим работать, они боятся и не хотят.’

[xc]‘Складывается впечатление, что там сплошь цисгендерное гетеросексуальное сообщество.’

[xci]‘У нас в организации такая позиция, что у нас много сотрудников, у нас много ЛГБТ-сотрудников, например, людей, которые ходят на митинги, например. Но у нас есть запрет, то есть мы ходим туда не как представителя организации, а ходим как мы по отдельности. Когда я участвую в ЛГБТ мероприятиях: пожалуйста участвуй, но [*the CSO*]

там нигде не указывай. Вот был круглый стол по ЛГБТ с инвалидностью год назад, который делал [*a grassroots, informal organisation*]. И это было настолько глупо, потому что это были все наши коллеги, которых мы знаем в лицо, но мне было запрещено писать [*the name of the CSO*] и все, зная друг друга, но, например, у меня на бейджике это не написано. И все время говоришь: сейчас я сотрудник крупной благотворительной организации в [*city*]. Это просто маразм. Но такова реальность. Потому что православные гранты, потому что организация активно взаимодействует с церковью.'

[xcii]'Меня просили там об этом не говорить, в [*formal CSO*], никак не демонстрировать свои близкие отношения с моей девушкой, которая работала рядом, и вообще не говорить на эти темы с [*people using the CSO's services*]. Было уже немного поздно, потому что уже были моменты, когда меня кто-то спрашивал: "А у тебя есть парень?" Я говорила: "Нет, у меня есть девушка." И люди уходили, думая об этом. Ничего страшного не происходило, тем более мы не нарушали закон, там люди были все старше 18, но тем не менее все равно было такое. Потом я работала [at a grassroots initiative in a state school]. […] Но там ж были такие же ограничения. Мне тоже, перед тем как взять меня на работу, сказали: "Удалите, пожалуйста, из своих соцсетей всю информацию, связанную с ЛГБТ-политикой и похожими вещами, потому что вы знаете, что у нас есть всякие православные экстремисты, которые об этом узнают, настучат, и весь наш проект закроют." Я на самом деле нашла выход, потому что я понимала, что я не могу удалить эту всю информацию, там очень много всего, я просто поменяла во всех соцсетях имя, чтобы сложнее меня было как-то сопоставить. […] У таких инициатив, получается, тоже есть свои ограничения при работе с государственными структурами.'

[xciii]'Если честно, я даже побоялся светить своим именем, потому что я боялся того, что на это могут натолкнуться знакомые моих знакомых, которых я совсем не хочу уведомлять о том, кто я. […] Теперь я более осторожен, и иногда, когда я пишу какие-то материалы, связанные с ЛГБТ и инвалидностью, особенно в какие-то очень публичные места, я иногда даже именем своим светить боюсь. Те, кто знает меня как активиста, те меня узнают. Те, кто меня не знает, какая вам разница?'

[xciv]'[я являюсь] […] небинарным транс-человеком, пансексуалом.'

[xcv]'Действительно, с этим есть сложности, потому что в ЛГБТ-сообщество я могу прийти и сказать: "Ребята, у меня инвалидность по [*impairment category identifier*]". Конечно, ко мне надо будет привыкнуть, но по большому счету всем будет начхать, серьезно. […] Но я уже очень давно не общаюсь с так называемом [*All-Russian Organisation, GONGO*], потому что это очень тяжело. Я не приду туда, потому что я не смогу там быть. Я смогу побыть там инва-активистом, это не проблема. Они, возможно, будут мне рады, потому что я довольно молодой и инициативный человек в меру, что называется, своих возможностей. Но я не смогу раскрыться там как ЛГБТ, потому что они погонят меня "поганой метлой", что называется, и я даже не пытаюсь. Нет, мне было бы интересно. Мне было бы интересно и, возможно, важно к ним прийти, самому что-то сделать, запросить у них какой-то поддержки. Но я боюсь, что это невозможно.'

[xcvi]'Я думаю, что я бы скрывал. […] Так что идти туда как транс-человек просто очень опасно, я думаю. Черта с два я там кому нужен.'

[xcvii]'Он много времени работал с людьми с инвалидностью, […] при этом он гей и значительная часть его дейтельности связана с ЛГБТ активистом. И как-то он мне

рассказывал, что однажды он понял, что как-то странно, что у него происходит, что у него вот жизнь как бы на две части поделяна, что вот есть как бы ЛГБТ там, геи, и как бы какая-то вот своя движуха, а тут есть вот как бы инвалиды и они как-то отдельно. А есть же люди, которые как бы вообщем попадают в обе катагории.'

[xcviii]'Когда я пришел в качестве активиста в ЛГБТ-сообщество, в квир-сообщество, я осознал, что тут ситуация еще интереснее. С одной стороны, все гораздо лучше, потому что в ЛГБТК-сообществе встречаются люди с разными идентичностями и многих из них тяжело чем-то удивить. А с другой стороны все несколько сложнее из-за того, что это довольно необычно, потому что я являюсь *[disabled; the participant specifies their disability*], небинарным транс-человеком, пансексуалом. Это очень интересное комбо, и люди удивляются тому, что у меня могут быть другие идентичности помимо того, что я [*disabled*], что я не отношусь к цисгендерному и гетеросексуальному сообществу. Я даже не знаю, потому что у меня, в принципе, не может быть какая-то гендерная идентичность и сексуальная ориентация.'

[xcix]'мероприятий с тифлокомментированием настолько мало, что люди, даже которые не относят себя к ЛГБТ и вообще, может быть, не очень интересуется квир-культурой, все равно пошли бы на [*our event*], просто чтобы послушать как им тифлокомментируют, потому что потребность есть такая. И в целом реакция, мне кажется, была очень позитивная'

[c]'когда я сделал каминг-аут [*online*] и сменил местоимения, в которых там о себе пишу, я стал освещать в том числе какие-то ЛГБТ-мероприятия, организации в которых я бывал, внезапно, ко мне [*online*] стали приходить люди, некоторые оставшиеся анонимными, а некоторые вполне открыто приходившие ко мне, которые сами являлись ЛГБТ с инвалидностью. Мы говорили о том, что для нас это очень важно, очень важно единение сообщества, когда мы встречаемся и когда для нас есть определенные пересечения в идентичностях. Например, одна персона пришла, она захотела остаться анонимной. Естественно, я не навязывал ей общения и не пытался ее деанонимизировать, она просто писала, что для нее очень важно читать мои посты. Другая персона пришла ко мне, она незрячая гомосексуальная женщина. Мы лично общаемся, […] для нее важно со мной общаться, потому что мало кто знает о том, что она гомосексуальная женщина, и она понимает, что я ее восприму нормально, поэтому у нас могут возникать похожие трудности. Мы можем задавать друг другу какие-то технические вопросы, какие-то правовые вопросы, всякие такие вещи. Была еще одна персона, мы с ней общаемся до сих пор […]. Мы с ней стали общаться, и у нее была похожая трудность, как и у меня: она была активной публичной персоной, она [had won prizes in competitions run within disability spaces], и все было очень круто, но она не могла раскрыться как ЛГБТ-персона. […] Ты постоянно общаешься с кучей людей, но ты не можешь сказать, что у тебя есть девушка, потому что ты не можешь сказать, что у тебя есть девушка. Получается, что как бы личной жизни у тебя нет, хотя на самом деле она есть. […] Когда ко мне стали приходить люди с инвалидностью и имеющие отношение к ЛГБТ сообществу, для меня это стало очень важным мотивирующим фактором, потому что, во-первых, они мне показывают, что мы не одни, а во-вторых, я своим активизмом и тем, что я пишу, показываю им, что мы не одни.'

[ci]'у них гораздо больше проблем с тем, что найти площадку, например, которая была бы доступна для людей с разными видами инвалидности.'

[cii]‘они мне показывают, что мы не одни, а […] я […] показываю им, что мы не одни’

[ciii]‘нам приходится много думать о своей репутации, о том, с кем там можно дело иметь, с кем нельзя, с кем можно ну как бы открыто входить в коалицию, кому ну можно помочь, но явно не как бы не светиться условно говоря вместе.’

[civ]‘Когда мы начинали какой-то взаимодействие с [*formal CSO*], то изначально это было то, что ну, да, давайте, мы работаем. Но мы как бы делаем это непублично. И в принципе на таких условиях они были готовы работать. И что-то мы делали совместно, то есть к нам приезжали люди от них на какие-то наши мероприятия и то есть нет какого-то запрета там от них, что нет, не ходите, такого не было. И опять таки это вот такое подковерное сотрудничество, но все равно некоторые свои плоды дало. Потому, что некоторые представители инва, они немножко шире смотрят на общую гражданскую повестку. Это как бы все равно плюс. [...] Но это просто крупица по отношению к абсолютно карт бланш, который дают ЛГБТ организации, которые говорят вот, все, типа, чуваки, делаем инклюсию и орем с каждого угла, что у нас теперь инклюзия. В отличии от государственных организаций, они орют, что у них инклюзия и у них есть эта инклюзия.’

[cv]‘Есть люди все равно, [которые] теперь немного знают об этом, учитывая, что это уже достаточно талентливые люди, да, что все равно занимаясь инва, они уже немножко другое видение имеют. И следовательно если потом лет через 10 они станут ведущими там, не знаю, игроками на арене инва движения за права людей с инвалисьностью, они уже будут более открыты и готовы, чем вот люди, которые сейчас находятся.’

[cvi]‘Я в последствии в НКО устроился работать […], потому что я почувствовал опять же, что я на этой позиции могу сделать больше’

[cvii]‘Я туда пришел с разными ожиданиями, надо сказать, большинство из которых оказалось ложными. […] [*CSOs now are*] настроены на выживание, на менеджмент, на экономику и в меньшей степени они нацелены на политизацию, на анализ текущей ситуации и на реальное вовлечение людей с инвалидностью. Они все говорят за людей, но очень трудно работать вместе с человеком с инвалидностью. И все они базируются на эксплуатации вот этого образа безвольной жертвы в основном, патернализм.’

[cviii]‘Мне лично как бы страшно в принципе расстаться с подопечными, потому что это как бы очень близкая история, мы боимся действительно, и я скорее хочу от ЛГБТ-организации поддержки, а не вот этих вот бросаний в лица: а чего вы боитесь. Да, то есть я на [*event*] не услышал никакой конкретной методики, как мы можем взаимодействовать. То есть были какие-то упреки взаимные, но, чтобы кто-то предложил какую-то модель... И потом они делают странно, они пригласили то есть нас, а не глав организаций, то есть людей, которые в принципе ничего не решают в организации. Я сказал, что: окей, если вы хотите приезжать в [where Artyom works], работать с людьми, я могу вас со всеми познакомить, но я не могу как бы отвечать за позицию организации, что у меня просто нет таких полномочий. То есть вот проблема была как бы в позиции вот этих активистов, проблема была в том, каким образом сделано мероприятие что, проблема в том, что не было предложено каких-то конкретных моделей.’