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An Unlikely Friendship: Rethinking State-Society Relations in Contemporary Russia

Candidate № 2190823

MSc in Russian, East European and Eurasian Studies

Acknowledgements

Abstract

This dissertation examines the relationships between state authorities and civil society organisations in Russia, using a qualitative case study of ten registered disability NGOs in Nizhny Novgorod. While much of the extant literature on state-civil society relations in Russia focuses on political claim-making, this dissertation looks instead at how disability NGOs partner with state institutions in order to provide welfare services. In doing so, it challenges several common assumptions about state-society relations in Russia: that collaboration between NGOs and the state in the absence of political contention is a form of puppetry, undermining the autonomy of the third sector; that the state does not have NGOs' best interests at heart; and that Russian civil society is *sui generis* and cannot be compared with its Western counterparts. On the contrary, by looking at how disability NGOs engage with the state to collaboratively deliver welfare services to their clients, the research finds that local state authorities can be a key partner for disability NGOs and that the two sectors complement one another in serving their clients' needs. In this regard, the relationships between Russian disability NGOs and the state may bear more similarity to those of their counterparts in more democratic states than most current literature would suggest.

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"You can complain about your neighbour's garden all you want. If you don't like it, sow your own".

Anonymous; Nizhny Novgorod, June 2018

1. Introduction

Over the past few years, the activities of the Russian government have drawn significant attention not only from academic and specialist publications but increasingly from the mainstream media as well. Overwhelmingly, the state is portrayed as a threatening entity with imperialistic designs in its foreign policy and as a repressive force limiting fundamental freedoms in its domestic policy. In 2018 alone, the poisoning of Sergei and Julia Skripal, the alleged plot to assassinate journalist Arkady Babchenko in Ukraine, the ongoing investigations into interference in other states' democratic processes, reports of irregularities in Russia's 2018 presidential election, and mass detentions of protesters have all added fuel to the fire.

This view of the state as a repressive entity is reflected in the burgeoning body of research on state-civil society relationships in Russia. Many have highlighted Russia's 2006 NGO law and its 2012 foreign-agent law as indicators that the state has successfully managed to limit the effectiveness of Russian civil society and to stem its development (for instance, Evans, 2006; Maxwell, 2006; Crotty, Hall and Ljubownikow, 2014; Ljubownikow and Crotty, 2016).

Recent studies focusing on Russia's so-called Socially-Orientated Non-Governmental Organisations (SO NGOs) – not-for-profit organisations recognised by the state as offering useful social services to vulnerable groups – purport to challenge this pessimistic view of Russian civil society, arguing that NGOs supporting social rather than civil and political rights enjoy greater support from and access to state authorities.

Yet these studies are nonetheless informed by the above context. As such, they still tend to characterise the state as a negotiating counterparty at best and an adversary at worst. This is

due, in part, to their disproportionate focus on the political claim-making and advocacy activities conducted by SO NGOs. Hitherto, scholars seeking to understand state-civil society relationships have looked primarily at the ways in which SO NGOs advocate for their clients' interests and influence the policy-making process, either by using their close relationships with the state, or (less often) by engaging in public demonstrations.

While policy entrepreneurship and rights defence are certainly important aspects of these NGOs' work, they are only part of the story. Much – indeed, most – of these organisations' work is service-orientated. Although some SO NGOs do engage primarily in politicised forms of rights defence – for instance, lobbying for social inclusion or taking legal cases of discrimination to court – for many, particularly those working at a local level, these activities are undertaken on an ad-hoc basis and are secondary to service provision. Yet service provision has thus far not been considered as an informative lens through which to examine state-NGO relations, with discussions of SO NGOs' welfare provision activities limited to ethnographic and anthropological studies. Despite this, much can be learnt about state-civil society relationships by looking specifically at the intersection between claim-making and service provision.

This is particularly true regarding organisations supporting the least visible, most marginalised and most vulnerable members of society, such as those with learning disabilities, complex and multiple disabilities, developmental disorders and mental health conditions. Due to the marginalised and underserved nature of their clientele, these types of organisations are often (though not always) small and grassroots-led and are thereby required to play multiple roles, combining service provision with rights advocacy.

As is explained further in chapters 3 and 4, the need for disability NGOs to combine rights advocacy and service provision has recently become even more marked due to a) changes in

Russian federal legislation supporting the rights of people with disabilities and therefore lessening the need for policy-based contention, b) new policies further enhancing NGOs' role as service providers and bringing closer collaboration with the government and c) state rhetoric around people with disabilities as both a de-politicised and yet politically significant group. In particular, since the introduction of new policies guaranteeing the rights of people with disabilities, many disability NGOs in the study shifted their focus from advocating for federal policy reform to working to implement said policies on a local and regional level. The study finds that when the aim is policy implementation and not policy reform, current theoretical frameworks describing state-society relations, which are largely focused on political contention, are not fully applicable.

This dissertation therefore examines the role of service design and provision in defining the relationship between NGOs supporting people with disabilities and regional state institutions. More precisely, it demonstrates how disability NGOs in the city of Nizhny Novgorod use their role as service providers to effect social change, thereby influencing the ways in which they conceptualise their relations with the state. It sets out a model that redresses the disproportionate focus on claim-making and political ideology in current literature on SO NGOs, focusing instead on the role of service provision in shaping state-civil society relationships. In so doing, it challenges the prevailing binary view of state-NGO relations as the state imposing policy from above on one hand and NGOs asking for policy or practical change from below on the other. It also challenges the assumption prevalent in the extant literature that NGOs best effect social change by political means. On the contrary, it shows how they can achieve profound social change and defend their clients' rights from a position of political and ideological neutrality. This in turn throws new light on the position and intentions of the state, allowing us to see the ways in which the state can be a positive and proactive partner in achieving such changes.

The dissertation begins with a review of existing literature on Russian civil society and contentious politics, including operational definitions of both terms. It then outlines current federal-level disability policies in Russia, describing the state and non-state infrastructure in place and highlighting the particular position of disability NGOs, who straddle service-provision and rights-defence roles. It further details the methodology used for this study, before concluding with a discussion of the findings and their implications for current literature on Russian state-civil society relations, with additional suggestions for further research.

Overall, the dissertation finds that current understandings of modes of political contention employed by SO NGOs can be greatly enriched by situating them within these NGOs' wider role as service providers. It finds that for NGOs supporting the most vulnerable yet least politicised client groups, relationships with the state can be characterised primarily as service-delivery partnerships and not as grounds for political claim-making in their own right. While the political claim-making described by existing research is certainly important, in order to understand state-civil society relations fully we must also look at the collaborations that take place outside of the claim-making realm. When we take this approach, what emerges is a state that appears genuinely grateful for the presence of SO NGOs, that seems willing to listen to their requests and that is able to forge successful partnerships with them to improve service provision and guarantee the rights of service users. While there are serious shortcomings in the state's provision of social services for people with disabilities, on the whole the state is viewed by SO NGOs as a constructive and willing partner to fix these. Although scholars have correctly argued for the need to view Russian civil society as fundamentally different from Western civil society with regard to politically or ideologically motivated activities, their focus on the advocacy activities of SO NGOs tends to mask the nature of the relationship between the state and SO NGOs as service providers. The findings

of this dissertation indicate that where SO NGOs operate as service providers, their

relationship with the state is not so different from that of their Western counterparts.

2. Literature review

2.1. Introduction

Current literature has done an excellent job in highlighting the ways in which SO NGOs manage to influence the state and express political contention despite often being state-sanctioned social service providers. It has also revealed the ways in which these strategies differ from those employed by more overtly political NGOs. However, much of the literature focuses on contention and advocacy and does not clearly explain the relationship between advocacy and service delivery. Although frameworks used to discuss civil society in Russia have evolved from the initial teleological democratisation approach to a broader focus on multiple modes of political contention, the political focus of these frameworks is still problematic when it comes to largely apolitical SO NGOs. Much can be learnt by not seeking to apply political or ideological narratives, instead focusing on state-society collaborations in the realm of service delivery. A detailed empirical study is needed, looking at how social change is implemented not only through political claim-making but also through designing services in collaboration with state authorities. This study sits at the intersection between literature on civil society, contentious politics and social welfare in Russia.

2.2. Conceptual frameworks of Russian civil society: from democratisation to "consentful contention"

Civil society is a term with many competing definitions. Most commentators agree that it describes a sphere of formalised organisations and non-formalised networks that belong neither to the state sector nor to the private market (for instance, Kuchukeeva and O'Loughlin, 2003; Henry and McIntosh Sundstrom, 2006; Jensen, 2006; Crotty, 2009). For many, however, the term also carries the normative assumption that civil society should "promote democratic values, provide models of active citizenship and temper the power of

the state" (Kuchukeeva and O'Loughlin, 2003, pp. 557–8). As the following paragraphs will demonstrate, this has led to a fundamental misunderstanding of the way in which civil society operates in Russia, where democratic transitions do not appear to be taking place and where options for "temper[ing] the power of the state" are limited.

Instead, the term "civil society" is used throughout this dissertation to describe "a space of citizen-directed collective action, located between the family and the state, and not directed solely toward private profit" (Henry and McIntosh Sundstrom, 2006, p. 5). This definition avoids making normative assumptions about what civil society's aims should be, describing only its societal role and economic structure. It includes both informal social networks and formalised not-for-profit organisations which are not officially incorporated into the state apparatus. The latter, which form the focus of this dissertation, are referred to hereafter as non-governmental organisations (NGOs) in keeping with common parlance, even though they may have loose affiliations with or even occasionally direct mandates from certain state institutions.

Recent scholarly literature has begun to reject characterisations prevalent in the early- to mid-2000s of Russian civil society as "weak and ineffective" (Crotty, 2009, p. 87). These conceptualisations focused variously on: the "relatively disabling environment" within which Russian civil society operated (Belyaeva and Proskuryakova, 2008, p. 7); the "unintended consequences" of extensive reliance on international funding, which forced a Western agenda not always appropriate to the Russian context (Henderson, 2002, p. 139); and the re-emergence under Putin of Soviet-style statism, or *gosudarstvennost'*, which many felt undermined civil society's purpose in holding the government to account and fuelling democratic transition (Hale, 2002; Evans, 2006; McIntosh Sundstrom and Henry, 2006).

The debate around this third claim is particularly relevant to Russia's Socially-Orientated NGOs (SO NGOs). While receiving relatively little academic attention, these organisations make up the bulk of civil society in Russia and are perceived by citizens to have equal or greater importance than the more-studied organisations promoting civil and political rights (Bindman, 2015).

In the early Putin years, some claimed that the close partnership between SO NGOs and the state, the outsourcing by the state of key social services to the third sector, and the reliance of these organisations on government funding amounted to state co-option of civil society, creating a "quasi-civil society […] in which organizations are subordinated to the authority of the state" (Evans, 2006, p. 149) putting society "at greater risk of falling into tyranny" (Hale, 2002, p. 307).

However, critics argue that this view is borne of a fundamental misunderstanding of the Russian context. Specifically, it views civil society through a prism of Western liberal individualism in which NGOs are expected to remain independent from and contentious to the state (Hann, 1996, p. 3; Fröhlich, 2012). In particular, negative views of Russian civil society's effectiveness have been criticised for their normative assumption that state and non-state actors should be independent from one another. The conceptualisation of civil society as "differentiated […] from the state" (Cohen and Arato, 1992, p. 2) is fundamentally linked with the teleological democratisation approach to civil society prevalent in Western usage of the term (Cheskin and March, 2015, p. 262). This view sees the facilitation of democratic transition as fundamental to civil society's role and therefore as demanding of full independence from the state (see, for instance, Uhlin, 2006).

Yet there is merit in viewing Russian civil society as outside the paradigm of democratic transition, particularly as this transition does not seem to be occurring in Russia which has

instead settled into a model of "managed democracy" (Cheskin and March, 2015). Without denying the benefits of a fully independent civil society in facilitating democratisation, it is necessary at times to view Russian civil society as separate from any democratisation processes.

Indeed, several recent studies have demonstrated that in the case of SO NGOs, the close intertwinement of civil society with the state can actually facilitate claim-making and advocacy, contrary to the view put forward by critics that this part of civil society has been "co-opted to assist the leadership of the political regime in pursuing the objectives that it has chosen for society" (Evans, 2006, p. 152).

SO NGOs have been shown to use a variety of techniques to advocate for their beneficiaries' rights and interests, either by seeking (or sometimes resisting) wide-ranging policy reform or by tackling individual injustices on a case-by-case basis. These techniques often involve collaboration with the authorities, including: private meetings with government officials to discuss individual cases; NGO representation on local government boards; participation in regional state-society "Civic Chambers" (*Obshchestvennye Palaty*); and loyalty to political candidates in exchange for support for the NGOs' beneficiaries (Thomson, 2006; Fröhlich, 2012; Bindman, 2015; Kulmala and Tarasenko, 2016). This relationship is one of interdependency rather than pure co-option: state bodies often rely on NGOs to implement key services on their behalf, while NGOs in turn use their closeness with the authorities to advocate for changes that favour their beneficiaries (Thomson, 2006, pp. 229–230; Henderson, 2011).

In light of these studies, an expanded framework of contentious politics has been developed to replace the earlier democratisation approach and to account for the ways in which SO NGOs manage to influence political actors despite the ostensible absence of open

contestation (Cheskin and March, 2015). As the following paragraphs demonstrate, theories of contentious politics have been helpful in enhancing understanding of Russian SO NGOs' political activities. However, their inherently political focus obscures the equally important apolitical activities undertaken by these organisations.

Contentious politics, as defined by Charles Tilly and Sidney Tarrow, "involves interactions in which actors make claims bearing on other actors' interests, leading to coordinated efforts on behalf of shared interest or programs, in which governments are involved as targets, initiators of claims, or third parties" and "thus brings together three familiar features of social life: contention, collective action and politics" (2015, p. 7). Theories of contentious politics are useful in understanding the Russian context in that they reduce reliance on normative assumptions about what civil society actors should be trying to achieve – assumptions which were a key weakness in the earlier democratisation approach. Instead, they describe only the processes and mechanisms by which these actors make politically motivated claims against holders of power.

Early frameworks for contentious politics focused primarily on public acts of dissent. As Sarah Henderson has noted, however, the relationships of Russian SO NGOs to the state are complex and cannot be explained using these frameworks alone. Due to their role as "critical partners" upon whom the state relies to deliver key services, they are able to "counter and balance the state by working with it, and cooperation is as much a part of state-society relations as is confrontation" (Henderson, 2011, pp. 13–14).

In order to better explain the actions of SO NGOs vis-à-vis the state and to include the notion of countering the state by working with it, Ammon Cheskin and Luke March (2015) have applied Jeremy Straughn's definition of *consentful contention* to the Russian context. Building on Straughn's definition of contention as consentful when "the claim maker enacts

the persona of a dutiful citizen while contesting specific actions or policies of the state"
(Straughn, 2005, p. 1601) they propose an expanded model of political contention and
dissent, encompassing four modes:

- Consentful compliance (compliance backed by ideological motivation)

- Dissentful compliance (begrudging compliance)

- Consentful contention (contention within state-sanctioned realms)

- Dissentful contention (contention driven by anti-regime sentiment)

(Cheskin and March, 2015, p. 266).

While dissentful contention is hindered in Russia, consentful contention – that is, contestation
of state actions and directives using dialogue within state-sanctioned realms – is not only
present in Russia but may potentially be aided by the state's paternalistic approach to SO
NGOs. Indeed, the close intertwinement of state and society opens up official channels of
dialogue between the state and civil society actors that may not otherwise have existed
(Fröhlich, 2012; Bindman, 2015).

Related to this is the distinction between "indirect" and "insider" forms of advocacy, first
outlined by Jennifer Mosley (2011) and applied to the Russian context by Sergej
Ljubownikow & Jo Crotty (2016). Indirect forms of advocacy are used in the absence of
direct channels of communication with the government and therefore involve engaging the
public and influencing public discourses. By contrast, insider forms of advocacy involve the
use of personal connections with governing decision-makers to influence public policy
(Mosley, 2011; Ljubownikow and Crotty, 2016). While Ljubownikow and Crotty find that
Mosley's model is too simplistic to be applied wholesale to the Russian context, the
distinction between "insider" and "indirect" forms of advocacy is useful in adding nuance to

descriptions of advocacy in Russia and in encouraging us to look further than simply at public mobilisations for examples of civil society advocacy.

The inclusion of consentful contention and insider advocacy in discussions of civil society allows us to view civil society as separate from the democratisation process and as effective even in the absence of overt political protest. These concepts, then, are more appropriate to the working environments facing SO NGOs, who – in contrast to NGOs working on politically charged issues such as the fight for free and fair elections – are supported by and have frequent access to state authorities.

However, the use of contentious politics as the primary framework within which to understand state-civil society relationships is fuelled by the underlying assumption that state-civil society relations are best explained by looking at political claim-making. It represents a shift from seeing political contention as general opposition to the authorities to seeing it as opposition to specific issues that can be resolved in direct dialogue with the authorities. Yet while SO NGOs certainly engage in political claim-making, it can hardly be said to be the defining feature of their interactions with state institutions, which are largely shaped by their desire to obtain the best results for their clients irrespective of political opinions.

While current scholarly literature does not claim that most interactions between civil society and the state are political in their nature, it does assume that those which are not are of little academic interest. Civil society scholars pay little attention, for instance, to the processes by which SO NGOs register as providers of social services, to the joint awareness-raising campaigns conducted by SO NGOs and state institutions aimed at the general public, or to the education and training that specialist NGO staff provide to government employees. While scholars of social welfare (as opposed to scholars of civil society) do look at these aspects of SO NGOs' work, they tend to do so in order to explain clients' lived experiences and not to

comment explicitly on the structure of Russian civil society and its relationships with the state (a few examples are Thomson, 2002, 2011; Iarskaia-Smirnova and Romanov, 2007; Iarskaia-Smirnova, 2011).

Perhaps the reason empirical studies of civil society overlook these aspects of SO NGOs' work is that the theoretical frameworks they employ (as described above) assume that a key marker of NGOs' effectiveness is their ability to influence or challenge the state – either openly by public protest or privately, following state-sanctioned channels. Although understanding of the ways in which NGOs challenge the state has greatly advanced, little recognition is given to the notions that the state, in specific circumstances, does not warrant challenging at all and that social change can therefore be accomplished by apolitical means. The following section examines some of this empirical literature in greater depth.

2.3. Empirical studies on political advocacy

Recent empirical studies focus on the ways in which SO NGOs interact with the state in order to advocate for the rights and interests of their beneficiaries primarily – although far from exclusively – within the bounds of private (or "insider") advocacy and using modes of consentful contention (key such studies include Cook and Vinogradova, 2006; Crotty, 2009; Kulmala, 2011; Fröhlich, 2012; Bindman, 2015; Tarasenko, 2015; Bogdanova and Bindman, 2016; Kulmala and Tarasenko, 2016). These studies can be divided into those that focus explicitly on political advocacy and dissent as a means of defending clients' interests (Cook and Vinogradova, 2006; Crotty, 2009; Kulmala, 2011; Fröhlich, 2012; Tarasenko, 2015; Kulmala and Tarasenko, 2016) and those which look more broadly at state-NGO collaborations as a form of political claim-making (Bindman, 2015; Bogdanova and Bindman, 2016). While the latter group in particular have advanced the conversation by including collaboration and partnerships as a means of achieving social change, they still fail

to give due attention to the role that service provision – outside the realm of political claim-making – plays.

The studies in the former group theorise why organisations may choose certain types of advocacy over others and seek to assess the extent of their successes. In doing so, several scholars highlight the role of organisational structure in determining advocacy goals and strategies (Cook and Vinogradova, 2006; Kulmala, 2011; Fröhlich, 2012). While scholars apply different labels to these varying organisational structures, substantively they can be placed into three broad categories: grassroots or membership-based organisations; Western-inspired (and sometimes Western-funded) "professionalised" NGOs; and government affiliates (Crotty, 2009, p. 90).

However, as we shall see below, the presumed importance of these structures is informed by the normative assumption that NGOs are "politicised organisations, which challenge and attempt to influence decision making within state institutions" (Crotty, Hall and Ljubownikow, 2014, p. 1255). The difference, for instance, between a government affiliate and a grassroots organisation becomes less important when the organisation's political claim-making activities are not the main object of study.

In his research on disability NGOs, Christian Fröhlich (2012) uses the theory of political opportunity structures to explain variations in different organisations' preferred advocacy strategies. He finds that due to their distance from state institutions and close involvement with international partners, "professionalised" NGOs find the greatest opportunities for advocacy in public-facing strategies such as the organisation of awareness-raising events. By contrast, grassroots membership organisations led by people with disabilities themselves tend to focus on individual needs rather than wide-ranging policy reform and to provide legal advice to participants to empower them to enforce their own rights. Finally, government

affiliates, which are most closely entangled with state structures, tend to prioritise "insider" tactics such as bringing priority issues to government attention, using their privileged position as consultants on state advisory boards.

Meri Kulmala (2011) similarly highlights a difference in approach between membership-based organisations run by beneficiaries and those run by paid staff or volunteers who do not belong to the relevant organisation's beneficiary group. She finds the latter to be generally more successful in effecting wide-ranging policy change precisely because of their closer relations with the state whereas the former focus more on individual case advocacy.

By contrast, Anna Tarasenko (2015) looks not just at advocacy *techniques,* but also at advocacy *aims*, examining how different kinds of organisations form claims. She classifies registered SO NGOs as "profit-seeking" due to the fact that they use state funds to produce public goods in the form of social services, from which the wider public can benefit. By contrast, she classes powerful membership-based interest groups as "rent-seeking" due to their lobbying activities, through which they claim a greater share of public funds to the detriment of the shares of other organisations without producing social goods of wider value to the public. Whereas Fröhlich and Kulmala both highlight political opportunity structures as the key determiner of advocacy tactics, Tarasenko focuses more on whether neoliberal welfare reforms favour or disadvantage the group in question. She finds that "profit-seeking" NGOs who, for the most part, provide services in exchange for government funding and subsidies are benefited by the reforms, while "rent-seeking" organisations tended to benefit from the previous paternalistic system and are more likely to resist change.

Linda Cook and Elena Vinogradova use a slightly different mapping process, differentiating between beneficiary-led grassroots organisations, staff-led grassroots organisations, traditional human rights organisations and "infrastructural" NGOs whose aim is the

development of the third sector in its own right (2006, p. 31). They argue that these organisations can be divided into those who exhibit real civic activism and "marionette" organisations who, under the guise of civic activism, simply represent the interests either of the state or of a select few group leaders.

All these scholars make two related assumptions: that contesting the state is an essential function of effective NGOs; and that, consequently, state-civil society relations are best described by looking at political advocacy – whether by resisting policy change (Tarasenko, 2015), or by demanding it (Cook and Vinogradova, 2006; Kulmala, 2011; Fröhlich, 2012).

This focus on political advocacy also explains why the cited scholars have given such great attention to organisational structure. The categories suggested – such as government affiliate/professionalised/grassroots – although ostensibly objective categories, in fact refer indirectly to the extent, nature and success of the political advocacy undertaken. For instance, Fröhlich (2012) and Kulmala (2011) note that grassroots organisations tend towards individual case advocacy, whereas professionalised NGOs undertake more public forms of advocacy. There is little evidence that, for instance, a professionalised NGO should differ significantly from a grassroots membership organisation except where political advocacy is concerned.

Moving away from pure advocacy, Eleonor Bindman and Elena Bogdanova have broadened the discussion with their research on state-SO NGO relations (Bindman, 2015; Bogdanova and Bindman, 2016) by including collaboration as a form of political claim-making. Bindman (2015) finds that SO NGOs interact closely with state institutions – particularly on a regional level – to influence policymaking and enforcement and that their closeness with the state assists in this by opening direct channels of communication with the authorities. Bogdanova and Bindman (2016), similarly, find that collaboration with the state is a necessary condition

for successful policy entrepreneurship. Both reframe the discussion about implementing social change by analysing not only overt contention but also collaboration as a means of influencing state actions and improving the social rights of vulnerable groups. By recognising that social change can be achieved in active partnership with the state, both these studies have broadened our understanding of state-NGO relationships in Russia.

Yet, as Kulmala (2011) further highlights, this is only half the story. In addition to studying the role of organisational structure in determining advocacy strategies, she also highlights the important point that organisations cannot be neatly divided into those focused on advocacy and those providing services. On the contrary, her study notes that many organisations fulfil both these roles (to varying degrees). As such, it is important to challenge the binary view of state-NGO relations as the state imposing policy from above on one hand and NGOs asking for policy or practical change from below on the other. Even though the cited studies have advanced the conversation by including collaborative and consentful forms of claim-making, they still focus disproportionately on claim-making over service provision, despite the fact that both occur at the same time, both involve state-NGO relations, and both can be employed to improve vulnerable people's social rights. To fully understand how NGOs interact with state authorities to achieve social change and defend their clients' rights and interests, we must look not only at how they make political claims but also how they deliver services.

2.4. Conclusion

Theoretical frameworks around civil society have recently evolved to become more useful in the specific Russian context and, in particular, to be more representative of the advocacy positions of SO NGOs. Simultaneously, several empirical studies have appeared to complement these theoretical developments. Some of these focus explicitly on political contention, seeking to explain why different SO NGOs approach advocacy differently. In this

regard, they highlight organisational structure as the key variable. Others highlight that political claims can also be made collaboratively, using official channels of dialogue with the state. However, in order to provide a complete explanation of state-civil society relations, it is important to look not only at political advocacy and claim-making but also at service provision in its own right. While most literature sees claim-making and advocacy as the primary ground for achieving social change, in a period when legislation has improved dramatically but practice has not yet caught up, the interactions that SO NGOs have with the state in the design and provision of services also reveal a great deal about the state's approach to civil society as a whole.

This is particularly visible when studying registered SO NGOs supporting politically non-contentious, vulnerable and marginalised groups with highly specific needs. A detailed study on precisely those organisations can provide greater insight into how they juggle their advocacy and service-provision roles to engage with state authorities, and whether and how their role as service providers can enhance their role as brokers of change in partnership with the state.

3. Disability policy and practice: Evolution from the USSR to contemporary Russia

As this chapter will show, disability NGOs provide a particularly salient example of organisations for which the boundaries between advocacy and service delivery have become blurred. The chapter outlines the historical development of disability legislation from the Soviet Union to contemporary Russia, the current environment in which disability NGOs operate and the effect of Soviet legacies still prevalent in the welfare system. It thereby illustrates the effect that this environment has had on contemporary disability NGOs' relationships with state authorities.

The infrastructure – both state and non-state – available to support people with disabilities in Russia today comprises remnants of the Soviet system combined with newer structures that have emerged as a result both of civil society initiatives and of state-led reforms towards neoliberalism.

Soviet approaches to disability were complex, underpinned by conflicting ideological considerations. The state took a "dual approach to addressing disability", embodied by "the provision of state support for the material needs of people with disabilities, but within a culture of stigma and social isolation" (Phillips, 2009). On the one hand, the ideology of state socialism saw the government as provider to the needy and guarantor of all its citizens' material needs. On the other, in a culture that prized work capabilities and physical prowess above all else, the presence of people with disabilities was problematic, seen as a blemish on society (Shek, 2005).

People with disabilities were – and to this day, still are – placed into one of three groups depending on the severity of their disability and received pensions calculated on the basis of their perceived lost income (Phillips, 2009). People in Group I were considered the most

severely disabled, unable to work and in need of constant care. Those in Group II were deemed capable of some work, but in supported conditions outside the mainstream environment. Those in Group III were considered to have lost some work capability, but still able to work at least part-time in a mainstream environment (Madison, 1989, pp. 171–2).

Those with the most severe disabilities were usually provided for in residential institutions – *doma-internaty* – often outside major cities. These homes provided holistic care (although of variable quality) including medical treatment, accommodation and sometimes education and/or supported employment. However, in doing so they tended to isolate people with disabilities from mainstream society. Furthermore, legislation introduced in 1968 forbade residents of *internaty* from pursuing work opportunities outside their institutions (Phillips, 2009).

Social exclusion also extended to those living outside the *internat* system. Those who were able to work often did so not in the mainstream economy, but within the confines of specially designated "artels" or "RabFaks" (*rabochie fakul'tety*, work facilities) which "functioned as a sort of closed mini-city with its own infrastructure, enterprises, and culture" (Phillips, 2009). Further examples of the social exclusion of people with disabilities include a secret state directive banning people in Group I from attending higher education faculties (Phillips, 2009) and the refusal of the Soviet Union to take part in the 1980 Paralympic Games, with one official reportedly citing as a reason the fact that "there are no disabled people (*invalidy*) in the USSR" (Fefelov, 1986).

Education was also a sphere that fuelled the isolation of people with disabilities. The Soviet state adopted an approach to special education called "defectology" (*defektologiia*). This was based on the understanding championed by psychologist Lev Vygotsky of disability as a primarily social handicap that necessitated treatment in the "proper" environment – usually

one secluded and outside the mainstream of public life (Grigorenko, 1998). In addition, those with the most severe disabilities – usually complex and multiple disabilities, neurodevelopmental disorders or severe to profound learning disabilities – were diagnosed as "uneducable" (*neobuchaemyi*) and denied any education at all.

The combination of these policies cultivated an environment where people with disabilities – although nominally protected by the state – were isolated and stigmatised. It also stymied the development of any kind of cohesive disability group identity (Phillips, 2009).

As Soviet culture did not officially permit organised civil society, there were few non-governmental groups supporting people with disabilities or criticising the state approach. Some grassroots interest groups did emerge, but most were disbanded by the 1950s. Those that survived often operated under the auspices of the state (Fröhlich, 2012).

This began to change in the 1970s when – dissatisfied with the status quo – civil society groups began to emerge in greater numbers, usually started by people with disabilities. Some – such as the Action Group to Defend the Rights of People with Disabilities in the USSR – engaged actively in political dissent, publicly mobilising to criticise widespread discrimination and the lack of accessible environments for people with (primarily mobility) disabilities (Fefelov, 1986; Raymond, 1989; Phillips, 2009). Others focused more on providing recreational, social and professional activities for people with disabilities (Fröhlich, 2012).

The fall of the Soviet Union and the ensuing financial crisis in the 1990s led to the closure of many state services and to the growth of non-governmental alternatives filling the gaps – a growth that was also aided by a repeal of the ban on civil society initiatives (Fröhlich, 2012). Faced with the prospect of economic collapse, the state began outsourcing a number of social service provisions to third sector organisations, which – in the case of people with disabilities

and their families – fostered the development of active communities that had previously been stifled (Thomson, 2006; Fröhlich, 2012).

This pattern has continued into the twenty-first century, with a number of state initiatives further shifting responsibility for welfare provision onto civil society – a trend seen by some as the hallmark of a retreating state (for instance Thomson, 2006; Kay, 2011; Alehina *et al.*, 2014) and by others as the resurgence of statism under the Putin regime (Cook, 2011), where the outsourcing of social welfare and the provision of grants and indirect subsidies to the third sector functions as a mechanism for control and limiting opportunities for contestation (for instance Hale, 2002; Evans, 2006; Uhlin, 2006).

In 2010, for instance, a new federal law created a formal register of "Socially-Orientated NGOs" (SO NGOs) who would benefit from direct financial assistance from the government as well as indirect subsidies and tax incentives.[1] Any organisations deemed to be "helping vulnerable social groups" are able to attain this status (Medvedev, 2009). In addition, another new law in 2013 "On the Foundations of Providing Social Services to Citizens in the Russian Federation"[2] created a register of for-profit enterprises and not-for-profit NGOs officially authorised to provide key social welfare services that would previously have been in the state's domain.

Alongside these structural reforms, the Kremlin has also introduced a number of legislative changes over the past five years which theoretically guarantee the rights of its disabled citizens. In 2012, Russia ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). This triggered a raft of policy changes within Russian legislation to bring domestic laws into compliance with the Convention. For instance, all

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[1] Federal law 40-FZ, 05.04.2010
[2] Federal law 442-FZ, 23.12.2013

children are now guaranteed the right to education in mainstream schools and parents are, in theory, offered a choice between mainstream and special education (although, as we shall see, this is far from the case in practice). The practice of diagnosing children with the most severe disabilities uneducable was abolished in 2013 (Human Rights Watch, 2015, p. 4) and efforts are being made to provide teaching assistants for students with additional needs in mainstream schools. Anti-discrimination laws have also been strengthened and guidance has been issued to employers to help tackle discrimination (Russian Ministry of Labour and Social Affairs, 2017). Similarly, guidelines on accessibility of public transport and spaces have been introduced as well (Human Rights Watch, 2014). These legislative changes indicate that people with disabilities are a politically significant group for the state, and one which the government – at least at a federal, theoretical level – is proactively looking to protect. The promises of inclusion and social integration also signal a move away from the Soviet model of viewing people with disabilities as "defective" and isolating them from mainstream society.

However, implementation of these policies in practice has proven difficult. Improvements to physical accessibility have been made in major cities, spurred in part by the 2014 winter Olympics and 2018 football World Cup, which brought in vast numbers of tourists and billions of roubles in investment. However, there are still significant barriers to physical accessibility. Many people with mobility impairments struggle to leave their homes or use public transport, for instance (Human Rights Watch, 2013; OHCHR, 2018).

For those with more complex needs, isolation and segregation are still significant issues. While all children are now theoretically entitled to an education, much of the time this still occurs in segregated institutions and is of variable quality (Dvornikova, 2017). Often, parents are forced to place their children in special educational schools (*korrektsionnye shkoly*) even

if their child might benefit from mainstream education. This happens due to insufficient adaptations, shortages of classroom assistants, or because staff lack training to accommodate children with disabilities (Valeeva, 2015; Avdiukhina, 2017). Although efforts are being made to support family-based care, institutionalisation is still widespread – especially of children with learning disabilities and developmental disorders (OHCHR, 2018). In some cases, parents are even now encouraged by medical professionals to institutionalise their disabled children at birth.[3]

In practical terms, Russia's policy changes – and the accompanying inertia in enforcing them at a local level – have led to a shift in the advocacy concerns of many NGOs. Previously, many disability NGOs had dedicated a concerted effort to advocating for legislative change (Bindman, 2015). Now, however, many have redirected their efforts to ensuring that federal legislation is implemented at local level (Alehina *et al.*, 2014; Valeeva, 2015). For the most part, this involves working closely with state authorities to give expert opinions on practical steps that need to be taken and, often, to provide services that enable people with disabilities to claim the rights that are now enshrined in Russian law. In cases such as that of disability NGOs, when policy implementation – and not policy reform – is the aim, service provision, advocacy and rights-defence become closely intertwined.

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[3] Personal interview with representatives of an educational centre for children with Down Syndrome.

4. Methodology

4.1. Summary

The research was conducted as a qualitative case-study of registered disability NGOs in the Western city of Nizhny Novgorod, using semi-structured, in-depth individual and group interviews. It addresses the question of whether and how Socially-Orientated NGOs use their role as service providers (and not just as political advocates) to effect social change and influence their relations with state authorities. The following chapter details the research methods used, explains the rationale for the approach taken and addresses the limitations of the study, including how some of these were mitigated.

4.2. Research methods and rationale

The research consisted of a qualitative case study, using ten semi-structured interviews with local NGO leaders, conducted over a period of 3 weeks in June 2018 in Nizhny Novgorod.

As outlined more fully in chapter 3, disability NGOs currently sit at the intersection between service provision and political advocacy. Their largely grassroots nature requires them to fulfil multiple roles, both acting as state-sanctioned service providers and as the voice representing their vulnerable clients' needs. Their work is not overtly politically or ideologically motivated and yet they often take a rights-based approach to protect their clients. As such, they are taken as a "paradigmatic case study" (Flyvbjerg, 2006) that calls into question currently accepted wisdom on how SO NGOs interact with state authorities.

The need to combine different roles applies to NGOs supporting people with all forms of disability, but it is especially marked with NGOs representing those particularly marginalised groups whose needs are the most specific – that is, those with complex and multiple disabilities, learning disabilities, developmental disorders and mental health conditions (Human Rights Watch, 2015, p. 27; OHCHR, 2018). As such, although NGOs representing

clients with all forms of disability were included in the study, a particular effort was made to include these highly specific and marginalised groups.

Nizhny Novgorod was then chosen as the fieldwork site for two reasons.

Firstly, it has been at the forefront of implementing legislative changes. Policies of inclusive education, for instance, were piloted in Nizhny Novgorod (and the surrounding Nizhegorodskaya Region) as well as in five other Russian regions in 2008-09, four years before Russia ratified the UN CRPD (Valeeva, 2015, p. 2313). Choosing a region where these policies were adopted early provides richer opportunities to study the development of policy into practice and the role of NGOs therein.

Secondly, the University of Glasgow has a partnership with Lobachevsky University in Nizhny Novgorod, which facilitated both the process of obtaining a research visa and of making initial contact with organisations in the city. Given the limited time available for the study, access to gatekeepers vastly increased its feasibility.

An inductive, theory-building approach was taken to the research. This is both due to the exploratory nature of the subject and the understudied nature of the target group (Miles and Huberman, 1984). Grounded theory techniques were employed in the data analysis, to help minimise researcher bias (Creswell *et al.*, 2007; Merriam and Tisdell, 2016). These included coding continuously throughout the research, seeking new evidence and examining disconfirming evidence in order to minimise any influences introduced by my own normative preconceptions about NGOs, which are no doubt informed by my personal experiences of the disability support infrastructure in the UK context. Additionally, the inductive, grounded theory approach allowed greater room for participants to voice their own interpretations of their role and relationship to the state. It was this inductive approach that revealed the

relatively greater importance of service provision rather than political claim-making as a guarantor of disability rights.

Suitable organisations to interview were initially identified from a publicly available list of all registered Socially-Orientated NGOs in the Nizhny Novgorod region (*Nizhegorodskaya Oblast'*) and contacted cold by email. Staff at the sociology faculty at Lobachevsky University also assisted in acting as gatekeepers and making introductions to additional relevant NGOs. A snowballing method was further used throughout the research to identify further participants. Interviews were conducted until a) participant saturation (i.e., no new names were forthcoming when asking participants for extra suggestions) and b) data saturation (i.e., no new concepts emerged) were reached.

10 organisations participated. 9 of these were "public organisations" (*obshchestvennye organisatsii*) supporting people with disabilities, all of which were already registered SO NGOs and five of which were also either registered providers of social services or in the process of registering. The tenth organisation was a government affiliate with a direct mandate from the Ministry for Trade and Industry to act as an intermediary between NGOs and social enterprises, large businesses, and the state.

The study comprised 7 individual interviews and 3 group interviews. The group interviews (conducted as such at the participants' request) included up to three members of staff at the same organisation (separate organisations were not interviewed together). Individual interviews were conducted with staff at director or deputy director level; group interviews included staff at director level accompanied by rank-and-file employees and, in one instance, a consenting service user. The participating organisations comprised:

- A grassroots parents' organisation for children with deafblindness and other multiple and complex sensory disorders. (Hereafter Org. 1)

- A parent-led professionalised NGO primarily supporting autistic children and adults. (Org. 2)

- A professionalised NGO providing integrated vocational training and recreational activities for people with physical and learning disabilities, elderly people, and teenagers. (Org. 3)

- A parent-led educational centre for children with Down Syndrome. (Org. 4)

- A grassroots-turned-professionalised educational centre for children with visual impairments. (Org. 5)

- Two grassroots-turned-professionalised NGOs providing legal advice and vocational training to people with various mobility impairments. (Orgs. 6 & 7)

- A government affiliate aimed at widening participation in higher education among students with visual impairments. (Org. 8)

- A grassroots parent-led organisation supporting people with mental health conditions. (Org. 9)

- A government affiliate aimed at supporting NGOs and small social enterprises, and facilitating their interactions with state institutions. (Org. 10)

With the exception of Org. 10, all these organisations were primarily service-providers who also engaged in political advocacy on an ad-hoc basis, as needed.

Questions focused on the legal structure and official aims of the organisations; key challenges facing their beneficiaries and possible resolutions; official and unofficial interactions with state bodies; and the effect of recent legislative and welfare reforms, particularly focusing on the ongoing outsourcing of social services. The interview guide used is included in Appendices 1 and 2, in Russian and English respectively.

The interviews were conducted in Russian and transcribed in full by the author, and analysed for common themes relating to interactions with the state. These included both collaboration and conflict, and the effect of political claim-making on the delivery of social services – and vice versa. The data were coded continuously throughout the research to identify new themes and adapt the theory as necessary, and to compare segments of data for similarities and differences (Merriam and Tisdell, 2016, p. 32). Some indicative coding frequency tables are included in Appendix 3.

Participants were assured of their anonymity and the data were de-identified during the transcription process. This said, many of the organisations participating are unique in their offering and may be identifiable by their descriptions. For this reason, consent was sought to name organisations (but not individual participants).

To further minimise potential researcher bias introduced by my own preconceptions or by potential language-related misunderstandings, all participants were offered the chance to review interview transcripts and make changes or clarifications where necessary.

4.3. Limitations

The small scale of the case study and its location in just one city pose clear limitations. Many respondents noted that although policy and legislation are handed down on a federal level, their enforcement is the responsibility of regional authorities and that approaches vary greatly from region to region. In addition, it is worth noting that Nizhny Novgorod is one of Russia's largest cities and is located firmly within the bounds of European Russia. It is to be expected that the situation there differs, for instance, from that in rural areas with less well-developed infrastructure. Likewise, there is no reason to assume that the situation is uniform across Russia's various autonomous republics, or in Moscow and St Petersburg, which are likely subject to greater international influences (Crotty, Hall and Ljubownikow, 2014).

However, this does not mean that the study is of no wider value. The present research can be seen as a pilot study, providing a single example of a population to whom existing theoretical frameworks do not fully apply. The study is used to generate an alternative explanation as to how these organisations interact with the state which, once formulated, can later be tested in other regions (Yin, 2009, pp. 43–44).

A second potential limitation is that of self-reporting bias. Participants were interviewed as official representatives of their organisations and, therefore, may be influenced to portray their activities – including their interactions with the state – in an artificially positive light. This said, most participants did not show any reticence to sharply criticise certain state policies and actions on occasion, suggesting that when they speak positively of the state they do so in earnest. Furthermore, the promise of anonymity and the offer of an option to review interview transcripts were made with the aim of reassuring participants and encouraging them to speak honestly and openly.

Observational metadata was also used to triangulate interviewees' self-reporting. I was able to spend time with four of the interviewed organisations outside of the interview context, attending meetings with partners and observing sessions with clients. I also had informal, off-the-record conversations with all participants in addition to the recorded interviews. This helped provide observational context to the activities reported in interviews and to build a trusting rapport with participants.

4.4. Ethical considerations

In view of the delicate nature of discussing state-civil society relations in Russia and of the vulnerable client group, due consideration was given to the ethical implications of the study. Full approval was obtained from the College of Social Sciences ethics committee prior to starting research. Plain language statements and written consent forms were provided in

Russian to all participants in advance of the interviews. All participants were offered anonymity as well as the option to review transcripts for inaccuracies. Although express permission was sought from experts and professionals to name the organisations they represent, they were also offered the option to request anonymity for their organisations.

5. Findings

5.1. Summary

The following section details the findings of the study. It begins by outlining the various activities and services offered by participating organisations, demonstrating how their portfolio of work is driven by client needs while remaining politically and ideologically agnostic, and how any political activities are always grounded in practical concerns relating to service delivery. It also highlights that this service delivery can itself be seen as a means of effecting social change and guaranteeing rights. It then looks at how this practical approach is applied in the current environment of improved federal legislation with poor local enforcement and how this leads disability NGOs to partner closely with state authorities to fill gaps in services. Finally, it examines how this environment affects the way in which disability NGOs view their relationship with state institutions. It questions the notion that "the state" can be seen as a single, cohesive entity and therefore also challenges the suggestion that the state acts from "above" while NGOs sit "below" it. Instead, it finds that NGOs' relationships with the state vary from institution to institution, depending on the individuals working there and on the task at hand. As such, the research explores some of the understudied aspects of state-civil society relationships, giving particular attention to those in which the state is the client of NGOs or in which both are seen as equal partners. The prevailing focus in current literature on political contention can, at times, obscure the nuances of these dynamics. Looking at other areas of activity – such as welfare provision and knowledge-sharing – reveals the diversity of state-NGO relationships.

5.2. Disability NGOs' activities: Welfare meets rights

When asked about their main activities, organisations identified a combination of welfare provision and rights-based services as well as a number of activities that straddled the two.

Some of these activities involved working directly with disabled clients. These included psychological counselling, additional educational support, medical advice, recreational and social activities, pro bono legal advice, and – if needed – addressing rights abuses, in or out of court. Other activities, however, supported people with disabilities indirectly by working with local businesses, government institutions and the general public to improve conditions. These included: training for schools, universities and businesses to help them better understand disabled students' and employees' needs; "accessibility audits" in local businesses and government institutions; the provision of expert opinions on regional legislation; and "kindness lessons" (*uroki dobroty)* to change public attitudes towards disability.

Some of the activities described can clearly be classed as "welfare services" – the provision of psychological counselling, for instance. Others – such as litigation in cases of discrimination or other rights' abuses – are clear cases of rights' defence conducted in the political realm.

Most, however, are difficult to categorise so clearly. The provision of pro bono legal advice to help clients understand their rights, for instance, is both a service and a form of rights defence. Equally, the accessibility audits conducted in local government institutions and businesses are at once a service – provided to the receiving organisation, not directly to the disabled target group – and a means of protecting this target group's rights by increasing opportunities for them to participate in public life.

This close interrelationship between rights-based work and welfare provision was recognised by interviewees:

> "It's impossible to defend rights without the necessary technical infrastructure and you can't develop that technology in the absence of rights."

<div align="right">Org. 1</div>

"You don't necessarily have to run around with slogans, shouting 'Defend their rights!' […] for me, rights' defence is creating opportunities for people to exercise their rights."

<div align="right">Org. 3</div>

As such, participants highlighted the importance of situating any rights' defence or politically-focused work within the wider portfolio of services they provided. Politically-orientated activities, such as providing opinions on legislation or taking discrimination cases to court, are conducted in order to complement other welfare services and should be taken within this context. Indeed, many interviewees noted that these more political activities were only undertaken when "the need arises" (Org. 3) and that, at times, they could be onerous tasks that detracted from the organisation's capacity to deliver its day-to-day services (Orgs. 1 and 8).

Moreover, some interviewees were outspokenly sceptical of political approaches that are not backed up by the provision of tangible services:

"What we do is educational technology – actual services, the creation of new services, and improving the quality of existing services […] I want to do something concrete […] I've had enough of rights defence conferences."

<div align="right">Org. 1</div>

"Of course, you can go around shouting about how bad the government is and at the same time not actually do anything. We don't do that […] we need to create the right conditions, the right environment for each person to understand that he has rights and opportunities."

<div align="right">Org. 3</div>

In this regard, interviewees were keen to highlight the importance of allowing their activities – political or otherwise – to be dictated by the clients' needs alone. Several gave examples of the consultation processes with clients and their carers that were used to define not only individual support plans but also their organisations' general annual strategies.

This focus on needs coloured interviewees' approach to more contentious forms of activity, such as litigation. Although several organisations did assist their clients with litigation in the case of rights abuses or discrimination, this was widely seen as a last resort – not because of ideological concerns, but because it was generally viewed as an ineffective strategy:

> "I'm approaching this from the perspective of effectiveness for our client […] if they take it to court, there's a 99% chance that they will lose the case."
>
> Org. 6
>
> "If a place in kindergarten is obtained via the courts, I don't think that will benefit the child. He won't feel comfortable there."
>
> Org. 1

Interviewees emphasised that their decision as to how best to support clients was not driven by any ideological or political underpinnings but, rather, by pragmatism – about what will achieve the best outcome for them.

This is an important point that has sometimes been overlooked in the extant literature. Although it has been recognised that Russian NGOs "wear many different hats in their relationships to the state" and that SO NGOs in particular have "become critical partners" to the state (Henderson, 2011, p. 13), civil society scholars (as detailed in chapter 2) have chosen to focus their attention primarily on those aspects of NGO-state relations that involve political approaches to influencing state policy. Without disputing the findings of these

studies, the above examples suggest that the activities they examine form a minority of disability NGOs' work and are conducted for the most part on an ad-hoc basis. The findings also highlight that even when disability NGOs do engage in policy entrepreneurship and rights advocacy, this activity is usually not motivated by ideological claims but by a simple need to get the best practical outcome for their clients by the most effective means available. Participants were keen to point out that social change can often be best effected and rights best guaranteed by non-political means, with political approaches only being taken as a last resort. Findings by some scholars that, for instance, NGOs have little systematic influence on regional policymaking (Cook and Vinogradova, 2006; Ljubownikow and Crotty, 2016) assume that influence on policymaking is, or at least should be, a key aim in its own right. As the findings above demonstrate, this is not necessarily the case. Policy entrepreneurship is one tool among many that SO NGOs have at their disposal to guarantee their clients' rights. As will be discussed in the next section, the current climate facing disability NGOs favours the use of other tools instead.

5.3. Partnering up to enforce the rules

As detailed in chapter 3, the environment in which disability NGOs operate in Russia has undergone significant changes in recent years. Most notably, disability rights have been reinforced in federal legislation. At the same time, the state has redoubled its initiatives to outsource social welfare provisions to private and third-sector organisations in an attempt to better meet these new legislative requirements.

As such, participating organisations no longer felt a need to engage in protracted political advocacy and preferred instead to focus on ensuring the practical application of new legislation. This practical approach is one that necessitates positive, collaborative interactions with local state authorities.

This is not to say that they shied away from political advocacy on principle. On the contrary, many of them had taken part in coordinated, cross-regional campaigns advocating for these reforms. Most notably, over half the organisations interviewed had taken part in the successful national campaign to allow children with disabilities the right to education in mainstream schools.

Many, however, were keen to point out that this was not an integral part of their mission but rather an ad-hoc activity driven by specific, time-limited needs. The signing and ratification of the UN CRPD and the ensuing federal legislative reforms reduced the need for this kind of campaigning and "required us to change our approaches" (Org. 6).

Opinions varied on the motivations behind these federal legislative reforms. Some interviewees felt that "this is not just a fashion […] this is a genuine desire to accept everyone as they are" (Org. 3) and that the changes signify that "society is moving the right direction" (Org. 7). Others, meanwhile, were more sceptical, feeling that they were empty promises enacted just "for show" to prove that "we're as good as other countries, that we're civilised too because we signed the Convention" (Org. 1).

Yet irrespective of their views on the motivations for the policy reforms, all interviewees noted that disability rights were now well enshrined in law. At the same time, they highlighted a new need to focus on the discrepancy between these new legal rights and their actual enforcement. On the whole, they expressed two principal ways of achieving this.

The first involved educating people about their newfound rights, as interviewees often found their clients had low levels of legal literacy:

> "We have much greater rights than it might seem. But we don't know how to use them. In fact, now all the rights are on the side of the parents."

<div align="right">Org. 1</div>

"The main problem we face is that our clients don't know their own rights."

<div align="right">Org. 6</div>

"Now we're not fighting for our rights so much as we are learning what we are entitled to."

<div align="right">Org. 4</div>

To this end, some organisations conducted legal literacy courses for their clients, while others engaged lawyers on a pro-bono basis to advise their clients on their rights. Others still set up informal experience-sharing networks, where people with disabilities or their carers could educate one another on their rights and how to claim them.

The second way involved improving the services that allowed people to access these rights. This was done both by advising the state on how to improve the services it delivered (such as education, healthcare and housing) and by offering additional provisions to cover gaps in the state's offering. As discussed in section 5.2, many interviewees saw services such as these as integral to any rights-based approach to supporting people with disabilities.

Neither of these directions – rights education or welfare provisions – is overtly politically motivated and nor does either of them necessarily require any kind of contention to the state. Moreover, the latter – welfare provision – was deemed to be most effective when delivered in collaboration with the state. Whereas some civil society scholars (such as Kulmala, 2011; Ljubownikow and Crotty, 2016) have interpreted a lack of systematic contention as a sign of weak civil society, this does not necessarily seem to be the case. On the contrary, the NGOs interviewed have found that their clients' needs can best be met and their aims best achieved without contesting the state either consentfully or dissentfully. The lack of contention is a conscious choice based on perceptions of how to best serve clients' needs, not one imposed by weakness or subservience to the state.

Most of the participating organisations were recipients of government grants that supported their work, with five having received prestigious federal-level Presidential grants. Many felt that their work would be impossible without this state support and none felt that this support undermined their ability to speak critically of the government if and when necessary. Similarly, interviewees spoke positively of the register of Socially-Orientated NGOs. In addition to giving them access to the aforementioned grants and to certain other subsidies, they appreciated the increased visibility that inclusion on the register gave their organisation, not only vis-à-vis the state, but also vis-à-vis the general public:

> "It's a question of image – firstly, it allows us to receive certain grants because we can demonstrate that we are part of this register. Secondly, it helps attract funds and sponsorship from businesses".

<div align="right">Org. 6</div>

> "It's yet another way in which we can remind those up on high that we exist."

<div align="right">Org. 8</div>

> "It gives us a more serious status and gives others greater trust in us. And it means that our accounts are open and can be audited. So it's another way of demonstrating that we're open, we're not hiding anything and we're not going to steal anything".

<div align="right">Org. 9</div>

In an environment where the government generally receives higher levels of trust than NGOs, being seen as a partner to the state can be helpful in boosting credibility and facilitating the procurement of corporate and philanthropic donations (Henderson, 2011). Indeed, just 25% of Russian citizens surveyed in the 2018 Edelman Trust Barometer expressed trust in NGOs – fewer than in any other of the 28 states surveyed. By contrast, 44% expressed trust in the

government (*Edelman Trust Barometer Global Report*, 2018). Given this climate, the reputational benefits brought by endorsement from the state are significant.

Interviewees were even more enthusiastic about the more newly created register of providers of social services, which was introduced in 2013 as part of a new law requiring the state to outsource 10% of its welfare services to social enterprises and NGOs.[4] While some did note that their clients were used to the centralised Soviet welfare system and had ideological objections to the new system, the interviewees themselves did not seem to espouse these views. On the contrary, they welcomed the extra financial support and official recognition for services that they had already been providing:

> "When that law came out I was the happiest person because I realised that it would give us the opportunity to receive funds from the state budget for social services [...] it's a source of stability for us."

<div align="right">Org. 5</div>

They also expressed frustration with the bureaucratic nature of existing state-provided welfare services and felt that the change would allow them to take a more effective, individualised approach to welfare provision:

> "The state apparatus is very big and in the time it takes just to turn around, we've already done everything."

<div align="right">Org. 4</div>

> "The difference between us and the state sector is that we're less regulated […] We can look at what a person needs here and now, regardless of the rules and regulations. In that respect NGOs are more effective."

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[4] Details provided in personal interview with Org. 10

Although some bemoaned the excessive paperwork and opacity of the registration process, as well as uncertainty as to how quality of services would be measured, they hoped that these were short-term kinks that would be ironed out with time; none could name any inherent disadvantages of either register. Instead, the material benefits of a guaranteed source of funding, the improved prestige and increased access to government actors were praised as advantages of the two registers.

Collaboration with the state to deliver services also went beyond the simple allocation of funds. A number of interviewees highlighted the ways in which they forged operational partnerships with state institutions to ensure smoother delivery of services and avoid overlaps. The nature of these partnerships varied from organisation to organisation and included the following: information-sharing arrangements to allow NGOs to serve people currently on waiting lists for state services; the use of NGO staff to vet the living conditions in state-run *internaty*; and NGOs taking on employees of state institutions (primarily psychologists, teachers and "defectologists") for temporary apprenticeships in new methods.

Interviewees felt strongly about the advantages of their systematic cooperation with state institutions and felt that both NGOs and the state sector had their clients' best interests at heart. As one interviewee put it, "we do the same thing – they help people and we help people" (Org. 9).

Moreover, this sentiment seemed to be echoed by the state itself. Both the SO NGOs and the government affiliate (Org. 10) who participated in the research agreed that NGOs and the state complemented one another, each bringing different skills to the table:

"When a certain service is offered by the state and it's of good quality, we don't want to compete […] we would never offer a service that already exists […] the authorities understand that we can do things that they can't."

<div align="right">Org. 5</div>

"Honestly, the state can offer the services [that are being outsourced] but I highly doubt that social entrepreneurs and NGOs are going to do a worse job. I think they will be better at it."

<div align="right">Org. 10</div>

Not only do disability NGOs feel able to interact with the state authorities, but reports from the NGOs interviewed as well as from the government affiliate indicate that the authorities also often initiate this interaction and are grateful to learn from NGOs' specialist experience. This differs from standard models of state-society relations. While recent studies do challenge the previously ubiquitous assumption that effective civil society must be fully separate from the state, they tend to do so by examining the way in which NGOs can contest or exert influence over the state even when closely intertwined with it (for example, Fröhlich, 2012; Bindman, 2015). The fact, however, that state institutions seem to be grateful recipients of NGO expertise and services highlights that contention is far from the only useful framework through which to view state-civil society relations in Russia.

In summary, since the conversation has moved on from policy reform to policy implementation through the delivery of services, disability NGOs have come to highly value their relationships with state institutions – and vice versa. In the interests of serving clients, NGOs seek to complement existing state welfare provisions with additional, individualised services which are more bespoke than those that the state can deliver and the state seems happy to facilitate this. Although there are inevitably moments of disagreement, these

increasingly fall as part of a healthy working relationship between disability NGOs and state institutions.

5.4. The many faces of the state

This section synthesises the remarks made in sections 5.2 and 5.3. It looks at how the combination of practical rather than ideological motivations, the heightened focus on delivering services in partnership with the state and the decreasing need to conduct policy entrepreneurship have all influenced the ways in which disability NGOs conceptualise their relationships with the state. Scholars have traditionally explained state-NGO relations in terms of binaries whereby the state is seen as an authority figure imposing policy from above, which NGOs can either accept or contest. Ljubownikow and Crotty (2016), for instance, highlight what they see as the importance of political advocacy in managed democracies and criticise Russian education non-profits for their failure to systematically contest state policy. Meanwhile, Cook and Vinogradova systematically dismiss government affiliate NGOs as "artificial constructs, not initiated from below" and therefore "not part of civil society" (2006, p. 35). While Bindman (2015) recognises the close cooperation SO NGOs have with the state and rejects suggestions that this cooperation transforms SO NGOs into "marionettes", she still frames their input in terms of "influence" exerted from below and often without the state's active participation, although sometimes with its tacit consent.

Yet this above/below dynamic is only one of several that can and do co-exist. As the study shows, at least on a local level, state-SO NGO relations can also exist as equal partnerships in which each party brings different expertise to the table, or even as client-patron relationships where the state is the client of NGOs.

While participants were not afraid to criticise certain state policies or actions, they were hesitant to pass overall judgement on whether their relationships were positive or negative.

Instead, they focused on individual achievements or setbacks, based on the practical outcomes for their clients. Many were able to criticise failings in the state system while also giving multiple examples of fruitful collaboration with state authorities.

When criticisms were voiced, they most often related to failings on the part of individual employees or departments in the state system and not to the state's overall position towards people with disabilities. Such criticisms included inefficiency, a lack of responsiveness to requests, bureaucratic barriers to achieving legal status and funding, and an unwillingness to provide specific (usually financial) resources to support policy aims. Many interviewees felt that ministers and civil servants saw them as a burden and this was particularly marked among those working with more complex or rarer forms of disability. These organisations often felt aggrieved that their target group was not seen as a priority by certain state institutions:

> "People in the state are not interested in such a small demographic, because the state needs a whole stream of people to meet their quantitative measures."

Org. 5

> "We try to work with the Ministry for Education, but to be frank, at the moment, children like ours don't fit into the education system, even if they are legally no longer considered uneducable."

Org. 1

At the same time, they were keen to point out that the state can be a "key partner" with whom they "interact very closely" (Org. 5).

That organisations can simultaneously criticise the state and highly value its partnership highlights the important point that "the state" cannot be seen as a single entity. Many

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participants found it difficult to describe their relationships with "the state" as a whole, instead describing their differing relationships with different departments and highlighting that "their staff are just people, too" (Org. 3). Almost all participants felt that the "human factor" (Org. 8) was key in determining their relationship with the state. Whether a relationship was deemed fruitful or strained was more a factor of individuals' characteristics than of the ideological or policy stance of the departments in question:

> "The head of the city's administration took up our cause, she likes it. You see, with the government here, an awful lot depends on personal contacts."
>
> Org. 4

> "We have a constructive partnership with the local Department for Education […] It was a bit more complicated with the regional Ministry for Education until the Minister changed. When we got a new Minister, things became a little easier."
>
> Org. 2

> "It all depends on the person […] over here personal contacts are often important."
>
> Org. 6

> "On the whole, we have a positive relationship with the department [responsible for children]. But a different ministry is responsible for adults. The people there are different and its' run by a different Minister […] that relationship is more difficult."
>
> Org. 5

It was evident that interviewees judged the state institutions with which they cooperated on the strength of these institutions' individual employees, not on the strength of the ideologies they espoused or the federal policies they enacted.

Organisations' pragmatic approach combined with their understanding of state institutions as a collection of individuals, not as a single entity, leads them to develop a wide variety of relationships across different state institutions, dictated by need and circumstance.

With the provision of direct welfare services NGOs felt that they were "equal partners" (Org. 5) with state institutions. As described more fully in section 5.3, several interviewees were keen to highlight that state institutions and SO NGOs are working towards a common goal and that they each bring different skillsets to the table. This is particularly clearly evidenced by the suggestion that NGOs have key strengths that the state lacks; most notably, that NGOs are not bound by the same strict quantitative targets as state institutions and that their staff members have specific expertise lacking in state institutions.

This is even more evident where NGO leaders are called upon by state institutions to give expert opinions on new legislation, to provide accessibility audits, or to give training on the needs of their client groups. In these instances, as Eleanor Bindman has noted, the state may need NGOs more than the other way around (2015). Indeed, some participating NGOs found the process of, for instance, giving expert opinions on legislation burdensome and were not always able to accept the state's requests for them to do so.

These significant variations in how SO NGOs characterise their relationships with state institutions demonstrate that it is impossible to categorise the state as a single, homogenous entity – a point which was borne out even more clearly in instances where participating NGOs challenged the actions of one branch of state authority with the assistance of another. This was the case, for example, when one organisation challenged a case of discrimination and bullying by the local employment centre against a client with learning disabilities with the assistance of the responsible Ministry. Similarly, the quality controls of state-run

residential facilities conducted by other organisations were done so via the regional Civic Chamber under the auspices of the region's Governor.

These examples, although relatively infrequent, bring into sharper relief the fact that the state cannot be conceived of as a monolithic entity. Consequently, the reduction of SO NGOs' relationship with state institutions to binaries is problematic. Traditionally, scholars seeking to understand this relationship have conceptualised the state as taking action "from above" and NGOs influencing, accepting, or challenging those decisions "from below" (for instance Bindman, 2015; Kulmala and Tarasenko, 2016, p. 139).

Of course, it would be erroneous to deny that in most cases the state, as lawmaker and law-enforcer, has ultimate authority over NGOs. This is particularly obvious in the realm of federal policymaking and in the bureaucratic processes through which NGOs are formally registered, hence why the "above/below" binary fits so well with discussions of SO NGOs' political claim-making. It would be equally mistaken to deny that in certain areas – particularly those which are more overtly politicised – the state exercises not just authority but also control over NGO activities. However, this study shows that when it comes to practical matters handled by autonomous local and regional state departments regarding depoliticised issues, the dynamic is much more complex.

5.5. Conclusion

The findings discussed above do not negate those of previous studies: that SO NGOs can and do engage in political claim-making (Fröhlich, 2012; Bindman, 2015; Tarasenko, 2015); that the ways in which they conduct this advocacy are influenced by their organisational structure and by the societal position of their beneficiaries (Kulmala, 2011; Fröhlich, 2012; Tarasenko, 2015; Kulmala and Tarasenko, 2016); and that, in particular, registered SO NGOs primarily make their political claims using modes of consentful contention (Fröhlich, 2012; Bogdanova

and Bindman, 2016). However, the findings do highlight that this claim-making activity is only one of many ways in which SO NGOs interact with state institutions. Looking exclusively at political claim-making leads us to see state-NGO relations from an exclusively binary perspective with the state acting "from above" and NGOs responding "from below." In an era of ever closer intertwinement between state and civil society, embodied by the continued outsourcing of social services, it is important to also give due attention to the other ways in which the state and SO NGOs interact – particularly the provision by NGOs of services on behalf of the state, but also their provision of expert advice to state policymakers. Indeed, the NGO experts interviewed saw these other activities as more important and effective than their political claim-making, and to ignore them would be to misrepresent their position. Looking at these activities highlights the ways in which NGOs can collaborate with the state to provide services and improve conditions for people with disabilities in a non-contentious environment and challenges the assumption that social change should be effected through policy entrepreneurship alone.

6. Conclusions and areas for further research

The question of how civil society actors manage to contest an undemocratic and repressive state is an important one, and one that has been well addressed by extant literature. However, it has led to a skewed perception of the *modi operandi* of Russia's Socially-Orientated NGOs, many of whom do not count political activity as an important part of their remit. This dissertation has shown that in order to have a complete and well-rounded understanding of state-civil society relations in Russia, we must look not only at political activities such as claim-making, but also at the various apolitical ways in which civil society organisations interact with state authorities.

The case of registered disability SO NGOs in Nizhny Novgorod shows that collaborations with local state institutions to provide services and improve living conditions are a key part of their relationship with the state. These organisations are motivated by the desire to achieve the best practical outcomes for their clients and not by political or ideological concerns. In the current climate, where disability rights are well protected by Russian federal law but patchily enforced due in large part to limited resources, disability NGOs find that the best way of guaranteeing these rights in practice is through the direct provision of welfare services. In this respect, the state can often be a useful partner with whom disability NGOs have a mutually dependent relationship.

More broadly, the study challenges the prevailing view of the Russian state as a repressive entity that tries to stifle change and silence dissent. On the contrary, it reveals a state with clearly expressed, progressive policy aims and a seemingly proactive desire to engage experts outside of the state sector. This is not to deny that the state acts repressively with regard to civil and political rights. However, it is to suggest that academics are often too quick to criticise the Russian state as a whole. In fact, SO NGOs in Russia's regions struggle to conceptualise the state as a single entity and have very little to do with federal-level

authorities. The lived reality of their relationships with "the state" is a complex network of partnerships with individual departments. What matters to them are the individual approaches taken by each local authority with which they work and not the overarching ideologies espoused by the Kremlin.

In questioning the assumption that the Russian state unilaterally and uniformly acts against the interests of civil society, the dissertation has also questioned the need to examine NGOs' advocacy and contention strategies. In doing so, it contributes to the nascent body of literature suggesting that collaboration in the absence of contention does not necessarily signify puppetry or co-option. It further demonstrates that this collaboration, in certain circumstances, can become a means of improving citizens' lives in its own right.

That said, I do not suggest that the Russian social welfare sector is without faults. On the contrary, the study shows that it is marred by the state's inefficiencies, its slowness to respond to requests, its unwieldy bureaucracy, its failure to provide adequate funding to support policy aims and its limited understanding of certain more complex needs. However, this is not specific to the Russian context. Comparisons could be made, for instance, with the UK's welfare sector, which has also experimented (many would argue unsuccessfully) with neoliberalism and outsourcing of welfare provision and which has also been damaged by budget cuts and inefficiencies. The difficulties that disability NGOs face when dealing with the state seem to have less to do with Russia's lack of real democracy and more to do with its struggling economy – a problem familiar to many more democratic states.

While the approach, as described in chapter 2, of treating Russian civil society as fundamentally different from Western civil society was certainly needed with regard to democratisation and political activity, it has perhaps been used too widely. It has led to a disproportionate focus on NGOs' political activity, fuelled by the underlying assumption that

their experiences of operating in a managed democracy require them to use their closeness with state institutions to express opposition. However, this dissertation has shown that there are instances in which NGOs do not contest the state, not because they cannot but rather because they do not see a need to.

If we are to accept that similarities between Russian SO NGOs and analogous organisations in more democratic states are greater than the literature would suggest, then a fruitful area for further research could be a comparative study. Such a study would further examine whether Russian civil society is *sui generis* or whether, in certain circumstances, it can be seen through the same prism as Western civil society.

Of course, as addressed in chapter 4, any conclusions drawn by the study must be viewed with due consideration of its small scale. In order to fully understand the nature of state-civil society collaborations within the social sector, a larger study is needed including other regions – particularly in rural areas and in the Asian parts of Russia, which are chronically understudied largely because of access difficulties. Nonetheless, this dissertation has at least begun to explore the idea that by looking away from political contention and examining the apolitical ways in which Russian SO NGOs interact with the state, certain fundamental assumptions about the nature of this interaction are called into question.

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Appendix 1: Interview guide (Russian)

Информация об организации

Название организации:

Главная цель/миссия:

Службы обеспечены:

Главные клиенты/бенефициарии:

Сколько сотрудников, волонтеров, членов и клиентов:

Юридический статус:

Взаимодействия с государством

Какие взаимодействия имеете ли Вы с органами власти или с государственными учреждениями?

Как Вы бы описали Ваше отношение с государством? Каким образом Вы общаетесь с ним?

Вам кажется просто или сложно общаться с государственными органами?

Когда Вы сообщите государственным сотрудникам о проблеме или о просьбе, слушают ли они?

Имеет ли Ваша организация статус «Социально-ориентированная НКО» и/или «Поставщик социальных услуг»?

Почему (нет)?

Какими являются преимущества или недостатки регистрации как СО НКО или как поставщик социальных услуг?

Представители Вашей организации участвуют ли в общественных палатах? Или в других консультативных советах?

Получаете ли Вы финансы или другую форму поддержку от государства?

Ситуация клиентов

Как Вы описали бы социальную ситуацию Ваших клиентов? *[по сравнению с другими уязвимыми группами]*

Чем являются главные социальные проблемы/сложности для Ваших клиентов?

Изменилась ли ситуация в последнее время? Вы заметили прогресс или ухудшение?

Занимается ли Ваша организация пропагандой насчет этих проблем? *[Если да]* Чем Вы занимаетесь? Примеры есть? *[Если нет]* Почему нет?

Appendix 2: Interview guide (English)

Organisational Information

Organisation name:

Main duties/purpose of organisation:

Services offered by organisation:

Main client/beneficiary group:

Size of organisation (staff numbers, volunteer numbers, client base, membership base):

Legal status:

Interactions with state

What kind of interactions do you have with state institutions/authorities?

How would you describe your organisation's relationship with the state?

Do you feel the state authorities are easy or difficult to speak to?

Do the state authorities listen to your concerns?

Are you registered as an SO NGO and/or provider of social services? Why/why not?

What do you see as the advantages/disadvantages of being registered?

Participation in civic chambers or other advisory boards?

Financial or other assistance from state?

Client group situation

How would you describe the social position of your client group? *[As compared to other groups?]*

Main challenges facing client group

Any recent changes in this situation? For better, for worse, or unsure.

Does your organisation take part in activities to address these?

[If yes] What does your organisation do to achieve this? Can you provide examples?

[If no] Why not?

Appendix 3: Interview coding frequencies

The following are indicative coding frequencies for key themes arising in interviews. They are given per organisation to give a clearer indication of the spread.

Type of activity conducted

	Education, expertise and advisory	Rights-based work	Welfare/service provision
Org. 1	7	6	5
Org. 2	7	3	5
Org. 3	6	1	5
Org. 4	9	3	3
Org. 5	4	3	4
Org. 6	3	8	4
Org. 7	7	2	2
Org. 8	9	7	5
Org. 9	1	1	3
Org. 10	*N/A*	*N/A*	*N/A*
Totals	**53**	**34**	**36**

Motivations mentioned for doing work

	Ideology	Needs/pragmatism
Org. 1		6
Org. 2		2
Org. 3		6
Org. 4		
Org. 5	1	2
Org. 6		2
Org. 7		
Org. 8		5
Org. 9		2
Org. 10	*N/A*	*N/A*
Totals	**1**	**25**

Assessment of current situation for people with disabilities

	Deterioration in the last 5 years	Improvement/ progress in the last 5 years	Lack of resources	Good legislation	Good practice	Poor legislation	Poor practice
Org. 1		1	3	4		1	6
Org. 2		6	3	2	2		1
Org. 3		5	1		1	1	1
Org. 4		7	2	2	1		
Org. 5		4		2			
Org. 6	1	3	2	2			2
Org. 7		3	1	1			
Org. 8		1	1	2			
Org. 9		2	1			1	
Org. 10	*N/A*	*N/A*	*N/A*	*N/A*	*N/A*	*N/A*	*N/A*
Totals	**1**	**32**	**14**	**15**	**4**	**3**	**10**

Views on state authorities

	Ineffective/inefficient /bureaucratic	Malicious/ repressive	Misguided/ ill-informed	Positive	Variable depending on institution/individual
Org. 1	5	2	2	1	2
Org. 2	2				2
Org. 3	5	1	2	4	2
Org. 4	2		3	8	2
Org. 5	7		1	5	4
Org. 6	1	1			2
Org. 7	3			2	1
Org. 8			1	1	3
Org. 9	2			1	1
Org. 10	2				
Totals	**29**	**4**	**9**	**22**	**19**

Description of relationship between NGOs and state authorities/institutions

	NGO as provider/ contractor, state as client	Complementing one another's services	Contentious	State as funder or supporter	NGO as intermediary between state and public	Lack of understanding between state and NGO	Active partnership	State boosting NGO's reputation
Org. 1	2	1		2			2	2
Org. 2	1		1	2			4	2
Org. 3	4	7		2		1	3	2
Org. 4	3	2		5		3	6	2
Org. 5		4	1	8	3	3	5	3
Org. 6	2	1	2	1	1	1	1	5
Org. 7				1			2	2
Org. 8	7		1	3		2	3	1
Org. 9		1		2			3	1
Org. 10	8	9		10	5		2	4
Totals	**27**	**25**	**5**	**36**	**9**	**10**	**31**	**24**

Appendix 4: Disability-positive terminology in English and Russian

While there is no universally – or even nationally – accepted terminology to describe various forms of disability, norms have emerged in both the UK and Russia. When using English language terms, I attempt to follow the UK Government's guidelines on inclusive language. For Russian terms, I use guidelines provided by Moscow-based disability NGO Perspektiva. The exceptions to this are a) in direct citations and b) when referring to historical usages. Examples of preferred terminology in both English and Russian are included below.

Avoid	Use
(The) handicapped, (the) disabled	Disabled (people)
Afflicted by, suffers from, victim of	Has [name of condition or impairment]
Confined to a wheelchair, wheelchair-bound	Wheelchair user
Mentally handicapped, mentally defective, retarded, subnormal	With a learning disability (singular) with learning disabilities (plural)
Cripple, invalid	Disabled person
Spastic	Person with cerebral palsy
Able-bodied	Non-disabled
Mental patient, insane, mad	Person with a mental health condition
Deaf and dumb; deaf mute	Deaf, user of British Sign Language (BSL), person with a hearing impairment
The blind	People with visual impairments; blind people; blind and partially sighted people
An epileptic, diabetic, depressive, and so on	Person with epilepsy, diabetes, depression or someone who has epilepsy, diabetes, depression
Dwarf; midget	Someone with restricted growth or short stature
Fits, spells, attacks	Seizures

Source: https://www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability [accessed 17 August 2018]

ИСПОЛЬЗУЙТЕ слова и понятия, НЕ создающие стереотипы:	ИЗБЕГАЙТЕ слов и понятий, создающих стереотипы:
Человек с инвалидностью (используемый в законах и нормативах официальный термин «инвалид» – допустим, но не рекомендуется к употреблению в речи и в текстах)	Человек с ограниченными возможностями, человек с ограниченными способностями; больной; искалеченный, покалеченный, калека; неполноценный; человек с дефектом/недостатком здоровья
при сравнении людей с инвалидностью и без инвалидности:	
человек без инвалидности	нормальный / здоровый
Человек, использующий инвалидную коляску; человек, передвигающийся на коляске; человек на коляске; человек на кресле-коляске	Прикованный к инвалидной коляске, паралитик, парализованный, «колясочник», человек на кресле-каталке
Человек с инвалидностью с детства / с врожденной инвалидностью; инвалидность с детства, врожденная инвалидность	Врожденный дефект / увечье / несчастье
Имеет ДЦП (детский церебральный паралич), человек (ребенок, дети) с ДЦП	Страдает ДЦП, болеет ДЦП, «дэцэпэшник»
Человек, перенесший полиомиелит; человек, который перенес болезнь; имеет инвалидность в результате…	Страдает от полиомиелита / от последствий полиомиелита; жертва болезни; кривоногий; стал инвалидом в результате...
Человек с особенностями развития / с особенностями в развитии, человек с ментальной инвалидностью / с особенностями ментального развития / с особенностями интеллектуального развития, человек с нарушением развития	Умственно отсталый, слабоумный, умственно неполноценный, «тормоз», имбецил, дебил, отсталый, человек с задержкой / отставанием в развитии/ , с интеллектуальной недостаточностью, с умственной отсталостью
Дети с инвалидностью	Дети-инвалиды
Дети с особыми образовательными потребностями	Школьники-инвалиды; официальный термин «дети с ограниченными возможностями здоровья (ОВЗ)»
Человек с синдромом Дауна, ребенок (дети) с синдромом Дауна	«Даун», «монголоид», «даунята» (о детях с синдромом Дауна), человек с болезнью Дауна

Человек с аутизмом, ребенок (дети) с аутизмом (официальный термин – «человек с расстройством аутистического спектра (РАС)»)	Больной аутизмом; аутист
Человек с эпилепсией	Эпилептик, припадочный, страдающий эпилептическими припадками
Человек с особенностями психического развития, человек с особенностями душевного или эмоционального развития	Псих, сумасшедший, люди с психиатрическими проблемами, душевнобольные люди, люди с душевным или эмоциональным расстройством
Незрячий, слабовидящий человек, с инвалидностью по зрению, человек с нарушением зрения	Слепой (как крот), совершенно слепой
Собака-проводник	Собака-поводырь
Неслышащий, слабослышащий человек, с инвалидностью по слуху, пользующийся жестовым языком, человек с нарушением слуха	Глухонемой (ни в коем случае!), глухой (как пень), человек (ребенок) с остатками слуха, использующий язык жестов
Говорящий на жестовом языке	Немой
Жестовый язык (такой же язык, как русский, английский или любой другой)	Язык жестов (это «самодельный» способ общения для иностранца, не владеющего местным языком, когда нет переводчика)
Переводчик жестового языка	Официальный термин «сурдопереводчик»

Source: https://perspektiva-inva.ru/language-etiquette [accessed 17 August 2018]