Social citizenship, disability and welfare provision in contemporary Russia: views from below

by

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Abstract

This thesis uses an area studies approach to examine the complex relationship between citizenship, disability and welfare provision. It does so through a bottom-up analysis of how the state welfare system affects the everyday lives of physically disabled adults in contemporary Russia. Drawing on thirteen months of qualitative fieldwork in the city of Kazan, I study how tensions between guaranteeing rights and providing care are balanced in social provision. My focus on physical disability offers a sharp insight into the socially constructed tropes of control and exclusion that can mediate experiences of citizenship and also seeks to rectify the lack of research on disabled people in non-Western contexts, especially the postsocialist region.

My research is underpinned by a theoretical and methodological framework that sees 'social citizenship' as an explicitly relational, emotional and embodied phenomenon and therefore values lived experiences of welfare provision. Each of my four empirical chapters considers a particular dimension of citizenship: needs interpretation, livelihoods, mobility and personal agency. Together they highlight that welfare provision is not always empowering and can create powerful inequalities. At the same time, I show that citizenship is often reworked from below through actions and discourses that challenge official ideas about the capacities and needs of disabled people.

Für meine Oma

Acknowledgements

My doctoral project has taken many twists and turns over its five-year evolution. Although only my name appears on the title page, this thesis was only possible with the assistance and encouragement of a host of colleagues, friends and organisations.

First of all, my utmost gratitude goes to my research participants who warmly and openly shared details of their lives with me. My thesis would have been very different without their willingness to devote time and energy to my research. Although I settled on the topic of disability somewhat unexpectedly, I have no regrets and am extremely pleased to have studied a group in Russian society that is sadly hidden and ignored in official circles.

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Table of contents

Terms and abbreviations

Except for Russian words that have become part of standard English, my thesis uses the British Museum system of transliterating Russian words into the Latin alphabet. Interviews and documents have been translated by myself unless a reference is given to an official English-language version. I have endeavoured to follow the guidelines of the British Sociological Association on using non-discriminatory language in research about disability.

Desnitsa	Disability organisation in the Volga city of Samara that promotes rights-based approaches and independent living
IPR	Individual Programme of Rehabilitation
MSEK	Commission of medical-social expertise
VOI	All-Russian Society of Disabled People
VTEK	Commission of medical-labour expertise

List of illustrations and diagrams

Illustrations

Tables

Boxes

Introduction

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Disability officially did not exist in the Soviet Union and indeed it was only after living in Russia for six months prior to my fieldwork that I first saw a wheelchair user in the country. The middle-aged man was propelling himself along the busy dual carriageway in the Moscow suburb where I lived. Where he was going and how exactly he had reached the road intrigued me at the time, but I did not approach him to find out more and eventually saw him hail an unlicensed taxi and travel away. At that time, my planned research was about everyday responses to welfare reform in Russia. A mixture of choice and circumstance prompted me to focus on disabled people, looking at how state policies ostensibly designed to support and 'care' for this group actually influence their rights and position in society. Knowing a lot more about the lives of disabled people in Russia, the man I saw back in 2006 continues to interest me.

My thesis asks how state welfare provision shapes the 'social citizenship' of physically disabled people in contemporary Russia. This concept refers to the well-being and societal participation of various citizens and groups, especially those defined as 'vulnerable.' These are important questions because many disability and human rights organisations in the postsocialist region criticise social policies for promoting the exclusion of disabled people from society and thereby undermining their rights (Sammon 2001: 10; Human Rights Ombudsman 2001; Johnson 2007). To date there has been no comprehensive study of how physically disabled people in Russia use and evaluate state services that allegedly promote their well-being. It is therefore unknown how ever-present tensions between guaranteeing rights and providing 'care' (Tronto

1993) are balanced in the Russian welfare system, especially in light of the Soviet past when disabled people were subjected to intensive control and exclusion by welfare state organisations (White 1999). I seek to answer these questions by looking at disabled people's personal experiences of social provision, thus giving a micro-level account of the frontline services provided by local and national authorities.

Through my study I aim to make several contributions to scholarly understanding of citizenship. The focus on Russia brings a non-Western perspective to a literature that is dominated by Anglo-American work and indeed my conclusions consider the transnational dimensions of a locally grounded study in the belief that 'by valuing and prioritising perspectives from the region through trans-national exchange we gain viewpoints from "outside" that may give us a different vision of issues within our own societies and inform our own self-understanding' (Flynn and Oldfield 2008: 10). The theme of disability is also novel because little research, especially on the postsocialist region, looks at provision and rights for people with various impairments even though physiological difference has historically been used as a justification for the unequal citizenship and exclusion of disabled people in many societies (cf. Carey 2009; Phillips 2011). Finally, the thesis joins a number of authors in studying citizenship and rights as socially embedded practices that are continually constructed and reconstructed in daily life (e.g. Engel and Munger 2003). Such work stands out from the legalistic and normative approaches often taken to questions of rights and seeks to address 'the imbalance between theoretical and empirical advances in our understanding of citizenship' that is heavily weighted in favour of the former (Lister 2007: 58).

My combination of participant observation, interviews and archival materials provides a bottom-up or ‘user’ perspective on disability provision and social citizenship in Russia in line with ideas that policy ‘must be grounded in knowledge of the context in which the disabled live their lives’ (Dunn 2000: 168). As elaborated in Chapter Two, the research draws on thirteen months of qualitative fieldwork conducted in the period from June 2007 to December 2008. I was mostly based in the central Russian city of Kazan, but made short visits to four other cities in the Volga and Ural regions. These locations offered a valuable regional perspective on disability provision in Russia and my main fieldwork base of Kazan was particularly interesting in light of official discourses concerning the city’s supposedly generous and innovative social provision.

This introduction first positions my work within a growing literature about citizenship and rights in the postsocialist region. I then explain why my empirical focus on physical disability is an excellent lens for studying formations of social citizenship since it draws attention to power inequalities, social difference and contested definitions of need. Finally, I outline the structure of my thesis, summarising the main themes running throughout the text and the questions that I seek to answer.

Citizenship and welfare provision in the postsocialist region

My thesis is part of an emerging literature on ‘citizenship in practice’ or ‘citizenship from below.’ Amidst highly conceptual and normative debates about ideal types of citizenship, there is growing academic interest in how rights are instantiated and interpreted in daily life (e.g. Dwyer 2004; Desforges et al 2005; Lister 2007). Such work seeks to address the neglect of ‘ordinary’ people in studies of citizenship by exploring the mismatch between formally ascribed rights and diverse lived experiences (Reeves 2009: 1). My main interest is therefore in ‘lived citizenship: how people understand and negotiate rights and responsibilities, belonging and participation’ as well as the symbolic meanings associated with these practices (Lister 2007: 55).

This emphasis on understanding local experiences, meanings and practices is a key feature of area studies, the discipline in which this thesis is written. Studying citizenship is especially interesting in the postsocialist region, where major political, economic, social and national transformations have dramatically altered the role of rights and the state in people’s lives. Both area studies and postcolonial thinking suggest that local studies can contribute to wider debates on citizenship by challenging ethnocentric or ‘Western’ approaches and messages (Sakwa 1999; Isin 2002). It is therefore unfortunate that ‘while mentioning the significance of eastern Europe in passing, many authors largely ignore experiences there as a serious challenge or supplement to existing thinking’ on citizenship (Smith 1999: 167). Indeed, the academic literature on citizenship can be enhanced and sometimes corrected by considering ‘the distinctive features presented by citizenship and social rights regimes, such as they are, in the ‘transitional’ post-Communist East European societies’ (Roche 2002: 77).

Research on citizenship in the postsocialist region has tended to focus on civil society, gender, migration and nationality (e.g. Lukic et al 2006; Salmenniemi 2008; Reeves 2009). All these topics are linked by an interest in how the state influences everyday life by categorising people, defining their needs and deciding if and how they will be met. Yet, ethnographic work has been crucially important in highlighting how such top-down interpretations of well-being are contested and reworked in daily practice. My thesis takes such a bottom-up approach to overcome the fact that very few studies of postsocialist citizenship consider the arena of welfare provision and what is termed 'social citizenship' even though it is 'useful to incorporate this dimension of citizenship when looking at Eastern Europe before 1989 and at the "balance sheet" since' (Hann 2006: 30).

It is very pertinent to ask how social rights in Russia have changed in the last two decades since a combination of state retrenchment and economic crisis in the 1990s undermined the comprehensive facilities and services offered to the population during the Soviet period (Standing 1997; Field and Twigg 2000). Not only were safety nets torn, but the amount and nature of care provided by state organisations radically changed in line with shifting government ideologies and resources. In the Polish context, Peggy Watson (2006) has described the 'unequalising citizenship' arising from market-oriented healthcare reforms that accentuate disparities within the population. Similarly, the Russian population no longer relies on state actors to fully guarantee living standards and provision in the fields of culture, health and social welfare. The era when the state assumed an exclusive and paternal role in defining and meeting social needs has thus ended even if popular expectations of such involvement persist long after the demise of the one-party system (Henry 2009).

As discussed in Chapter Three, it was against this backdrop of political and socioeconomic disarray that the first buds of genuine social citizenship for disabled people in Russia emerged. Disability was one of several social issues whose existence had been officially denied during the Soviet period and it was only after 1991 that services such as special day schools and community rehabilitation centres started to develop (cf. Thomson 2000). These and other transformations of care and welfare provision in the postsocialist region are the subject of a small body of qualitative research (e.g. Yaroshenko 2001; Haney 2002; Caldwell 2004; Round and Kosterina 2005; Read and Thelen 2007). Such work finds that ‘a range of state bodies, actors and institutions, far from being in retreat, continue to shape social life in the region’ (Read and Thelen 2007: 9). It thus challenges dominant messages in research from the 1990s that postsocialist states abandoned or lost their welfare functions and that populations were therefore focussed on ‘survival,’ coping and struggling against marginalisation (Bridger and Pine 1998; Field and Twigg 2000; Round 2006). Such assumptions of ‘state withdrawal’ from the social sphere are refuted in work tracing the establishment of new state services in the postsocialist region, including those for victims of domestic violence, homeless people, rural inhabitants and men (Iarskaia-Smirnova et al 2004; Hojdestrand 2009; Kay 2006; Kay 2011a; Kay 2011b; Johnson 2009). For some groups, the postsocialist state therefore matters very much and strongly affects experiences of citizenship.

Disability as a lens for understanding social citizenship

The experiences of disabled people are particularly revealing of social citizenship since they are often significant users of welfare services and have historically been victimised and oppressed by them. Indeed, ‘disability is an essential element in understanding state and market agendas as well as political struggles around citizenship’ (Meekosha and Dowse 1997: 51). Citizenship is a major theme in disability studies, which emphasise the need to look at processes of control and objectification underlying state policies (Rioux 2002). Disability movements (as well as those of other minority groups) have enjoyed success in many countries precisely because their claims for equal treatment and social inclusion were eventually recognised as citizenship rights. However, these rights must be woven into everyday life and practice in order to be effective. Bottom-up research strategies of the kind taken in my thesis are valuable in revealing ‘how the declaration of new civil rights for historically marginalised groups actually affects their lives’ (Enger and Munger 2003: 4).

Although disability studies are overwhelmingly dominated by scholars working on Western Europe and North America, interest is growing in experiences of disability in other areas of the world (e.g. Deshen 1992; Stone 1999; Ghai 2002; Meekosha 2004; Kohrman 2005; Ingstad and Whyte 2007). The case of physically disabled people in Russia offers a particularly sharp insight into the tropes of control and power that can mediate experiences of social citizenship. Although social rights formally underlay the USSR’s constitution of 1977, its comprehensive welfare state was in fact underpinned by elements of compulsion and an understanding of entitlements to state provision as based on personal contribution, especially in the form of work (Zaslavsky 1982). Disabled people were one of several groups excluded from many arenas of Soviet citizenship by an oppressive welfare system. It is the restructuring of welfare provision and consequently social citizenship for this group since the fall of the Soviet Union in 1991 that interests me in this thesis.

It is telling that ethnographies of citizenship and the postsocialist state often examine issues of disability, health and the body. The official construction and purported solutions of social and health issues can be seen as a window into ‘state projects and the new ways that states produce materially and socially variegated spaces’ by shaping infrastructure, knowledge and attitudes (Cullen Dunn 2008: 244). Adriana Petryna thus uses the term ‘biological citizenship’ to describe the ‘relationship between an emerging medical classification of Chernobyl’s ill effects and the social process of distribution of disability entitlements’ (Petryna 2003: 118). Jill Owczarzak similarly sees the case of HIV prevention in Poland as ‘a powerful lens for interrogating the differential effects of transition and the redefinition of the terms of citizenship’ (2007: 10). Sarah Phillips has looked at how physically disabled people in Ukraine ‘are transforming themselves – and being transformed – into particular types of citizens in a changing welfare state’ (Phillips 2005: 1). She considers both how the state manages the group of the population it calls ‘invalids’ (*invalidy* in Russian) and how informal systems of social support have developed as an alternative to the ineffective and contradictory state apparatus. In common with all this work, I am interested in the contested nature of state-citizen relations in the postsocialist region, especially over matters of physiological difference.

As explained in greater detail in my theoretical chapter, experiences of disability are generated by the complex interaction of negative societal conditions and bodily impairment, be it physical, cognitive, emotional or psychological (cf. Thomas 2007). My thesis focuses on the everyday lives of physically disabled people who live in community settings, either with or apart from their families. The experiences of this members of this group are highly relevant to a study of 'social citizenship' since there is no doubt over their mental capacity to choose how to live their lives, meaning that any discrimination or exclusion arises due to social inequalities, discourses and practices around impairment (cf. Carey 2009). Most of my research participants were wheelchair users, although some of them could walk short distances with the use of frames or support. Given that the state is one of the most powerful actors in constructing disabling conditions in society (Stone 1984), my study concentrates specifically on persons who have been officially assessed and classified as an *invalid* since this lets me track the distinctive citizenship and pathways in life that this label generates. As Sarah Phillips writes, people designated as disabled 'are all subject to a system that would evaluate, monitor, penalise and reward them according to the extent of their [disability]' (Phillips 2011: 10). Almost all my research participants had been classified as 'severely disabled' by the state apparatus and are thus an ideal group for analysing how the state is implicated in the production of disability, well-being and inequality. This is not to suggest that I agree with the official classifications awarded by the welfare system, but rather to explore the wider consequences of such labels in a state and society that has historically been extremely intolerant of bodily difference.

As will be discussed in Chapter Three, the citizenship of people with impairments was not acknowledged by the Soviet regime, which regarded disability as a shameful and defective phenomenon. Disabled people were thus isolated in a system of care homes that prevented them from working, studying or participating in societal life. With the end of Soviet rule, families and activists were able to achieve official recognition that physically disabled people should live in family and community settings.[1] Disabled Russians are thus no longer subject to the harsh treatment so vividly described in Ruben Gallego's harrowing autobiography about life in Soviet residential institutions (2006). It is estimated that 72% of disabled children in Russia now live with their families (Unicef 2005: 13), which is likely to be higher than the proportion of adults since very few people leave the system of state care. I am interested in the everyday experience of this group's citizenship and societal inclusion given the relatively recent development of community-based disability services and Russia's inauspicious history of disability provision. Some of my conclusions may pertain to Russians with other forms of disability or who live in residential care, but I do not seek to generalise for fear of producing 'totalising, meta-historical narratives that exclude important dimensions of disabled people's lives and of their knowledge' (Corker and Shakespeare 2002: 15).

A bottom-up study of the lives, societal position and citizenship of physically disabled people is important our understanding of the postsocialist region because the thirteen million people classified as disabled in Russia have little presence or voice in research by local and overseas academics. A comprehensive study of the Russian welfare state published in 2007 made no reference to disability (Cook 2007) while only scant

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[1] There have been similar bottom-up campaigns for people with mental disabilities to live with their families in local communities, but they have aroused far more professional opposition and societal debate than the case of physically disabled people (cf. Thomson 2000).

mention can be found in major World Bank and United Nations publications on well-being in the country (World Bank 2005; UNDP 2007). Since an edited volume published when Russia was still part of the Soviet Union (McCagg and Siegelbaum 1989), there has been no book-length publication in English on disability in any postsocialist country and just a smattering of doctoral theses (Thomson 2000; Katsui 2005). Even Russian-language publications are very thin, largely based on the work of Elena Iarskaia-Smirnova's team in the southern Russian city of Saratov (e.g Romanov and Iarskaia-Smirnova 2006). Disability is thus very much missing in scholarly work just as disabled people in Russia are themselves absent from the country's streets and public areas. Beyond policy-oriented documents (Maleva et al 1999; World Bank 2008), research on disability in Russia and the postsocialist region has mostly focused on residential institutions (Human Rights Watch 1998; Rosenthal et al 1999; Sammon 2001), children and schooling (Bridge 1999; Thomson 2002a; UNICEF 2005; Iarskaia-Smirnova and Romanov 2007) and disabled people's organisations (Katsui 2005; Thomson 2006; Philips 2006). A significant amount of this work was completed during the 1990s or by scholars who have since moved onto other topics. My thesis offers a different perspective on disability in Russia by considering the experiences and narratives of adults and focusing on state welfare provision.

Outline of thesis

This thesis offers an insight into social citizenship in Russia by exploring how welfare provision affects the everyday lives and place in society of physically disabled people. It strives to relay their experiences, concerns and feelings, thereby giving a peoplecentred account of social policy. The first three chapters of the thesis set out the theoretical, methodological and historical background to my work and are followed by four empirical chapters that consider the themes of interpreting needs, livelihoods, mobility and personal agency. In the conclusion I draw together my empirical findings on the nature of post-Soviet social citizenship and consider their wider implications for policy and theoretical debates.

Chapter One provides the theoretical framework for my research by relating the concept of citizenship to disability and social provision. I begin by arguing for an understanding of citizenship as everyday practices that are instantiated in specific spatio-temporal contexts and constellations of social relations. The chapter draws on theories of care to unpack the relationality of citizenship and draw attention to power inequalities, forms of agency and the emotional dimensions of citizenship. The emerging 'mobilities paradigm' in the social sciences is used to consider how dynamics of spatial inclusion and exclusion are shaped by social relations, discourses and infrastructures. In linking my experiential and relational concept of citizenship to social provision, I explain that the 'welfare state' can be seen as a set of power-inflected actors, norms and practices that attempt to impose their own understandings of need and appropriate practice that may conflict with user perspectives. Ultimately this chapter provides the conceptual underpinnings for my empirical chapters on the social citizenship of physically disabled people by highlighting the issues of interpreting needs, livelihood, mobility and personal agency.

Chapter Two discusses the qualitative research strategy I used to investigate the social citizenship of disabled people while based in the city of Kazan. It emphasises the value of ‘thick description’ through references to ethnographic studies of disability and welfare provision, particularly in the postsocialist region. I also introduce my fieldwork sites and explain how my thirteen months of fieldwork progressed. I pay particular attention to ethical and reflective aspects of my work, explaining how I strove to ensure the research process did not negatively affect participants and reflecting on my own role in constructing and interpreting data.

Chapter Three offers greater detail on the substantive focus of the thesis – disability provision in Russia – by discussing how the welfare system for physically disabled people developed in the Soviet and post-Soviet periods. In so doing, I offer a historical assessment of social citizenship and the welfare state in Russia. The chronological ordering of the material reveals that changes to disability policies and services have been incremental given low political priority and weak influences from abroad. Highly medicalist and exclusionary approaches from the Soviet period have been ‘recombined’ with newer ideas and practices in ways that are not always supportive or beneficial to disabled people. I also highlight the growing regional diversity in Russian disability provision, thereby strengthening my case for a bottom-up study that can capture local developments.

Chapter Four is the first chapter based on fieldwork data and looks at official procedures for classifying disability and defining the needs of disabled individuals. I consider the rhetoric about disability used in official documents and how my research participants reacted to negative governmental discourses about ‘invalids.’ I then examine how ‘expert’ medical commissions confer disability status and discuss the hierarchy of disability that exists in Russian law based largely on Soviet ideals of labour and military service. The dominance of biological or medical conceptions of disability leads me to consider the provision of healthcare and rehabilitation services in the second half of the chapter, which finds that the unsatisfactory delivery of these forms of state assistance discourages its use and thereby reduces state-citizen interaction.

Chapter Five discusses how state provision affected my research participants’ livelihoods and position in society by examining policies in the interlinked fields of education, employment and material well-being. I first highlight that disabled school pupils and university students have few possibilities to study alongside their non-disabled peers despite their strong preferences for inclusive education. The question of employment for disabled people is similarly acute with state services doing little to overcome a trio of barriers: discriminatory attitudes among employers, an inaccessible built environment and legal obstacles to work. I show that disabled people try to challenge these exclusionary currents in state policies by drawing on social connections to improve their opportunities for societal participation. The chapter ends with a discussion of making ends meet, explaining that although low disability pensions annoyed my research participants, they were more concerned by the absence of decent work, inclusive state structures and other socially embedded influences on their lives and citizenship.

The main theme of Chapter Six is how state policies shape the mobility and access to space of physically disabled people in Russia, thus addressing questions of autonomy and inclusion that are central to citizenship. In line with the mobilities paradigm, I explore the embodied and emotional experience of (im)mobility by looking at the physical, policy and social constraints on movement. The chapter begins by looking at the immobility and related frustrations that arise from living in housing that was not designed with disabled people's needs in mind. Consideration of two recently built housing projects finds that disabled people living in architecturally accessible buildings may still be socially isolated and controlled by state institutions. The issue of immobility and confinement at home leads onto a wider discussion about moving around and the physical, social, organisational and temporal barriers preventing access to space. Inclusion and mobility ultimately do not seem to be key themes of state provision with the result that disabled people's place in society is strongly affected by the built environment and social relations.

In light of the many obstacles and barriers already discussed, Chapter Seven focuses on the personal agency of my research participants and their efforts to realise social rights and entitlements to welfare. I talk about the strategies used by disabled people to obtain state assistance and the difficulties encountered, especially the physical and emotional burdens of long queues, poor information, paperwork and a system that provides assistance only when prompted. I go onto consider agency in the broader context of non-governmental organisations, family and close friends. Finally, the chapter rounds off discussions of citizenship by considering how my research participants talked about their rights and relationship to the state, showing that they linked specific complaints about welfare provision to broader questions about official understandings of disability and the country's social orientation.

The conclusion of the thesis returns to the question of social citizenship and summarises what it represents for my disabled research participants. I also consider the implications of their experiences for scholarly analyses of citizenship and future research on rights and disability provision in Russia.

Chapter One

Conceptualising citizenship, disability and welfare provision: views from below

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This chapter draws on the concept of 'social citizenship' to develop an analytical framework for exploring how welfare states affect the lives and well-being of citizens, especially those with disabilities. I start by arguing that academic and policy debates must move beyond discussions of citizenship and rights as formal statuses belonging to supposedly universal and disembodied individuals. I instead offer an understanding of rights as flexible practices that are constructed and negotiated on a daily basis. Recognition that citizenship is not a blanket or homogenous experience requires attention to be paid to everyday experiences and societal diversity. In explicating the contours of a concept of 'lived' citizenship sensitive to social difference, I draw on theories of care and mobility to highlight the importance of social relations, time and space. Conceptualising rights as practices embedded in socio-spatial contexts helps to make discussions of agency and self-determination more sophisticated by acknowledging the interdependence of citizens on each other and the world around them.

The latter parts of this chapter consider how this bottom-up notion of citizenship can be used to interrogate the workings of the welfare state, especially inevitable power inequalities between state structures and users of welfare services. Drawing on disability studies and feminist theories of care, I complicate Marshallian ideas of an unambiguously positive link between welfare policies and social rights by showing how policies designed to ‘care’ or ‘protect’ may seek to regulate people and their activities. As part of this discussion, I offer a bottom-up understanding of welfare states as collections of loosely connected organisations, norms, staff and procedures. The elements of the welfare system can be seen as sites of power-related negotiations in which state organisations and personnel attempt to impose their own understandings of need and appropriate practice. Ultimately I argue that welfare support is underpinned by inherent tensions between providing care and supporting rights whose balance will be mediated by social and spatial relations.

The lived experience of citizenship

From authoritarian regimes to civil rights movements, what it means to be a citizen is highly disputed. Citizenship is ‘an essentially contested concept’ that reflects ‘complex political, moral and ethical issues concerning the individual’s relationship to the state and the wider society’ (Lister 2003: 14). Questions of who should have rights and what these rights bring are intensely political, reflecting value judgements about the nature of a community, interrelations between citizens, individual behaviour and role of the state in people’s lives. An increased awareness of socio-political issues and inequalities that challenge existing conceptions of citizenship has prompted an ‘avalanche of literature over the past decade, as the field of citizenship studies has established itself’ (Lister 2007: 49). Research topics framed in the language of citizenship include, but are by no means limited to, poverty (both in the global South and industrialised countries), environmental problems, migration, multiculturalism, statelessness and sexuality. Such work has expanded citizenship studies beyond traditional concerns with political and civil rights within defined states to include issues of identity, cultural recognition and socio-economic rights at a variety of political levels (e.g. Voet 1998; Isin and Wood 1999; Ong 1999; Siim 2000; Isin and Turner 2002). They reflect how 'multiple definitions of citizenship may coexist and different understandings of the appropriate relations between state and society may compete' within a single community (Henry 2009: 52). This literature is united by an interest in the nature of 'the right to have rights' that defines citizenship, looking at both the criteria for being a member of society – for 'belonging' – and what this membership entails. It is this second question that I address in this thesis, using the lived experiences of physically disabled people in Russia to provide a critical insight on 'what is citizenship's meaning and what are the substantive benefits and costs, the rights (if any) and obligations, that accrue to those who already possess its status' (Somers 2008: 21).

While undoubtedly important as foundations for policy and practice, legal and normative postulations of citizenship do not necessarily illuminate the role and value of rights as resources and opportunities in everyday life. Focusing on the formal status of citizens fails to explicitly recognise that 'citizenship is as much about recognition as about access to formal rights' (Lister 2007: 51; cf. Fraser 1997) and that rights must be implemented to have real meaning and value. Citizenship in practice is complicated and varied, as shown by the history of how rights have been patchily extended to – and sometimes removed from – social groups as well as current struggles to overcome continuing discrimination and incomplete realisations of citizenship (Bosniak 2006; Somers 2008; Canaday 2009; Carey 2009). Awareness that the instantiation of rights is not guaranteed is a key reason why scholars are increasingly looking at citizenship 'in practice' or 'from below' (Engel and Munger 2003; Lewis 2004; Dwyer 2004). Indeed, citizenship is a key example of how 'law is one of the elements that constitute the categories and routines of everyday life; and, in turn, these very categories and routines – and the individuals who participate in them – give form and meaning to the law' (Engel and Munger 2003: 11). Rights are theorised within this strand of citizenship studies as context-dependent practices or 'enforceable claims that are *variably and contingently* appropriated … and in turn given meaning only in the practical context of power and social relations' (Somers 1994: 79, author's italics). Citizenship studies therefore focus on the concrete experiences of being a citizen in particular contexts rather than the formation of rights at a legislative or policy level.

Citizenship, difference and disability

One of the most powerful critiques of classical discussions of citizenship focuses on how the homogeneity and universalism often assumed to exist among citizens ignores the many forms of social difference and related power inequalities that affect the lived experience of citizenship. Citizenship in Western discourse has long been constructed around dominant images and norms, for example being male, white, employed, non-disabled and heterosexual. Such a conceptualisation emphasises sameness and rejects difference as incompatible and unworthy of equality. Critical reformulations of citizenship therefore argue for the recognition and protection of diversity, be it based on race, gender, sexuality, ability or other social markers (Fraser 1997; Benhabib 2002; Nussbaum 2000). They seek to promote a 'universalism of difference' (Dean 1996: 10) that recognises human variety within a framework of equal rights and mutual respect.

Citizenship is thus reconceptualised to both extend rights to marginalised groups and offer new interpretations of existing rights, for example through thinking on personhood, autonomy and the body (cf. Lister 1997: 126-8).

Disability in particular is missing from wider citizenship debates (Meekosha and Dowse 1997; Morris 2005) even though it 'represents an important terrain for the theoretical challenge of addressing the tension between citizenship's universalist promise and the recognition of difference' (Lister 2007: 54). Indeed, the denial of substantive citizenship to disabled people means that they often end up with 'the status of "dis-citizens," a form of citizenship minus, a disabling citizenship' (Devlin and Pothier 2006: 2). It is therefore unsurprising that rights and citizenship are crucial themes in research about people with physical and mental impairments (e.g. Rummery 2002; Parker 2004; Beckett 2006; Bartlett and O'Connor 2007; Carey 2009).

With a few caveats relating to the need to acknowledge corporeal experiences,[2] I embrace a social constructionist interpretation of disability in my research. The 'social model' of disability draws attention to the heterogeneity of society in physiological, cultural, social and many other ways. It makes a distinction between bodily impairments and actual disability, attributing the latter not to the functioning of the human body, but to unfavourable conditions in society.[3] Social and institutional structures are seen as discriminatory and disabling when they curtail the activities and opportunities of people with impairments (Thomas and Corker 2002: 18). Put directly,

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[2] I have much sympathy for reformulations of the social model that explicitly recognise how pain, tiredness and illness may be an inherent part of impairment, but cannot be explained in over-socialised accounts of disability (Terzi 2005: 202; Thomas 2007).

[3] This argument also broadly applies to forms of mental disability (e.g. Beresford 2000b; Carey 2009: ch. 2).

the social constructionist view of disability holds that ‘disablement is nothing to do with the body’ (Oliver 1996: 35), but rather arises when society does not facilitate the activity and well-being of people with bodily impairments. Such conditions might include wheelchair-accessible architecture, non-discriminatory attitudes and a legal framework that enforces equal opportunities.

The social model stands in contrast to individualistic views of disability that have connotations of deviance and abnormality (Barnes, Oliver and Barton 2002: 3). Often called the ‘biological’ or ‘medical’ model of disability, this conceptualisation views disability as stemming from physiological flaws that require medical treatment or ‘rehabilitation’ to achieve or approximate ‘natural’ bodily functioning. People whose health cannot be restored are seen as deviating from a norm of healthy, ‘able-bodied’ individuals and thus deserving of help and pity. As a result, they are often seen as partial or non-citizens. In the words of a leading theorist of the social model, the ‘normality’ espoused in medical interpretations is actually ‘a construct imposed on a reality where there is only difference’ (Oliver 1996: 88). This is an important point, for impairments and the social conditions precipitating disability vary greatly. Sociological research long focused on the discrimination and stigma faced by disabled people without challenging fundamental thinking about how disability itself is conceptualised (Thomas 2007). Even today there are fears that ‘disability continues to be perceived as being *about* disabled people rather than as a relational concept which has ramifications for the social position and way in which everyone thinks, feels and acts’ (Marks 2001: 172, author’s italics).

The implication of the social model of disability for citizenship studies is that ‘it is not impairment which determines whether disabled people can be full and equal citizens, but socially constructed barriers’ (Morris 2005: 34). Such a theorisation challenges binary ‘us-and-them’ conceptions of disabled and non-disabled ‘when the more nuanced reality is that disability might be better understood as a dynamic and contextualised range’ (Devlin and Pothier 2006: 5). As such, it is not disabled people who should adapt to society’s demands, but society that must facilitate and accommodate the varied needs of the entire population, including people with disabilities (DFID 2000: 7). The medical model gives a monolithic conception of disability that ignores a myriad of other differences between people (Terzi 2005: 200). Viewing disabled people through the single lens of their impairment can be dangerous by providing grounds for an exclusionary separation between disabled and ‘normal’ individuals. Chapter Three will discuss how this was precisely the situation in the USSR, where a focus on impairments and their ‘cure’ led to the segregation of disabled people from society on a wide range of levels.

Care perspectives on citizenship: relations, power, agency and emotions

Situational or everyday perspectives on citizenship emphasise that ‘rights are necessarily practiced in relationship with other people and that the practice of rights is socially mediated for all citizens’ (Carey 2009: 25). With their focus on the relations and practices underlying the provision of support,[4] theories of care are especially

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[4] My use of care theorisation reflects recent attempts to build bridges between disability studies and feminist literature, which have traditionally had an antagonistic relationship over the nature of care and whether to emphasise the perspectives of care-givers or care-receivers (Watson et al 2004; Hughes et al 2005; Fine and Glendinning 2005; Beckett 2005; Levy and Little 2008). The focus of my thesis on

insightful in exploring how citizenship is mediated by social relations and the potential effects – both positive and negative – of imbalances in power associated with this relationality. The notion of care also emphasises the centrality of emotions and feelings to lived experiences (Read and Thelen 2007). Indeed, care is ‘a way of seeing the embodiments of our abstract ideas about power and relationships’ (Tronto 1993: 124).

Theorisations of care start from the basic fact that humans are not isolated and autonomous individuals, but explicitly social beings. Social interaction lies at the heart of citizenship and human relationships given that ‘we assert a right in order to influence or alter the actions of someone else, and therefore rights mediate and transform our relationships’ (Carey 2009: 28). Concepts of citizenship should thus not promote the idea of an abstract, disembodied individual since independence is empirically and philosophically unproven: a social construction and misleading normative discourse (Kittay 2011: 57). Citizenship must rather start from a standpoint emphasising the connectedness or ‘interdependence’ that arises from the fact that all people require care and support at various stages of their lives (e.g. childhood, older age, some cases of disability and illness).[5] The ‘inescapable fact of human interdependence’ (Fraser and Gordon 1994: 6) means that speaking of *individual* rights and independence is in fact misleading since ‘caring is by its very nature a challenge to the notion that individuals

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disabled people inevitably entails prioritising the perspectives of care receivers, although I recognise that the stories and well-being of carers are also crucially important.

[5] I use the terms ‘connectedness’ and ‘interdependence’ in preference to the notion of ‘dependency’ that frames Eva Kittay’s work on an ethics of care. Although feminist authors argue hard for a positive interpretation of the term ‘dependency,’ it is important to note the reservations of disability scholars over this word since there is a risk that ‘challenging the alleged dependency of disabled persons by claiming that they are (merely) among the universally dependent ignores the social construction of dependency in favour of a biological model that has not served disabled people well. All dependencies are not the same’ (Levy and Little 2008: 11; cf. Shakespeare 2000). Speaking of ‘interdependence’ is therefore less controversial and nicely pulls out the relational and interpersonal aspects of citizenship emphasised in care theories that are most valuable to this chapter’s conceptualisation (cf. Watson et al 2004; Bowlby et al 2010).

are entirely autonomous and self-supporting' (Tronto 1993: 134). Instead feminist theorisations of citizenship focus on the 'relational rights' (Minow and Shanley 1996) arising from the fact that people's lives are shaped by webs of social connections. In a challenge to individualistic conceptions of rights and autonomy, care theorists worry that 'the dominance of an ideology of independence will eclipse the positive experience of connectedness' experienced through interdependence. (Kittay 2011: 56). The upshot is that citizenship needs a nuanced idea of independence that embraces the need of many citizens for support whilst recognising their voice and opportunities for making decisions. Citizenship therefore needs to be understood through 'a framework within which due recognition can be given to the interdependence that is quintessential to human relationships … in particular those involving the giving and receipt of care' (Lister 2003: 106).

In emphasising the importance of relations, care theories highlight that power imbalances are an inherent feature of life and the social context of care (e.g. Tronto 1993; Kittay 1999). Indeed, 'real relationships involving care can embody a complex mixture of love and abuse, and an emphasis on the social value of care must not ignore the problems of its absence or inadequacy' (Bowlby et al 2010: 43). Awareness of 'how completely care is implicated in structures of power in society' (Tronto 1993: 126) is useful both for constructing a normative 'ethics of care' and also for the empirical analysis of how needs are constructed and supposedly met. Eva Kittay (1999) has made a valuable distinction between inequalities in power – which are inevitable – and the exercise of domination and the abuse of this power. This conceptualisation is very helpful in highlighting that power inequalities are ever-present, but not automatically negative. As such, ‘oppression arises not from the fact of needing or giving care, but from the social meanings and practices attached to those who need or give care’ (Levy and Little 2008: 22). These meanings and practices are often associated with social differences and ‘fragmented conceptions of care operate as they do to perpetuate gender, class and racial structures of power and privilege through the construction of “otherness”’ (Tronto 1993: 101). These difference-inflected power contestations may shape personal interaction in caring processes (Dodson and Zincavage 2007), but can also be created at a structural level by welfare systems, as will be explored in later sections.

Yet, power must not be understood in exclusively negative and oppressive terms. Consideration of the possible abuse of power in caring and welfare relationships – a major feature of feminist and disability literature – needs to be balanced with acknowledgement that power can be used positively. Recent theorisations of social care have thus framed power in terms of empowerment and capabilities by drawing on the ideas of Amartya Sen (1999) and Martha Nussbaum (2000). Such work sees power as the possibility to do something rather than to control and influence another person (Fine and Glendinning 2005: 616). Such a formulation can be found in theorisations of an ideal ‘ethics of care’ in which care – whether private or state-provided – involves responsibilities for other people’s flourishing (Kittay 2011: 55). By focusing on strengths and seeking to avoid a discourse of victimisation, notions of ‘power as energy’ (Lister 2003: 40) raise the question of how people and groups in unequal structural relations can nonetheless exhibit agency.

Emphasising the contested nature of citizenship and the interdependence of citizens demands a nuanced notion of agency in relation to the wider structures framing care. While the idea of human agency suggests that actors are capable of choice, action and self-development, this autonomy and capacity will be rooted in wider social relations and structures such that people can simultaneously be ‘the subordinate objects of hierarchical power relations and subjects who are agents in their own lives, capable of exercising power in the generative sense’ (Lister 2003: 41). Given the ‘masculinist’ and individualistic imaginary of [physical] independence underlying many discourses around citizenship, there is a real danger that disabled people and other groups who use care will be represented in academic and policy literature as passive and dependent (Hughes et al 2005). Such an interpretation rests on a conflation of decisional and executional autonomy (Fine and Glendinning 2005: 610). The reverse situation is also possible when people with impairments are championed as ‘heroes’ who have overcome great personal and social obstacles. In both cases disabled people are ‘portrayed as more than or less than human, rarely as ordinary people doing ordinary things’ (Oliver 1990: 91). What is important is ‘seeing and researching disabled lives as both constrained by social structures and as an active process of production which transforms social structures’ (Corker and Shakespeare 2002: 15). Citizenship studies should therefore not focus solely on negative structural obstacles, but also recognise that agency shapes experiences of rights and entitlements (cf. Lister 2003: 37-42). Indeed, practices and ‘notions of caring exist as a struggle of interests between individuals, social groups and the state’ (Watson et al 2004: 342) and people’s personal actions should therefore be studied within the broader context of the barriers and opportunities affecting them.

The question of agency is important within disability studies because it links to broader questions about independence. The disabled people's movement has traditionally utilised a very pronounced discourse of independence and individual rights as encapsulated in the models of 'independent living' and 'personalisation' that evolved as reactions to the abuse and exclusion often found in supposedly 'caring' institutions (Shakespeare 2000). However, the formulation of autonomy given in such models has been criticised on empirical and ethical grounds since it 'does not adequately observe the role of interpersonal relations between parties involved in the caring nexus' (Watson et al 2004: 339). Bill Hughes and his colleagues have written extensively about the highly individualistic formulation of independence perpetuated in disability activism: 'the disabled people's movement has adopted a pragmatic and materialist interpretation of care that is commensurate with its masculinist ethic and idealises masculinist notions of autonomy' about individuals completing tasks by themselves (Hughes et al 2005: 263). In so doing, it ignores human interdependence, especially the everyday experiences and emotional dimensions of being in relationships of assistance and support (cf. Levy and Little 2008). There is also a risk that ideas of *individual* independence may gel with neoliberal ideas about autonomy in ways that devolve responsibility to individuals for solving their problems:

> 'For disabled people, the resulting strategies of self-help, in a context of rolling back welfare services, have served to (re)define their lives in ways which do not necessarily "open up" the city and its multiple spaces. For many, "empowerment" is reliance on often-elusive networks of social contacts'
>
> (Imrie 2001: 235).

These concerns over the definition of independence explains why Ruth Lister draws on Young’s distinction between independence as autonomy (the ability to make and act upon one’s choices) and independence as self-sufficiency (not needing help or support in meeting one’s needs) to argue that autonomy should not be ‘misinterpreted as the kind of atomistic individualism implicated in the notion of self-sufficiency’ (Lister 2003: 107). The upshot is that when considering the independence that is undoubtedly embedded in the concept of citizenship, we should understand that ‘autonomy, and the agency that derives from it, is only made possible by the human relationships that nourish it and the social infrastructure that supports it’ (Lister 2003: 114). Being in a relationship of care, indicate any form of attachment, is not necessarily negative for autonomy, but depends on the constellations of power between the figures involved.

Conceptualising agency and autonomy as intensely relational is an interesting way to approach literature on ‘new’ forms of citizenship that utilises a conception of collective agency and struggle. The feminist scholar Iris Young (1990) has thus argued for a ‘politics of group assertion’ that parallels arguments in queer and critical race studies. Disabled people’s struggles for full citizenship in much of the ‘Western’ world have often been pursued through group action, for example UPIAS (Union of the Physically Impaired Against Segregation) in the United Kingdom and the Independent Living Movement in the United States and Scandinavia (Fleischer and Zames 2001). Such approaches arise from a belief that individual agency and strength needs to be combined to achieve beneficial goals for individuals and the collective alike. It is however appropriate to question whether groups can be genuine vehicles for rights, voice and citizenship. Concerns centre on the ‘difficulties of establishing which groups are most pertinent to political identity; the dangers of freezing identities and of ‘group closure’ so that change and the development of wider solidarities are blocked; and the near impossibility of achieving accountability’ (Lister 2003: 80). There is therefore conceptual and practical worry about whether differences between members can be accommodated in single-issue group actions, particularly in light of emerging recognition of intersectional identities and positions. While identity and politics do not have to overlap completely for group-based action, the organisational rigidity needed for effective group representation may indeed undermine collective goals and strategies. There are also concerns over the moral and practical consequences of different groups (assuming they can be defined) pursuing separate strategies and therefore competing for recognition and resources. Indeed, the exhortation of needs and subjectivities based on groups or cohorts seemingly obscures the interdependence that is an inescapable feature of life and should be valued accordingly (Watson et al 2004: 344). There have therefore been moves to encourage cooperation between various agendas and standpoints, for example feminism and disability (Watson et al 2004; Beckett 2007).

From an area studies perspective, it is important to acknowledge critical voices about how individual and organised forms of agency fit with local cultural and political patterns in the postsocialist region (Hann and Dunn 1996; Katsui 2005; Ghodsee 2006). Ethnographic research has highlighted how notions of ‘civil society’ and ‘democratisation’ fail to consider local logics of governmentality and a lack of faith in collective organisation on the part of Russian society (e.g. Hemment 2007; Salmenniemi 2008; Kulmala 2009). Indeed, research on disability organisations in central and eastern Europe reveals that many of them adopt a consensual and service-oriented mode of interaction with authorities in contrast to the challenging and awareness-raising stances often taken by their Western counterparts (Holland 2008). These lessons highlight that a bottom-up study of citizenship must focus on local interpretations of different forms of agency.

A final way in which theorisations of care contribute to understanding citizenship concerns the embodied and emotional experiences of being in a care relationship, whether with state institutions or other individuals. Care scholars reject clinical, functional and impersonal formulations of care and citizenship in favour of approaches that see feelings and physical experiences as integral to – rather than separate from – experiences of social reality (Shakespeare 2000; Watson et al 2004). How those involved in care relationships feel about the process is crucial, meaning that research must consider 'the changing ways in which emotional care [is] constituted within different kinds of exchange' (Read 2005: 139; cf. Dodson and Zincavage 2007). Emotions are clearly socially conditioned and 'the bodily-in-the-world socially mediated experience of caring will influence the feelings that we have about all aspects of our caring activity' (Bowlby et al 2010: 47). Self-esteem is an important emotion in relation to citizenship because it is a precondition for speaking in one's own voice and exerting the agency needed to influence one's own life (Lister 2003: 39-40). Material resources will certainly affect confidence in one's own separate identity and abilities, but more ephemeral factors are also important relating to the social and cultural construction of a person's situation. Indeed, the effects of societal stigma around disability – for example hostile looks and assumptions of inability – will be a crucial dimension of a disabled person's identity and subjectivity (Marks 1999).

There is a significant feminist literature that draws on Arlie Hochschild’s notion of ‘emotional labour’ to consider how the delivery of particular emotional responses is tied up with particular professions. Interestingly, whilst profit-oriented care settings are increasingly emphasising the need for warm and positive emotional interaction between care workers and clients (Read 2005; Dodson and Zincaavage 2007), many disability activists have been trying to ‘professionalise’ and depersonalise the relationship between disabled people and their carers. Rejecting the language of care as paternalistic and oppressive, they promote ideas of ‘assistance’ that turns support into the fulfilment of functional tasks without emotional attachment (Beckett 2007: 371). Yet, critical scholars worry that ‘in developing a masculinist approach to care, the DPM [disabled people’s movement] seeks to promote autonomy for disabled people but eliminates emotion from the caring process by transforming it into a formal, contractual, exchange relationship’(Hughes et al 2005: 271). Such an individualistic formulation of care is founded on empirical and normative myths about individual autonomy that ignore the emotional and relational dimensions of human interaction.

Care perspectives are therefore useful for explicitly rooting the concept of citizenship in social relations with an attendant focus on unequal power relations and expressions of agency. They highlight that ignoring the roles of personal feelings and identity would greatly undermine the attempt to see citizenship as an experiential phenomenon. Without these contributions, citizenship would seem highly individualistic and a formal rather than a socially constructed practice. Indeed, thinking about citizenship ‘from below’ demands that attention is paid to its embodiment and lived experiences.

Mobility and spatial dimensions of citizenship

I have so far grounded the concept of citizenship in everyday experiences through discussions of difference, social relations, power inequalities, agency and emotions. These dimensions must be complemented by consideration of the spatial and temporal dimensions of people's interaction with wider society and the state's influence on this interaction. Indeed, access to space is an important issue given the promise of inclusion and participation in society incorporated in the notion of citizenship (Morris 1994: 2). These issues can be explored by drawing on the 'mobilities paradigm' emerging in the social sciences that studies the movements, representations and practices underpinning the daily use of space (cf. Cresswell 2010). The concept of mobility is especially relevant to understanding disabled people's citizenship and place in society since 'struggles around mobility and movement are a core feature of disabled people's everyday lives' (Imrie 2000: 1645). My analysis affirms the centrality of power imbalances, embodiment and social relations to the lived experience of citizenship.

The relevance of the 'mobility turn' to a study of everyday practices of citizenship, especially those of physically disabled people, arises from how it 'connects the analysis of different forms of travel, transport and communications with the multiple ways in which economic and social life is performed and organised through time and across various spaces' (Urry 2007: 6). It is useful to think of mobility as comprising three elements: the fact of physical movement; the meanings and representations associated with movement; and, lastly, the embodied experience and practice of movement (Richardson and Jensen 2008: 228). Indeed, 'understanding physical movement is one aspect of mobility. But this says next to nothing about what these mobilities are made to mean or how they are practised' (Cresswell 2010: 19). Each of the three aspects of mobility is closely associated with a 'politics of mobility' that interrogates inequalities in how people move around spaces by 'tracking the power of discourses and practices of mobility in creating both movement and stasis' (Sheller and Urry 2006: 211). Rather than being a neutral activity of moving between fixed points in space, mobility is crucial to such arenas of citizenship as work, family, leisure, politics and protest (Urry 2007: 12). The concept therefore goes beyond the simple study of movement as a brute fact to interrogate the social world as 'a wide array of economic, social and political practices, infrastructures and ideologies that all involve, entail or curtail various kinds of movement of people, or ideas, or information or objects' (Urry 2007: 18).

The mobilities paradigm shares with theories of care an explicit focus on [unequal] social relations, analysing their influence on practices, representations and experiences of movement. Its relational approach lies in focusing on the personal attachments and connections that 'form and reform space itself (as well as the subjectivities through which individuals inhabit spaces)' (Sheller and Urry 2006: 216). The notion of a 'relational' politics of mobilities demands consideration of social difference since the 'spatiality of rights is attached to boundaries in the social world, such as those that demarcate men and women, black people and white people and able-bodied people and disabled people' (Cresswell 2006: 741). Indeed, critical studies of immobilities have identified that inequalities in society, for example related to gender, ethnicity and class, also affect mobility in terms of actual movement, the experience of travel and its wider representation (e.g. Massey 1994; Uteng 2009; Richardson and Jensen 2008). It is because of these unequal social relations that ‘mobility can be possibility-creating just as it can be action-limiting … similarly, it can be an asset or a burden’ (Freudendahl-Pedersen 2009: 20).

A focus on how inequalities of power inflect mobility highlights the important distinction between actual mobility and potential mobility or the ‘way in which an individual appropriates what is possible in the domain of mobility and puts this potential to use for his or her activities’ (Kaufmann 2002: 37, quoted in Uteng 2009: 1056). A simple journey does not fully reveal the factors facilitating and constraining a person’s movement, which are ‘neither obvious nor straightforward and can refer to a multiplicity of possibilities, including the perceptual and imaginary nature of space’ (Imrie 2001: 232). The division between actual and potential mobility may make the concept ambivalent, but this is ‘a prerequisite if we wish to understand how and why individuals are in movement’ (Freudendahl-Pedersen 2009: 20) since it draws attention to the ‘unequal power relations which unevenly distribute motility, the potential for mobility’ (Hannam, Sheller and Urry 2006: 15).

Studies of the discourses and infrastructures shaping mobility highlight that they are infused with exclusionary norms about who should travel and how they should do this. Mobility systems ‘are designed for certain imagined types of citizens and … planners’ and policymakers’ imaginaries of how these particular types of citizens will want to move in time and space’ (Richardson and Jensen 2008: 220). Attention thus needs to focus on ‘how particular modes of mobility are enabled, given license, encouraged and facilitated while others are, conversely, forbidden, regulated, policed and prevented’

(Cresswell 2006: 735). Representations of mobility may circulate at official and societal levels or reflect individual attitudes. State structures have a leading role in imagining landscapes and terrains, for example in designing public spaces and developing transport plans. Rob Imrie's work has long criticised policymakers and planners for excluding people with impairments from their visions of public space. He condemns how 'mobility and movement are defined through discourses which serve to alienate impaired bodies and to prioritise the movement of the so-called "mobile body"' (Imrie 2000: 1642). Dominant conceptions of mobility promote an image of the body as independent from bodily functions and thereby ignore corporeal experiences. Indeed, 'the way in which rights, mobility, freedom and citizenship have been wrapped around each other in liberal discourse has naturalized mobility as the property of the individual moving able-bodied subject' (Cresswell 2006: 752). This pathologises bodies with impairments that do not conform to hegemonic images of mobility such that they 'dys-appear' in everyday practice (Paterson and Hughes 1999). As a result, disabled people seem out of place and are unwelcome in public spaces in similar ways to veiled women or ethnic minorities (Uteng 2009). Indeed, people with impairments have long been victims of medical attitudes that see bodily difference as abnormal and something that should not be part of public life. Such ideas have often found concrete representation in policies of institutionalisation to isolate people with impairments.

Interrogating the possibilities for mobility inevitably raises questions of agency, choice and freedom that are at the heart of the citizenship concept. Indeed, several authors concerned with mobilities have deconstructed dominant codings of mobility that tie it to rights, citizenship and the notion of a good life (Imrie 2000; Cresswell 2006;

Freudendahl-Pedersen 2009). Mobility as freedom is ‘composed both of opportunities to travel when and where one pleases and the feasibility of the choice not to travel’ (Sager 2006: 465). Such a notion of positive right or freedom to mobility (Urry 2006: 206) means that immobility does not automatically signify a lack of freedom or agency if it is a desired state. This is because the links between (im)mobility and (un)freedom can ‘only be illuminated by integrating the intentions of the individual and the reason that makes them mobile’ (Freudendal-Pedersen 2009: 6). Although literature on the ‘politics of mobility’ tends to focus on constraints on mobility and characterise them as negative for creating inequalities, they still recognise a role for agency since ‘subjects involved in or excluded from everyday mobility practices may appropriate new infrastructures or modes of mobility in unpredictable ways’ (Richardson and Jensen 2008: 222). This reflects the more general point that ‘as people, capital and things move they form and reform space itself (as well as the subjectivities through which individuals inhabit spaces) through their attachments and detachments, their slippages and “stickiness”’ (Sheller and Urry 2006: 216). In so doing, people will rework the representations of mobility imagined by planners and politicians in their daily practices and create ‘new and possibly alternate identities and subjectivities at the “street level”’ (Richardson and Jensen: 221). It is this contestation of dominant ideas and expected practices around movement that represents agency in the context of a relational and experiential concept of mobility.

In incorporating a focus on lived experiences and practices, the mobilities paradigm highlights that movement has corporeal and emotional dimensions. Just as care theories emphasise the need to acknowledge feelings and identities, ‘the recentring of the corporeal body as an affective vehicle through which we sense place and movement, and construct emotional geographies' is crucial for recognising the materialities of mobilities (Hannam, Sheller and Urry 2006: 14). Studying movement is thus far too narrow to grasp the complex experience of mobility. We should instead be interested in whether people can be and do what they want with a minimum of pain, frustration and embarrassment (Imrie 1998: 141). As Davies and Lifchez (1987: 40) noted in relation to the concept of place, 'how one feels about a place, how one interprets it, or even whether one can adequately interpret it – these are all less quantifiable, but crucially important, aspects' of mobility. Studying mobility and access to space therefore demands consideration of personal and subjective experiences, making it unfortunate that 'the complexities of disabled people's corporeality and experiences (of mobility and movement) are rarely described, acknowledged, nor understood' (Imrie 2000: 1652). Traversing a bumpy road in an uncomfortable wheelchair may be long, dangerous and tiring while the same journey in a car generates feelings of freedom, speed and autonomy. The corporeal and emotional components of mobility will vary depending on 'the messy world of multiple and everchanging embodiments' (Imrie 2000: 1643).

Although there is a tendency among mobility scholars to champion and valorise movement, critical studies emphasise that mobilities are contingent upon spatial, infrastructural and institutional 'moorings' (Hannam, Sheller and Urry 2006). Movement in itself is not necessarily helpful and is only given meaning in specific social contexts. Indeed, 'everyday life is still fixed, to some degree, in specific places, such as the places in which we live' or undertake other regular activities (Freudendahl-

Pedersen 2009: 21). Mobility generally involves reaching particular destinations at specific times, which makes the nature of its ‘moorings’ important. Attention therefore needs to be paid to ‘the dynamic relation between changing mobilities and networks, on the one hand, and the sorts of relations, sites and practices that are important for social inclusion’ (Cass, Shove and Urry 2005: 540). So whilst it is valuable to incorporate mobility into the concept of citizenship to ensure that it is not a static and sedentary notion, we must be aware that ‘mobility is always located and materialised, and occurs through mobilisations of locality’ (Scheller and Urry 2006: 210).

One of the most important moorings in people’s lives is the home, which – like mobility itself – must be understood as an embodied and emotional experience. As with public space, the design and expected use of homes reflect ‘a broader and powerful, social and cultural encoding of what constitutes appropriate domestic space and [its] legitimate (bodily) uses’ (Imrie 2004: 748). Bodies with impairments are generally absent in cultural and policy scripts about homes such that many living spaces are poorly designed for disabled people, for whom domestic space may not be conducive to well-being or the positive feelings of privacy, security, independence and sanctuary conventionally associated with the idea of the home (Saunders 1990).

The question of how moorings affect citizenship and mobilities raises the notion of access to and exclusion from particular places since ‘a lack of citizenship or new kinds of social exclusion are said to be resulting not only from social inequality per se, but also from a combination of distance, inadequate transport and limited ways of communicating’ (Urry 2007: 190). In his study of disabled people’s journeys, Rob

Imrie (2004: 1648) found that ‘the facilitation of their mobility was meaningless if nothing was done to improve their access into the places they choose to visit.’ The construction of the built environment is crucial given the assumptions historically made about how people move through space: ‘the emphasis on sameness, on uniformity, was problematical for its failure to differentiate between users and how places and spaces need to be multi-functional to cope with human diversity’ (Imrie 1998: 139). Yet a traversable terrain is ultimately insufficient for mobility since access is not just about the physical nature of the built environment, but also has financial, organisational and temporal dimensions (Urry 2007: 191). Indeed, the mobilities paradigm highlights that focusing on access is in fact too narrow to capture the factors shaping immobility.

Broadening the concept of access to encompass concerns of social exclusion explicates the role of social relations in structuring mobility and immobility since ‘social inclusion increasingly demands the capacity to form and develop various social networks’ (Cass, Shove and Urry 2005: 545). Access should therefore ‘not be limited to describing the exclusion of predefined social groups from certain formal or public services’ (Cass, Shove and Urry 2005: 553). Instead it must encompass spatial and temporal access to social networks that may themselves be mobile: ‘social inclusion is a matter of overcoming constraints of space at particular moments of time so as to gain access to the informal networks of work, leisure, friendship and family’ (Urry 2007: 193). Mobilities must thus be considered ‘in differential and relational ways’ that account for power and context (Adey 2006: 83). Indeed, the ‘location of key life activities plus differences in the ability to trade time for space in movement and interaction through various forms of mobility can effectively exclude some individuals and groups’ not just from the ‘institutions, services and information that are standard for a particular society’ (Uteng 2009: 1069), but also social networks that give meaning to everyday life, identity and citizenship.

Ultimately the mobilities paradigm helps to explore the terrains of everyday life or what some care theorists have termed ‘caringscapes’ that ‘consider the complexity of spatial-temporal frameworks and reflect a range of activities, feelings and reflective positions in people’s mapping and shaping of routes through caring and working’ (Bowlby et al 2010: 6). In asserting that not all times or spaces are equal, a ‘caringscape’ or mobilities perspective ‘incorporates both time and space allowing a view of everyday life that has the potential for disempowerment to be reduced and exploitation to be redressed’ (Watson et al 2004: 341). It is this embodied and experiential formulation of citizenship that I apply when looking at disability provision in Russia, thus demanding consideration of how welfare systems construct rights and well-being.

Citizenship and state welfare provision: a complicated relationship

Welfare provision is frequently associated with the question of citizenship because it represents an important arena of interaction between individuals and modern states. In British sociology, social policies were most famously linked to citizenship by T. H. Marshall, who argued that ‘social citizenship’ was the culmination of a gradual process by which the population received greater rights and entitlements from the state. For him, ‘social rights’ went beyond civil freedoms and political rights to assert that citizens should be included in societal institutions, allowed to participate in society and have basic needs met (Marshall 1950). He felt that state welfare provision should underpin this equality and form an integral part of citizenship rather than a form of charity, contract or philanthropy that could be withdrawn at any moment (Powell 2002: 231). His firm conviction that inclusion in society is crucial to citizenship and should be guaranteed by state welfare policies led to ‘a fundamental transformation of our thinking on equality, [which] became more than a formal principle (equality in status), involving some measure of socio-economic reality (equality in practice)’ (Jenson and Papillon 2001: 9).

Although it can be criticised as empirically and normatively unproven,[6] Marshall’s concept of social citizenship should be valued for inspiring ‘the study of social rights and of the ways in which they were or were not served by welfare systems and social policy’ (Roche 2002: 70). He highlighted that welfare states can affect life chances, social position, levels of inclusion and respect from others, although how they do this is an open question that requires empirical research in specific contexts. Indeed, large differences in the evolution of social policies around the world mean that ‘the national specificity of citizenship is most easily acknowledged when social rights, especially in welfare state regimes, are compared’ (Saraceno 1997: 28). The social citizenship concept is therefore best used to analyse the consequences of welfare policies and systems: ‘the pivotal question is not whether the state has to take public responsibility for care and whether the state has to guarantee citizens the right to give or receive care; the question is to what extent, at which costs, and on the basis of what assumptions and

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[6] Marshall’s concept of social citizenship has been variously questioned on the grounds that it neglects welfare cuts, ignores social difference, fails to consider informal family care and does not recognise how state intervention in people’s lives may be negative or controlling (e.g. Roche 2002; Powell 2002).

conditions is this responsibility undertaken' (Knijn and Kremer 1997: 349). This demands consideration of how the state purportedly 'cares' for the population.

In seeking to unpack how the state is experienced in everyday life, particularly in terms of structuring the well-being and social position underlying 'social citizenship,' we first need to understand the nature of a state. Investigating social citizenship 'from below' entails a conceptualisation of states as patchworks of disparate actors and institutions with interests, norms and practices that often clash (Morgen and Maskovsky 2003: 328). Such a pluralistic concept of the state challenges the positivist thinking often found in political science and legal studies that reifies 'the state' as a coherent actor (cf. Clarke 2004: 18; Cullen Dunn 2008: 245). A multi-layered and fragmented conceptualisation of the state has distinct consequences for the study of citizenship, requiring us to look at the 'complex bundle' of links between individuals and the miscellaneous organisations and practices falling under the banner of the state (Kubik 2009: 2). It also muddies ideas of the state having clear margins, revealing that 'the boundary between state and society is not given once and for all, but constructed, contested and deconstructed through [everyday] practices' (Bierschenk 2008: 1). Research therefore needs to be sensitive to the 'multifaceted and contradictory nature of state bureaucracies' (Read and Thelen 2007: 5) and grasp the complex ways in which the state apparatus may shape daily experience. Informed by the cultural or postmodern turn in social sciences, John Clarke therefore urges us to 'think of welfare states as more than income distribution systems – and to grasp their relationship to social landscapes in much more dynamic, contested and complex ways' (Clarke 2004: 1). Welfare states and social life directly influence and mutually constitute each other such that citizens 'not only tap state institutions but also articulate them in their social lives and cultural values' (Ganesh et al 2005: 3-4).

Given the force and resources commanded by state systems, power is central to analysing state-citizen relationships. This is because the supposedly benevolent functions of the welfare state are entwined with the exercise of authority and control. It is highly revealing that Wendy Brown sees states as 'a significantly unbounded terrain of powers and techniques, an ensemble of discourses, rules and practices cohabiting in limiting, tension ridden, often contradictory relation to each other' (1995: 174). It follows from a pluralistic concept of the state as a collection of disparate organisations that power can be exerted in many ways and sites such that experiences of citizenship will depend on specific contexts. The disjointed nature of the state is therefore important for understanding how users of social services may be oppressed by state provision. Joan Tronto's lucid account of how the separation in caring processes between decision-making and actual welfare delivery deflects control and responsibility is useful for thinking about how policymakers act:

> 'Generically, those who are responsible for "taking care of" a problem, and perhaps spend money to alleviate a problem, do not feel that they need to supervise the interaction of care-givers and care-receivers. If care-receivers feel aggrieved, they cannot complain to those who have not provided the direct care, because that is not their responsibility. Dividing up responsibility privileges those who are excused by not needing to provide care; thus, the privileged avoid responding directly to the actual processes of care and the meeting of basic needs'
>
> (Tronto 1993: 121)

Thus, policymakers determine the resources, structures and practices used by frontline care workers to deliver care, but can ultimately evade direct accountability for their decisions by being remote and removed. At the same time, it is important to add that the distance between policymakers, frontline staff and users of state services creates room for bottom-up agency and the reworking of rules and regulations as they are interpreted and implemented in local contexts (e.g. Stone 2000; Read 2007). Indeed, the relations and agency underlying citizenship means that dominant discourses and official practices concerning rights and entitlements can be contested, reworked and subverted from below, as highlighted in various anthropologies of welfare (Curtis 1999; Morgen and Maskovsky 2003).

How does the welfare state disable?

The critical perspectives on welfare provision offered by disability and care theorists highlight that, far from guaranteeing citizenship, state social provision entails a constant 'tension between promoting rights, enabling citizenship and paternalistic protection' (Rioux 2002: 211). This ambiguity stems from the possibility that the inherent power inequalities in caring relationships will be abused such that care becomes 'an imposition and intrusion which can be oppressive and, when it turns the disabled person into a supplicant, is experienced as being at odds with dignity' (Kittay 2011: 50). Claims to state-provided 'care' and 'protection' have historically been more widely available to disabled people than rights to equal citizenship and inclusion in society, explaining why the term 'disabled citizen' can sound contradictory (Meekosha and Dowse 1997: 50). Indeed, 'not only has state welfare not ensured the citizenship rights of disabled people, but through some of its provisions and practices it has infringed and even taken away some of these rights' (Oliver 1996: 52).

Conceptualising the state as encompassing multiple actors, discourses and practices implies that a wide range of institutions, norms and personnel influence constructions of social citizenship. Care theories are useful in examining how states affect everyday life and well-being through their focus on relationships and power inequalities. Although it originated in the study of informal and familial relationships – for example between a parent and child – the concept of care has been extended to encompass the study of state welfare and citizenship (e.g. Knijn and Kremer 1997; Sevenhuijsen 1998). The resulting notion of 'social care' helps to explore how 'welfare states have the potential to alter the nature of social rights (social citizenship) quite substantially' through policies and reforms (Daly and Lewis 2000: 294). Joan Tronto's framework for understanding care as four interrelated processes – caring about, taking care of, care giving and care receiving – is especially useful for clarifying how welfare states influence citizenship and well-being (cf. Ganesh et al 2005: 4-5).

'Caring about' and the construction of needs form the starting point for unpacking the dynamics of how welfare states care, including how control becomes entwined with care when power inequalities are exploited. The 'politics of need interpretation' (Fraser 1987) requires an analysis of 'what can be described as ideologies or social discourses that delineate who should give and who should receive care and in what social circumstances' (Bowlby et al 2010: 38). The definition of needs and appropriate care are intensely context-specific and must therefore be interrogated through historicisation and 'genealogical' investigation (Fraser and Gordon 1994). This helps to reveal the dominant ideas and socio-economic context behind care since 'changing forms and sources of support are as much cultural and ideological as they are economic' (Read

2005: 137). Such work reveals that care is inherently conflictual since it involves 'judgements about needs, conflicting needs, strategies for achieving ends, the responsiveness of care-receivers, and so forth' (Tronto 1993: 137). Indeed, 'care requires societal and personal resources – materials goods, time, skill – that are central political issues in terms of which caring needs, relationships and practices are valued' (Ganesh et al 2005: 5). One danger is the commodification or reification of needs in which processes of care are sidelined and users of services become associated with their purported needs (Tronto 1993: 138). A classic example is that welfare policy 'may classify a disability by a medical condition, and therefore offer the care that condition requires, or it may classify the services that are available and offer provision from these services' (Beckett 2007: 371). Both scenarios offer little scope for the holistic needs of a concrete individual to be considered and do not prioritise the needs and interests of those deemed to require support.

Constructions of need shape citizenship and well-being both by determining the terms on which people can interact with state structures and also by creating particular images and messages about those involved in practices and relations of care. In identifying the messages encoded in policy interpretations of needs, care theories demonstrate how the identification of needs is a morally loaded process in which considerations of deservingness and community affect 'the ways in which certain needs and relationships are validated and supported, whilst others are viewed as blameworthy and deserving of punitive and controlling, rather than supportive responses' (Kay 2011a: 46; cf. Fraser and Gordon 1994). Feminist scholars have long exposed the association of care giving and receiving with a 'feminine other' that signifies weakness, deficit and dependence (e.g. Kittay 1999). Thus, Fraser and Gordon (1994) explored how requiring care and support from other actors became a stigmatised moral identity in Western societies whose modernist precepts emphasise individual autonomy and physical ability. Indeed, the presence of care needs is often ‘conceived as a threat to autonomy, those who have more needs than us appear to be less autonomous, and hence less powerful and less capable’ (Tronto 1993: 120). If such messages underpin the state’s approaches and messages, then it will be implicated in their distribution and legitimation so that ‘these metaphors or discourses are embedded in a wide range of social institutions and practices’ (Bowlby et al 2010: 44).

Examining official concepts of disability is therefore a crucial step in revealing how policies structure the relations between disabled people, state organisations and society. There are strong grounds for arguing that ‘the language of disability is always and already an exercise in categorisation, regulation and discipline’ (Devlin and Pothier 2006: 17). Drawing on the idea of ‘leaky bodies’ (Shildrick 1997), Bill Hughes and his colleagues suggest that the association of disabled people’s bodies with defects constructs them as tragic, burdensome and repulsive ‘waste bins into which non-disabled people project their emotional anxieties about bodily decay and decline’ (Hughes et al 2005: 267). Labelling and categorisation are common topics in disability studies and medical sociology, which highlight how these processes are infused with power inequalities and normativity (e.g. Marks 1999: ch. 6). Deborah Stone’s pioneering *The Disabled State* established that ‘the concept of disability is fundamentally the result of political conflict about distributive criteria and the appropriate recipients of social aid’ (Stone 1984: 172). Matthew Kohrman (2005) has similarly argued that classifications of others reveal much about policymakers' self-image and anxieties through his charting of how official procedures for assessing disability in China developed in line with pressures to appear modern on the international stage. In this vein, Chapter Three discusses the historical evolution of official thinking on disability in Russia, explaining that the medical and productivist undertones of Soviet conceptions of citizenship promoted the disregard of disabled people at rhetorical and resource levels.

Yet, analysing official concepts yields just a partial explanation of how people are categorised as disabled. It is also important to look at the interpretation and utilisation of labels by those allocating and receiving them, which will help to explore the wider issues of agency and identification discussed earlier in this chapter. Micro-level research reveals that processes for classifying people with impairments are contested and flexible in that individual assessments are strongly affected by considerations of deservingness and fairness on the part of professionals (Griffiths 2001; Meershoek, Krumeich and Vos 2007). Another important set of work looks at people's reactions to the assessments they undergo and classifications they receive, considering the 'tension between embracing disability as a fundamental aspect of the self and being categorized as disabled by authoritative others' (Crooks, Chouinard and Wilton 2008: 1837). This type of research asks how people regard and use their disability categorisation in their daily lives and interactions with various state institutions, thus raising questions of self-esteem and emotional engagement with welfare structures. Drawing on Leo Howe's analysis of discourses around unemployment, Rebecca Kay (2011a: 47) comments that 'moral categories of 'deservingness', 'responsibility' and 'contribution' are often tacitly acknowledged and shared by both the affiliated and marginalised,' which may lead to self-exclusion. The study of official conceptualisations of need must therefore be complemented by bottom-up analysis of personal interpretations and reactions to them. As such, Chapter Four on procedures for classifying disability in Russia also discusses how my research participants viewed their legal status as 'invalids.'

Once needs have been defined, caring individuals and organisations must address 'taking care of' aspects that involve 'assuming some responsibility for the identified need and determining how to respond to it' (Tronto 1993: 106). Such tasks require the prioritisation of resources since caring is an activity that 'occurs between those who have needs and those who can provide for those needs' (Tronto 1993: 145), thus creating an inevitable inequality and power imbalance between the welfare provider (often the state) and recipient. Indeed, the state is tasked with regulating risk, resources and behaviours through the credence it gives to particular claims (Fine and Glendinning 2005: 611; cf. Beckett 2007). It must thus design the systems to take care of citizens identified as requiring care, which is a question complicated by 'the existence of conflict within care, by the cultural diversity of what constitutes adequate or good care, and by the scarcity of material or other resources' (Tronto 1993: 110). There is also a risk – strongly associated with beliefs about the expertise of professionals and policymakers – that paternalistic assumptions inform both the definition of needs and decisions about the most appropriate provision to offer (Kittay 1999). Indeed, a lack of opportunities for disabled people to articulate their needs and preferred forms of support means that 'invisibility and voice are conditions that often attend disability and care relations' (Levy and Little 2008: 13).

Tensions between citizenship and the delivery of state social provision and citizenship are an important theme in disability studies, which in many countries developed as a reaction to policies of institutionalisation that excluded disabled people from society and often exposed them to harsh treatment and daily regimes (cf. Finkelstein 1980; Oliver 1996). Such oppressive measures were deemed appropriate for these ‘incomplete’ citizens in order to protect both them and society. The strongest depiction of state care as a mechanism of control is the idea of ‘total institutions’ in which prison-like conditions, for example in asylums, regulate daily life and incarcerate certain groups from mainstream society (Goffman 1961; Ignatieff 1983; Foucault 2006). Speaking of a physically disabled woman living in a state care home, Darja Zavirsek writes that ‘she is included through her “invalid” category but her inclusion is, at the same time, an exclusion from full citizenship rights as she is spatially, politically, economically, and socially excluded. The concept of citizenship rights remains in this way a flexible category’ (Zavirsek 2006: 188-9). Such oppressive policies perpetuate negative messages about disabled people since ‘the “solutions” – the programs and technologies that are being implemented, or that are imagined and planned – influence people’s perception of what the problem is’ (Ingstad and Whyte 2007: 14).

In their explanation of how ‘care giving’ by healthcare personnel may be disempowering, Little and Levy note that ‘the authority of individual health care providers is “nested” within the power of the health care establishment to define disability and impairment, demand compliance with its treatment and rehabilitation regimes, and to deny access to various social benefits by acting as gatekeepers to institutional and governmental programs' (Levy and Little 2008: 7). Here the loci of access and power rest with professionals rather than those to whom care is targeted. It would however be wrong to characterise disabled people and other users of welfare services as powerless in the face of official constructions of need and arrangements for meeting these needs. Bottom-up studies have highlighted that even in conditions of severe oppression, 'weapons of the weak' may be employed to offer some resistance and assert a small amount of autonomy and power (Scott 1985; Curtis 1999; Morgen and Maskovsky 2003). Indeed, Anne White (1999) has explored how disabled residents of Soviet care homes were able to organise correspondence-based networks of mild resistance and even dissidence despite their social and spatial isolation. The power relations exerted within a welfare system should therefore not be seen as exclusively one-way flows, but the result of contestations in which human agency subverts or reworks structural conditions. As discussed in the previous sections about care and mobilities, this agency will be dialectically linked to social relationships, inequalities and broader structures.

In closing the discussion of how welfare states influence citizenship, it is important to recognise that they can be vehicles that promote empowerment and redress inequalities in society. Despite the historically oppressive relationship between state services and disabled people, welfare systems, or at least certain parts of them, have also been the means by which disabled people received support to become equal citizens and overcome their history of discrimination. As Marshall posited, social provision can be an important vehicle of empowerment and inclusion for citizens. Moves to refocus welfare on the priorities of service users have thus been implemented by state structures, albeit in reaction to social pressure (Bereford 2000a). A classic example of welfare states being positive forces comes from the Nordic countries, where voluntary organisations and social reform movements campaign for ‘more state’ in order to solve social problems (Kay 2011b: 4). Indeed, social rights can be ‘both a form of empowerment and a technology of control’ (Carey 2009: 35). Welfare states may therefore both support and undermine the citizenship of groups within society; indeed, their fragmented nature means that these two dynamics may co-exist simultaneously.

Conclusions: a framework for analysing citizenship

The discussions in this chapter aimed to conceptualise the links between citizenship and state welfare provision, thereby providing a theoretical framework for studying the experiences of physically disabled people in contemporary Russia. I argued for the study of citizenship to be grounded in personal experiences in line with research that ‘has moved discussions about social citizenship away from the purely theoretical level by making the practical concerns of citizens an integral part of current debates’ (Beckett 2006: 15). Accounts of citizenship must therefore look at how ‘time, space and place inter-weave with care interdependencies to form caringscapes’ at an individual level (Bowlby et al 2010: 36). Theories of care and mobilities are useful for developing a bottom-up view that sees rights and citizenship as fluid and socially constructed practices shaped by the ‘mutually constitutive relation between personal lives and social policy’ (Lewis 2004: 7). This situational approach to citizenship uses a sociological eye to analyse the concrete relationships, norms, cultural values and struggles over resources that underlie rights in a particular context. Rather than offering a normative benchmark for discussing rights, such work ‘examines the processes involved in claiming and using a right even after it has been legally established’ (Carey 2009: 35). In so doing it finds that ‘the meanings that are attributed to caring work are never ‘given’ but are variable, mutable and … contingent upon the biographical and present resources of the people in the caring relationship, by the public ideologies that bear upon them’ (Watson et al 2004: 342)

An important foundation for this sort of study is a conception of the welfare state as a varied collection of actors, norms and practices. The empirical complexity of the state is why studies of welfare ‘need to ground explanations and ideas in the real and varying world of caring relationships, service providers and governments’ (Bowlby et al 2010: 8). While social provision has the potential to promote inclusion and well-being, its controlling and regulatory functions must also be acknowledged. Furthermore, the determination of entitlements to support is intensely political because ‘categories of need and deservingness are all-too-easily mapped to socially constructed identities and representations of the “respectable” citizen and the “unworthy”, and potentially threatening, “other”’ (Kay 2011a: 46). The case of disabled people shows that welfare systems may undermine equal citizenship by utilising negative conceptions of disability and isolating people with impairments from wider society. Discursive, relational and spatial dynamics of inclusion and exclusion must therefore be the key foci in citizenship studies along with the balance between structure and agency exhibited in people’s interactions with the welfare state. At the same time, citizenship is not just about the ties between individuals and state organisations since wider social relations are crucial to the realisation of rights, be they family, friends, civil society or other citizens.

Overall, bottom-up approaches to citizenship are well-placed to yield insights into how tensions between rights, power and protection play out in the field of welfare provision. Such a perspective admittedly does not allow for easy judgements about whether people 'have' certain rights, but instead gives 'a set of tools and concepts with which to analyse history and the practice of rights in all of its complexity and ambiguity' (Carey 2009: 35). With this in mind, the next chapter on methodology discusses how I used the experiences and narratives of the disabled people I met during my fieldwork to study everyday formations of their social citizenship.

In considering how the concept of citizenship can be used to understand everyday life and experiences of welfare provision, I have deliberately not provided a functional schematic framework around which I will organise empirical material on disabled people's interaction with the Russian welfare system. I instead wanted to present theories from the disability studies, care and mobilities literature holistically and in their context since they come from different disciplines with often divergent political agendas (cf. Hughes et al 2005). This leaves me open to weave references to the various themes and issues explored in this chapter throughout my empirical discussions rather than specifically associating them with a single topic or policy area. Indeed, it should be clear from my theorisation of social citizenship that social relations, power inequalities, mobility and agency are always important dimensions of everyday life. Each of my four empirical chapters does however put emphasis on a particular issue in the practice of citizenship:

- Chapter Four deals with the 'micro-politics' of need interpretation by interrogating the messages contained in the concepts and practices used to classify people as ‘disabled’ in Russia. It therefore considers how the relationship between a disabled citizen and the state is formed and its conceptual foundations.

- Chapter Five focuses on how state organisations structure disabled people’s social relations and position in society through policies that shape their livelihoods, namely education, employment and material well-being. Here I explore official thinking about how disabled people should interact with society and what type of livelihoods they require.
- Chapter Six concentrates on questions of mobility since it looks at the factors facilitating disabled people’s movement and grounding them in particular spaces. It considers the homes of my research participants as important ‘moorings’ in their lives and also looks at the barriers to mobility resulting from the design of the built environment and transport system.
- Chapter Seven addresses questions of agency by considering how people tried to challenge and rework the practices of the welfare state at discursive and practical levels.

It must be recognised that many of the themes in this dissertation cut across chapters, policy areas and sections of life. Indeed, questions of power, agency and mobility ultimately point to the fact that citizenship is constructed through our relations with other people and institutions. My thesis is devoted to studying this inter-relationship between disabled people and the wider world, particularly as it is mediated by the welfare state.

Chapter Two

Disability and social citizenship in Russia: methodological considerations

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In this chapter, I discuss the methodology underpinning my research on how state welfare provision influences the everyday lives and social citizenship of physically disabled people in Russia. As explained in previous chapters, my work seeks to answer calls for more bottom-up studies of citizenship that value people's experiences and opinions. It also addresses the lack of research on lived experiences of disability in Russia. In line with qualitative studies of disability in other settings, my work combines ethnographic data with textual and interview materials. I start this chapter by considering the epistemological issues raised by the qualitative tools I used. I then introduce my fieldwork sites in central Russia, describe the course of my fieldwork and reflect on the practical and ethical issues I encountered.

Developing a qualitative research strategy for studying disability in Russia

My thesis draws on detailed qualitative information to offer a bottom-up perspective on the social citizenship of physically disabled Russians. Qualitative research is premised on the idea that the 'thick description' of a small, purposively selected sample reveals much about their lived realities and daily experiences. It seeks to present individual viewpoints and understandings and to interrogate the wider norms and processes underlying social practices. In so doing, it emphasises that people's agency is embedded within broader social settings and indeed shapes this structural context.

Qualitative work also highlights that cultural, economic and political practices are inextricably linked and dependent on 'local' contexts (Burawoy and Verdery 1999: 14).

My research utilised several qualitative methods by weaving together participant observation with semi-structured interview material and textual analysis. I hesitate from characterising my work as fully ethnographic in view of the strict definitions of this term sometimes adopted by scholars, particularly social anthropologists. However, the liberal interpretations of ethnography given in methodological texts suggest that my thesis falls broadly within this category of research (Brewer 2000: 10-11; Hammersley and Atkinson 1995: 1). Certain work on disability that defines itself as ethnographic or anthropological is actually based on very short fieldwork periods (e.g. Haualand 2007) or else relies significantly on interviews and other non-participating forms of data collection (Kohrman 2005; Phillips 2005). While I spent a total of thirteen months in Russia, I cannot claim to have the closest possible degree of familiarity and insight into how state provision affects the lives of disabled people since I did not reside with my research participants and did not see the same people on a daily basis. Yet, I was frequently invited and reinvited into homes, workplaces, rehabilitation centres and non-governmental organisations, where formal and ad hoc communication gave me an insight into how my research participants live and use state welfare services. Such experiences as pushing an adult wheelchair user seven hundred metres down a busy dual carriageway certainly represent extremely insightful participant observation. I therefore suggest that there are ethnographic dimensions to my methodology, although it was not the only research technique I used.

Rather, my mixed-method research strategy has much in common with other qualitative studies of disability (Deshen 1992; Kohrman 2005; Phillips 2005a). Sarah Phillips, for example, uses multiple forms of data in her anthropological critique of the 'politics of disablement, welfare reform, and changing citizenship regimes in the former Soviet Union' (Phillips 2007: 2). Spending a total of nine months in various Ukrainian towns for her research, she conducted fifteen life history interviews to 'introduce readers to pivotal facets of disability experience' and complement her observations when interacting with activists, policymakers and other professionals in the field of disability provision (ibid.: 3). Such research greatly parallels my thirteen months of fieldwork and attempts to understand how social rights are woven into the fabric of everyday life. The similarities are perhaps unsurprising because the alienated and isolated nature of how disabled people in the post-Soviet region live makes dispersed and multi-sited fieldwork appropriate in the absence of a 'community' of disabled people that researchers could join.

The empirical chapters of my thesis draw heavily on the experiences and narratives of the disabled people that I met during my research. This reflects a belief that people themselves are the best experts about their life experiences and priorities. Such ideas can be found in disability, social policy and development studies, strands of which seek to give people a voice and outlet for expressing their experiences and priorities (cf. Chambers 1995; Charlton 2000; Beresford 2000a; Dwyer 2004; Lister et al 2003). This is seen as empowering respondents, who often hail from vulnerable groups, and making the research less 'extractive' and exploitative. I cannot claim to have a fully participatory methodology in the sense of including people at all stages of the research from developing questions to analysing data and producing conclusions. However, I do share fears that many research methods accord interpretative power to the researcher, simply viewing respondents as passive sources of data. The voice of those who have given their time to share information is frequently lost or quietened in such work. This raises uncomfortable moral questions about the legitimacy of denying people the opportunity to put across their concerns, especially if they are in a weak position. I hope that my methodology helps to allay these concerns by drawing directly on the experiences that people shared with me. Overall, my bottom-up, qualitative approach sought to place people and their own experiences of welfare provision at the centre of attention. This allows for a more equal relationship between researchers and researched, thereby attempting to answer the ethical concerns raised in disability and welfare studies.

Bottom-up studies are important in ensuring that concepts are grounded on real experiences. The sensitive application of theoretical concepts to local contexts is a special concern of area studies in light of concerns that methods, models and theories developed in other regions may be inappropriate in the postsocialist setting (cf. Falkingham 1999; Kandiyoti 1999). One of the greatest strengths of ethnography is its fine detail, which can challenge dominant macro- and meta-level discourses. In my thesis, I am interested in what the experiences of physically disabled people in Russia say about social citizenship and welfare provision in the country. Is it true, for example, that wheelchair users are really physically ‘unable to work’ as posited in Russian law? Or that segregated schools provide the best learning environment for both disabled and non-disabled children? In-depth knowledge of events and structures is a powerful counter to prevailing messages in politics and society about welfare policy and service users. It has for example challenged many of the normative and behaviourist notions behind the ideas of ‘underclass’ and ‘culture of poverty’ (Morris 1994). Qualitative insights can ‘humanize welfare recipients and deconstruct, complicate and contest the ideologically saturated policy discussions of welfare’ (Morgen and Maskovsky 2003: 323). Indeed, the many assumptions and misunderstandings about disability in social research make the study of lived realities very important (Barnes and Mercer 1997).

Qualitative methods have been subject to severe criticisms from both users and opponents of these techniques over their inherent subjectivity. During the 1980s, ethnography suffered a crisis of conscience over the extent to which researchers themselves were responsible for ‘writing culture,’ that is shaping and interpreting research in line with their own background and personal beliefs (Clifford and Marcus 1986). This line of thinking challenged the notion of ‘grounded theory’ that claimed to derive concepts from pure empirics (e.g. Hammersley 1992). In light of such concerns, it is now accepted that it is not possible to approach a topic without some form of personal and theoretical ‘baggage.’ It is therefore important to take a pragmatic approach, acknowledging that the inherent subjectivity of qualitative research does not undermine its worth and in fact raises the question of whether any information in the social sciences can be truly objective. Rather than claiming to find an objective truth, qualitative researchers believe in and represent multiple perspectives and interpretations of events, highlighting the messiness of human life and social reality. Research thus becomes an activity that attempts to convey experiences and representations. The importance of the researcher’s background is being explicitly recognised and great emphasis put on reflexivity to acknowledge the role of personal interpretation in research findings. This involves thinking back on the research process and one's place in it, thereby expanding the 'field' (cf. Brewer 2000: 126-7; Thomas 1993: 46-47). To this end, I consider my own role in 'constructing' the research below, especially in my interactions with research participants.

Fieldwork

This thesis is based on information collected during thirteen months of fieldwork mainly in the central Russian city of Kazan, although I also made short research trips to four other cities in the Volga and Ural regions. I first visited Kazan in December 2006 on a week-long exploratory visit to find a suitable field location. I cannot deny that its relative prosperity and cosmopolitanism appealed in addition to academic and practical reasons for conducting research there. My main fieldwork period lasted from June 2007 until May 2008 and was supplemented with a follow-up visit from October to November 2008.

A strong motivation for making Kazan my fieldwork base was the desirability of undertaking fieldwork in a regional city in Russia. Social provision and living conditions in Moscow and St. Petersburg are highly unrepresentative of Russia due to their better resources and greater international contacts. This is not to argue that Tatarstan or indeed any other city can be regarded as typical of Russia. It is one of the most economically successful regions in the country with distinctive local and political cultures. Although there is a reasonable literature on Tatar national culture and the region's authoritarian politics, no English-language research has been carried out on social provision and welfare policy, let alone disability, in the region. Even most Russian-language research on these topics is limited to unpublished doctoral theses or short grant reports (Kamaltynov 2006; Kuznetsova-Morenko and Panchenko 2008). Indeed, qualitative research on Russia's regions has generally focused on other Volga cities of Samara, Saratov or Ul'yanovsk (Thomson 2000; Yates 2004; Walker 2010), the latter two of which have strong social research centres that support overseas researchers. The upshot is that Kazan along with large swathes of Russia has been overlooked in social research.

What made Tatarstan an even worthier research base was the fact that it has some distinctive disability policies compared to its poorer and politically less influential neighbouring regions. As explained below, Kazan has several new rehabilitation centres and educational programmes for disabled people. Furthermore, disability and other social issues were key themes in Tatarstan's political discourse at the time that I started my fieldwork. This was because the region's president, Mintimer Shaimiev, proclaimed 2007 to be the 'Year of Charity' in Tatarstan and his annual speech to the state parliament explicitly mentioned disabled people as a policy priority.[7] Such rhetoric suggested that social policy developments were likely to happen during my fieldwork period.

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[7] Speech of President Mintimer Shaimiev to the Tatarstan State Council, 2007, available in Russian at http://www.msrt.ru/main/expert/priority/message_pres_gossovet [accessed 8 March 2009, inaccessible on 30 June 2011]

My base in Kazan was the Department of Sociology in Kazan State Medical University (KSMU). The support and interest of colleagues there in my work were important factors in deciding to conduct fieldwork in the city. Indeed, the backing of a local research institution is important for foreign researchers in Russia and I am grateful for the many forms of support provided by staff in Kazan. An earlier research stay at the Higher School of Economics in Moscow had taught me that it is rare to find Russian social policy scholars who conduct and value empirical, qualitative research. The view of an established Moscow academic that two weeks 'in the provinces' would suffice to gather data for my doctoral thesis is not an uncommon attitude to qualitative work in Russia. However, the sociologists at KSMU strongly support the use of qualitative analysis. Indeed, I benefited greatly from discussions with them and was also pleased to work with an institution that so efficiently assisted with visas, registration, housing and many other practical matters that afflict foreigners in Russia.

A social portrait of Kazan and Tatarstan

Kazan is the capital of the Republic of Tatarstan,[8] a region located in the European part of Russia on the Volga river and trans-Siberian train line (see later map in this section). It is Russia's ninth largest city with a population of 1,106,900 people.[9] The city celebrated its 1000-year anniversary in 2005 and whilst the city centre boasts an impressive Kremlin dating back to the time of Ivan the Terrible, the residential suburbs

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[8] Under Russian law, certain regions with non-Russian titular nationalities are allowed to call themselves 'republics' as opposed to regions or areas (*oblast'*, *okrug*).

[9] This and much more detailed information on Tatarstan is available on the page 'Social Portrait of Tatarstan' maintained by the Independent Institute for Social Policy in Moscow, available at http://atlas.socpol.ru/portraits/tatar.shtml [accessed 30 June 2011].

were mainly built during the Soviet era, with most of the population living in apartment blocks no different from those in other Russian cities.

The region of Tatarstan is named after the Tatar national group who are nominally Muslim and some of whom speak Tatar – a Turkic language – as their first language.[10] Roughly equal proportions of ethnic Russians and ethnic Tatars live in Kazan and Tatarstan as a whole, along with small groups of other national groups from the Volga area. Following long Mongol rule, the region was incorporated into the Russian Empire in 1552 and Kazan became an important city for trade and education in the eighteenth and nineteenth centuries, not least due to its population of wealthy German inhabitants. Tatarstan was denied the status of Union Republic during the Soviet Union, which would have placed it on a par with the Baltic, Caucasus and Central Asian states that became independent states in 1991. During the early 1990s, pro-independence movements prompted academic interest in the region, which was perceived as having the potential to become as separatist and conflict-ridden as Chechnya (Derluguian 1999; Frombgen 2001; Robertson 2002). Strong nationalist feelings were first fanned and then subdued by the region's President Mintimer Shaimiev, who then established one of the most tightly controlled and authoritarian regional administrations in Russia (Yemelianova 1999). Widely known in the region as 'Baba' or father, he has ruled since 1991 and always ensured that Tatarstan enjoys significant political autonomy and financial privileges from the federal government (Kusznir 2007). Although he openly

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[10] Both Russian and Tatar are official languages in Tatarstan, but policies of Russification in the tsarist and especially Soviet periods mean that many Tatars, especially those living in larger towns and cities, do not speak Tatar fluently if at all (Wertheim 2003). In general, I found that almost all the inhabitants of Kazan speak Russian and indeed all my interviews were conducted in Russian. Only some Tatar residents speak Tatar language and very few Russians speak Tatar even though it is now a compulsory subject in schools.

supported an unsuccessful rival candidate in the federal presidential elections of 2000, Shaimiev quickly became one of Vladimir Putin's closest allies, returning impressive election results for the pro-Putin United Russia party in return for carte blanche control within Tatarstan (Lussier 2008). This has helped the region to maintain its comparatively generous budgetary and political terms vis-à-vis Moscow.

Tatarstan is today one of the richest regions in the Volga area of Russia. The republic ranks fourth in the UNDP's ranking of human development in Russian regions (UNDP 2007: 118) and average incomes compare favourably to poorer neighbouring republics, from which many students and workers hail. Poverty rates are lower than the Russian average. Significant oil supplies and a chemical industry in the east of the region ensure healthy state finances, while its agricultural sector is among the most successful in Russia thanks to state support and favourable environmental conditions. The fact that many Tatars live in villages means that rural living standards are an important political priority, as a result of which housing in Tatarstan's countryside is of a far higher standard than in general in Russia, with impressive rates of gas and central heating provision in Tatar villages.[11]

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[11] See webpage 'Social Portrait of Tatarstan' maintained by the Independent Institute for Social Policy in Moscow, available at http://atlas.socpol.ru/portraits/tatar.shtml [accessed 15 January 2010]

Map of Kazan, Tatarstan and subsidiary fieldwork sites

The city of Kazan is located in the region of Tatarstan in central Russia, approximately 900km east and thirteen hours by train from Moscow. The region's second city, Naberezhnye Chelny, is due east of Kazan. Of the four other Russian cities I visited on fieldtrips, Yekaterinburg, Chelyabinsk and Tyumen are to the east of Kazan in the Urals and western Siberia, while the Volga city of Samara is in the south.

Source of map: MSN Encarta website, accessed 15 September 2009, http://encarta.msn.com/encnet/features/mapcenter/map.aspx?refid=701516973

Official discourses in Tatarstan have a strong social orientation, making it a very interesting region for studying social citizenship in practice. For much of the 1990s, the regional authorities were proud of what they termed Tatarstan's 'soft landing' to market capitalism (*myagkoe vkhozhdenie v rynok*), which was reflected in subsidised consumer prices, wage equalisation and comparatively generous social assistance schemes. Although local scholars have dismissed this as mere rhetoric (cf. Sergeev 2005), the government is keen to appear innovative in social affairs. In recent years this has meant abandoning previously paternalist social policies in favour of neoliberal social reforms of the sort encouraged by the federal government. Such moves reflect both recognition of the problems afflicting the region's unreformed welfare sphere and a desire to please the federal government. Indeed, loyalty to the Moscow Kremlin means that Tatarstan is often one of the first regions to implement policy recommendations emanating from Moscow, for example the cashing out of social benefits (Wengle and Rasell 2008), creation of social welfare 'agencies' and development of a 'social mortgage' system to replace housing grants. Nonetheless, it would be inaccurate to characterise Tatarstan's welfare system as particularly innovative or distinctive since such rhetoric belies a system that has seen little reform and only partly moved away from Soviet principles (Alexandrova, Surkov and Tesliuc 2008). Other Russian regions have arguably been more innovative in the design of their social programmes, including Samara, Tyumen and Moscow. Yet, there were sufficient interesting developments and elements in Tatarstan's disability policy to make it a worthwhile base for exploring physically disabled people's experiences of social provision.

Disability provision in Kazan and Tatarstan

As shown in the table below, 8.6% of Tatarstan's population is registered as disabled including 15,500 disabled children and 51,690 people classified as having severe disabilities (MTZSZ 2007: 1). 41% of the disabled population are of working-age, which in Russia goes up to fifty-five for women and sixty for men. In line with national trends, the number of officially registered disabled people in the region greatly increased during the 1990s, reflecting a mixture of material hardship and less stigma surrounding disability.

Disability statistics in Tatarstan (accurate on 1 October 2006)

Classification of disability	Number of people
Disabled children	15,500
Adults with III-degree inability to work (most severe)	51,690
Adults with II-degree inability to work	153,834
Adults with I-degree inability to work	88,878
People disabled during the Second World War	5,178
Disabled veterans of other wars and conflicts	11,624
Former concentration camp victims, deemed disabled	118
TOTAL	326,882 8.6% overall population

Source: MTZSZ 2007: 1

The Tatarstan authorities have had an ambivalent approach to disabled people since 1991. Although the former Soviet Supreme Council of Tatarstan approved a regional law on the rights of disabled people in its first reading, the new parliament or *duma* that replaced it after the disintegration of the USSR did not pursue pass such a bill into law (*Gazeta Vybor*, No. 15, February 1994). It also failed to pass regional legislation on disability that would have implemented and strengthened the declarations in the 1995 federal law ‘On the Social Protection of Disabled People.’ The furthest that such legislation proceeded was a draft bill in November 1998. The failure to achieve such a law was much regretted by local disability organisations in Kazan, which publicly supported Mintimer Shaimiev during his [successful] 1995 campaign to be re-elected as President of the region (*Gazeta Vybor*, March 1996). Funds for new rehabilitation centres and work with international partners were less forthcoming in Tatarstan than other Volga cities like Samara and Saratov, arguably reflecting a lack of policy attention and political priority (*Gazeta Vybor*, 21.07.1999, p.6). The relative underdevelopment of disability services may also have been affected by Tatarstan’s tightly controlled political culture that discouraged independent movements and civil society, especially interaction between local organisations and overseas bodies. The upshot was very little policy to improve services and social infrastructure for disabled people.

Nonetheless, there were some useful developments in Tatarstan. The creation as early as 1993 of a newspaper, *Gazeta Vybor* (‘Choice’), for disabled people was an impressive development on the part of the Ministry of Social Protection. This publication’s range of news reports, life stories, legal advice and lighter materials was a valuable source of information for readers and me, as I discuss in later sections of this chapter. A combined day school and rehabilitation centre for disabled children opened in Kazan in 1993 following pressure from parents. It provided a unique opportunity for physically disabled pupils to receive education while living at home. This alternative to institutionalisation in isolated residential homes was a significant advance towards community-based rehabilitation and social inclusion. Unfortunately, the construction of the centre's facilities continues to this day due to very limited funding. Financial pressures also undermined the building of wheelchair-accessible housing in Kazan, plans for which were put forward in 1996, but only partially achieved in 2007.

In recent years, two prestigious rehabilitation centres for physically disabled adults have opened in Tatarstan. One is located in a new housing complex for wheelchair users in Kazan and will be discussed in Chapter Six, while the second is in the region's second-largest city of Nabarezhnye Chelny and was opened in 2007 as a flagship centre of a European Union-funded project that promotes the employment of disabled people. While these centres represent important developments in provision for disabled people, other changes have been less positive. The Tatarstan authorities made cuts to disability provision following national reforms that increased regional responsibilities for social welfare. For example, a technical rehabilitation centre in central Kazan was closed in January 2007, bringing an end to free driving lessons and support in converting cars to hand control. The administrative argument was that such facilities were unnecessary given the abolition of state-provided personal automobiles by the federal government in 2005 (*Gazeta Vybor*, 01.12.2006, p.3). Other changes included the cancellation in Tatarstan legislation of fines on employers who do not observe quotas of disabled employees, which is now simply an administrative offence. Furthermore, regional tax breaks for offering work to people with disabilities ended (*Gazeta Vybor*, 18.08.2006, p.7).

Evaluating the achievements in the field of disability policy in Tatarstan is difficult. The positive rhetoric of the regional Ministry of Social Protection belies the reality for most disabled people, namely exclusion in many arenas of economic and social life. The construction of several educational and rehabilitation facilities has been beset by funding problems, suggesting that disabled people are a low political priority. Nonetheless, Tatarstan has arguably made more progress than many other Russian republics due to higher resources and a political desire to appear innovative in the social field. Indeed, ministerial reports on disability provision from the neighbouring regions of Mari El and Udmurtia can find little new or positive to report beyond the renovation of existing residential care institutions.[12] The case of Tatarstan therefore is one of mixed results, with new projects and policy innovations being offset by inertia or negative developments in other fields. As such, disability policy in the region represents a distinctive mix of Soviet legacies, national regulation and regional developments. Such complexity highlights the importance of ground-level studies, particularly in such a large country as Russia where regional diversity is a key feature of social provision (cf. Stoner-Weiss 1997).

Research methodology

The bulk of my research materials were collected during my main period of fieldwork in Kazan. I speak fluent Russian and conducted all my research in this language. This eleven-month period was valuable in several ways. Firstly, it facilitated the long

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[12] Reports from regional ministries about disability provision can be found on the website of the Volga Resource Network for the Rehabilitation of Disabled People, http://www.sid-vd.ru/?id=1303, accessed 9 March 2009

process of making contacts and gaining insider knowledge. Secondly, it let me track developments in social provision and the lives of research participants over quite a significant period of time. Indeed, I was in frequent contact with a number of disabled research participants and several disability organisations in Kazan. In line with the reasoning given above, I used a range of qualitative methods, aiming to capture the broad spectrum of experiences of disability and policy while also selectively investigating certain issues in greater depth.

Interviews with disabled people: I conducted a total of twenty-four extended interviews with physically disabled people in Kazan and Samara, whose details are listed in Appendix 1 under pseudonyms. I was fortunate to have a wide range of respondents, including young adults, disability activists, military veterans and pensioners. I had three lucky breaks that brought me in contact with these people, which are discussed below in the section on ethical issues. Most of my interviews were recorded on tape and later transcribed by a student at KSMU for me. The formal interviews tended to last one or two hours, although in general the meetings took three or four hours. This was due to the need to introduce ourselves to each other and the great hospitality I was shown, for example drinking tea or meeting other family members. Such communication was no less helpful to gaining an understanding of how disabled people live in Kazan and the fieldnotes that I later wrote (as soon after the meeting as possible) proved to be an invaluable aide and source of information when producing my empirical chapters.

The vast majority of my interviews were conducted with individuals at their home. I considered organising focus groups, especially to discuss my preliminary results. However, this would have been extremely difficult to arrange, requiring a minibus, driver and several volunteers to help research participants reach an accessible building. Indeed, I witnessed the problems encountered by local disability organisations in organising events for disabled people, which demonstrated at first hand the isolated lives of disabled people in Kazan. It was clear that it was much easier for me to travel to respondents even if it meant meeting them separately. This also ensured that the interviews were conducted on ‘friendly’ territory and gave me the opportunity to view their living conditions, thus complementing my interview material and giving an important impression of their everyday life.

At times, friends or relatives present at the home of my research participants also took part in the interviews, which often contributed useful information, especially when we were talking about events that had happened in childhood or been solved by these people. While I did not encounter any overt attempts to influence or cut off the conversation, the presence of parents or other people may clearly have affected responses. For example, people may have been unwilling to share frustrations about daily life or dynamics within their families if they would reflect badly on someone present. The mother of one person to whom I spoke proved very talkative and provided very interesting material on certain questions, but in so doing prevented her adult son from taking part. He even suggested that he could retire to his room and that his mum would finish answering my questions. Even if people were in a different room to us, I felt a little wary of asking probing or possibly sensitive questions, for Russian flats are small and notoriously poorly insulated, making discussions very audible. However, my theoretical focus on the welfare system meant that the bulk of my discussions concerned state provision and everyday life, which are not such intimate topics.

The interviews I conducted were loosely structured. Although I had a list of issues to cover, I was also interested in concerns and themes that emerged naturally during conversation. When beginning the interviews, I explained to research participants that I was researching the everyday life of disabled people in Russia – how they lived, worked, relaxed and made use of state services. This was to avoid forcing the conversation to focus on specific topics and also to capture the many ways in which welfare provision may affect life experiences. I asked people to start the interviews with an autobiographical sketch, a practice that helped to break the ice and gave me an insight into their life history. I then started to explore themes pertinent to everyday life and social policy as outlined in Box 1. The order of questions was not fixed, but rather varied in line with responses and the flow of conversation.

Interview framework

- Short biography – where born/lived, education, employment, marriage, relatives. How long in house/area.
- Where they do their shopping? How they get there?
- Meetings and communication with friends/family. Leisure activities
- Sources of information on social policies
- Use of transport. Did they acquire free transport ticket?
- Use of medical facilities, sanatoria and chemists. Opinion of them.
- Ease of obtaining support from state services. Dealing with social workers and bureaucracy.
- Has life got better in past few years? Why?
- Do they receive assistance from family or friends? Do they give anything in return?
- Links and knowledge of NGOs
- Describe a typical day. Does this change, e.g. during the year?
- What would improve their lives?
- How best to say ‘disabled person’ in Russian.
- Fears, problems and hopes
- Do they know of friends or people who might be willing to give an interview?
- Possibility of follow-up interview?
- Anything they want to add on what has been said or on theme of well-being?

Interaction and observation: during the course of my interviews, I became friends with several of the disabled people I met and thus met them in less professional, more social contexts, usually at home, but sometimes in cafes located in accessible shopping centres. In addition to being extremely pleasant, such meetings gave me valuable insights into their everyday life, concerns and experiences. Another form of interaction was my participation in events organised for disabled people, for example round tables of students, focus groups with mothers of disabled children and events organised every year in Russia to mark the International Day of Persons with Disabilities. Local non-governmental organisations or activists generally invited me to these events. They provided an opportunity to meet more people, hear their concerns and find out more about their lives. Such interaction tended to be spontaneous and not in a formal interview format, so my accounts come from handwritten notes taken at the time and later written up as fieldnotes. These activities meant that I came into contact with a much wider group of disabled people than my twenty-four interviewees.

Archival research in *Gazeta Vybor*: an important part of my empirical material comes from the Tatarstan newspaper *Vybor* (Choice), which is written by professional journalists for pensioners, disabled people and other clients of social policy. It is an independent newspaper with a critical stance towards the regional authorities, who provided financial resources until 1997, but then tried unsuccessfully to close the organisation due to its critical stance. Although the publication charges a low price of eight roubles for each issue (roughly twenty pence), it survives largely on a grant from a federal government agency for non-commercial media. It reports on social policy issues from the point of view of those in need, giving information on legislation, financial questions and important events in addition to more light-hearted items such as horoscope, television programme, recipes and tips for the dacha. The newspaper was founded in 1993 and its archive therefore represents a comprehensive history of regional social policy throughout the post-Soviet period. The editor gave me full access to the archives of back issues and I was able to work through the full collection from 1993 to 2008, including letters written by readers. The newspaper was an extremely useful source of information on the development of welfare services and user assessments of them.

In addition, the journalists published an interview with me about social policy in Britain, which contained a request for disabled readers to write or contact me to tell me of their own experiences of welfare provision. This led to two very interesting interviews with people that otherwise would have been difficult to contact (Ludmila and Venera). I usually spent one or two afternoons each week at the newspaper, which gave me an excellent insight into how this small organisation operates. The newspaper's staff were a great source of insider information and after a few months I was incorporated into their 'group,' participating in tea breaks and conversations.

Visits to welfare centres: I visited the main social assistance centres serving disabled adults and children in Kazan (see list in Appendix 2). In most cases, I was able to gain access through my own efforts, although personal friends did arrange a visit to a residential home for children with mental disabilities on the outskirts of the city. Several institutions were used to visits from local and foreign delegations (one of my friends noted that 'otherwise they wouldn't let you come'), but their directors still dedicated much time and effort to showing me around and answering questions openly in formal interviews as part of my visits. In addition, I talked to several policymakers, ministerial experts and medical specialists (listed in Appendix 3). The most useful meetings were with people who had concrete experience of disability services. My requests for interviews were denied on three occasions: by two heads of district-level social services and by the civil servant explicitly responsible for disability policy in Kazan. All referred me to superiors in the regional Ministry of Social Protection, a stalling tactic which colleagues at KSMU agreed amounted to a no. These rebuttals were however not damaging to my study given its focus on disabled people's own experiences of welfare provision. They also perhaps reveal awareness within the state sector that disability provision is not as impressive as official rhetoric suggests.

Visits to disability organisations in Kazan and the Volga-Ural region: during the course of my fieldwork in Kazan, I visited most of the non-governmental organisations and self-help groups working with disabled people in Kazan to find out about their work (see list in appendix). *Gazeta Vybor* publishes an annual list of organisations and service centres working with disabled people, which greatly eased the process of compiling contacts. Although I was based in Kazan, I also made short research visits to five other cities in Russia. Samara and Ekaterinburg are large wealthy regional cities like Kazan, while Ioshkar-Ola is the small-town capital of the poor Mari El region neighbouring Tatarstan. Chelyabinsk is an industrial city in the Urals, while Tyumen is a small, but wealthy city in Western Siberia and hub for natural resources. Due to limited time, the usual format of these trips was to meet with local disability activists and organisations to discuss their assessments of local provision. I made three trips of several days to the disability organisation *Desnitsa* in Samara, whose staff happily talked to me about personal experiences and work. They also invited me along to events where I could meet disabled children and their parents. In Tyumen I was fortunate enough to visit a school and employment centre for disabled people, organised by the extremely helpful guide I had from the local branch of the Russian Association of Disabled People, known by its abbreviations *VOI*. These visits provided a valuable comparative perspective on policies and provision in Tatarstan as well as an insight into Russia’s disability movement.

As discussed earlier in this chapter, my mixture of interviews, documentary analysis and participant observation follows the methodologies used by other qualitative researchers in the fields of disability and welfare provision (Haney 2002; Kohrman 2005; Phillips 2005). However, it was also shaped by opportunities in the field. For example, the valuable archive work I conducted in *Gazeta Vybor* was only possible due to its existence in Kazan and the editor's kind permission to carry out research there. In a different city, I would only have had mainstream press archives at my disposal. Similarly, several key contacts helped me to contact potential research participants, without which my access would have been more limited (the potential implications of such using 'gatekeeper' figures are discussed in the next section).

In explaining how my fieldwork progressed, it is valuable to mention what I did not do or what turned out to be unfeasible. As mentioned above, I did not try to organise focus groups with disabled people due to logistical difficulties. I was also slightly concerned that people would not be as open or comfortable in focus groups as they would in individual settings (cf. Dudwick et al 2002: 17). My focus on disabled people who live at home with families meant that I unfortunately did not receive the opportunity to speak to people who had been disabled for a significant length of time during the Soviet period, most of whom probably live in state residential institutions. I did not try to visit such care homes because I am interested in concrete experiences of citizenship available to physically disabled people living in community settings. As such, my study cannot be seen as universal or representative of all disabled people in Russia. Yet its location and selection of participants are useful since the themes of mobility and spatial access running throughout my thesis are arguably most pronounced with the group of disabled people who supposedly are included in society.

I deliberately concentrated on urban settings in this thesis given that the density of social services is higher in cities and 73% of the Russian population live in urban areas. I also lacked personal contacts that could facilitate access in villages and smaller towns, where I did not want to appear unannounced. Although the archives of *Gazeta Vybor* contained fascinating letters and articles about disabled people living in the Russian countryside, there is no rural dimension to my study. Certainly, rural lifestyles in Russia differ so greatly from those in towns and cities that experiences of disability and citizenship are likely to be dissimilar.

Positioning myself in the research: practical and ethical issues

Before starting my fieldwork, I tried to anticipate the personal, logistical and ethical challenges raised by conducting bottom-up research, especially in an overseas context. In particular, I tried to be sensitive to issues of ‘power’ in the ways that I gathered and later used information. These concerns are perhaps doubly important when working with groups that have traditionally been marginalised, for example disabled people.

Especially when investigating sensitive topics, establishing trust with respondents is essential. Researchers involved in the *Voices of the Poor* project suggested that conducting their work was more difficult in Eastern Europe than other areas of the world since people are not used to speaking openly, especially about their problems (Narayan et al 2000: 11; cf. Kusa 2002: 153). Certainly, ‘unknown interviewers asking questions about income, activity in the shadow economy, attitudes towards public authorities and the like are not necessarily greeted with trust and openness’ in Russia (Piiranien 1997: 47). Most of my research participants were referred to me by mutual acquaintances, which built up some trust, especially among those who had already heard about the nature of my interviews. Furthermore, the interviews usually took place in people’s homes, providing a familiar environment for them.

My communication with people in Kazan naturally had to happen in Russian since English is rarely spoken in the country, especially by older people. Furthermore, people can best express their experiences and opinions in their native tongue and are thus often more comfortable in interviews. Local colleagues told me that my spoken Russian was near-native in level and it was rarely an impediment during my fieldwork. I certainly did not have to employ a translator and could even arrange all meetings myself by telephone. The few misunderstandings that did occur were sometimes even useful, as people reformulated what they had said or elaborated on particular points. Since my interviews took the format of a conversation rather than tight question-answer format, I was able to elicit much information with just gentle prompts, which reduced the speaking that I had to do. I employed a student at Kazan State Medical University to transcribe my recorded interviews, thus ensuring an accurate rendering of the conversation. Translations are my own, in which I have placed more emphasis on portraying the meaning of what was said in Russian rather than offering a literal account in light of the fact that ‘language is not simply a neutral medium of communication, but inextricably bound up with politics' (Mueller 2007: 208). This is true when working in just one language and especially perilous when translating between languages. For example, the term *invalid* is widely used in Russian, but the translation 'disabled person' does not fully reflect its negative connotations in English. Similarly the Russian terms used in opposition to disability, for example *zdorovyi* (healthy) and *normal'nyi* (normal), imply that non-disability to be valued as positive. In my empirical chapters I therefore give the Russian language term and a contextual explanation of its definition when useful to emphasise the intended – or indeed ambiguous – meaning of a word from an interview extract or document.

An important element of establishing rapport involves giving a research participant a feeling of truly participating and having control over the research. I asked each person I interviewed whether they wanted to 'get to know each other' (*poznakomit'sya*) first or whether we should complete the semi-structured interview and then talk. Either option let me obtain important information and break the proverbial ice. I emphasised that people could pass on any question and did not broach certain topics when they seemed to be problematic or sensitive. Also, I enquired whether people would prefer to conduct the interview without a tape recorder and whether they wanted to hear the recording once completed. No one rejected the recorder or seemed to mind its presence, although one interviewee did ask me to erase certain parts of an interview (names and personal details) after I played the recording back to him. Rather than taking a formal question-answer format, the meetings were more like conversations. People themselves often asked many questions, both about my work and more widely about my past and family. I was often asked why I was researching the lives of disabled people in Russia, sometimes being told melancholically that only a foreign researcher would be interested in such a topic. Interestingly, the Tatar respondents would focus their questions on the ‘republic’ or ‘Tatarstan’ while Russians were more general in their comments and enquiries about the country as a whole. Indeed, I heard fascinating stories and opinions about Russian-Tatar relations within Tatarstan ranging from those that fitted with my academic understanding of the situation to interpretations which were quite emotional and sometimes highly politically incorrect.

Meeting and spending time with welfare users in a way that facilitates observation and frank discussion is often tricky, requiring assistance from ‘gatekeeper’ figures familiar with the local context. I was lucky with the support I received. Firstly, one of the researchers at Kazan State Medical University had conducted a small piece of research on education for disabled people in Kazan (Kuznetsova-Morenko and Panchenko 2008) and was able to put me in contact with several possible research participants. Since they had already participated in research interviews, these people were both familiar with answering questions and prepared to talk. I was able to ‘snowball’ from these respondents, who often knew other disabled people from school or rehabilitation centres. A second break was when I met representatives of the disability organisation *Desnitsa* at a conference held at KSMU. They invited me to visit them in the city of Samara and organised in-depth interviews with their staff and visits to certain institutions in Samara. Thirdly, the director of the recently opened housing/rehabilitation centre in Kazan was very supportive of my research and put me in contact with twenty people living at her complex. Although I initially feared that her selection process would be biased, the experiences and opinions I heard about were in fact very mixed. I therefore do not feel that those who facilitated my research had a particular agenda or filtered my access to respondents. Rather, they were all keen for the topic of disability to receive wider attention since they themselves understood the everyday restrictions on disabled people caused by a lack of political attention and resources.

It would be misleading to suggest that I never felt frustrated, lonely or upset during my fieldwork period. There certainly were days when I did not want to phone around to organise interviews and when even small features of daily life in Russia unduly annoyed or unsettled me. Also, I heard some depressing stories of how disabled people in Kazan are forced to live. However, at these times I was able to look over interview transcripts or continue my archival research at *Gazeta Vybor*, which provided a pleasant and quiet working atmosphere. In general, however, I found interviews and meetings very stimulating and useful in maintaining the momentum of my research. I was lucky that I did not have to engage with figures who I found unpleasant or frustrating during the course of my research; the worst problems were extricating myself from a particularly talkative local activist in Kazan or consuming the substantial amounts of homemade vodka plied on me by the head of the Association of the Blind in the region of Mari El.

Like all foreign researchers in Russia, I had to 'navigate the bureaucratic quagmires of Russian officialdom' before and during my fieldwork which can be somewhat physically and mentally draining (Caldwell 2004: xiii). The first stage is often visa-related, but my host university was able to arrange an official one-year, multi-entry visa for me and register me with the police in Kazan, so I did not have any problems with my paperwork. My fieldwork period in Kazan fell over both parliamentary and presidential elections in Russia, as well as several diplomatic incidents between Russia and the United Kingdom. I personally received no attention from official structures, although my supervisor at Kazan State Medical University did tell me that the authorities (either Federal Migration Service or Federal Security Service, the successor organisation to the KGB) telephoned her to enquire about my activities in the city. My focus on disabled people's experiences meant that I did not have to interact with many officials or politicians and therefore did not draw significant attention to myself.

Throughout my stay in Russia, I was aware of how my status as a young, foreign male affected attitudes towards me and how I could conduct research. Apart from the reluctance of some civil servants to talk to me, my foreignness did not seem to impede my research and perhaps even facilitated it in that it was novel for an Englishman to be interested in disability issues in Russia. Given the gendered nature of Russia's social sector, the professionals I met were mainly women; the only men I interviewed were the director of a refurbished rehabilitation centre in Naberezhnye Chelny and the heads of various disability organisations. Gender dynamics were not so important in interviews with professionals, but did play out in discussions with disabled people. In particular, I could not talk about such issues as sex and having children with female research participants, for such intimate conversations rarely take place across the sexes in Russia. I was also unaware of whether the health problems of my research participants might affect their sexual activities and did not want to pry. However, I did broach occasionally the issues of relationships and sex with male interviewees who were married or had a girlfriend. They surprised me with their open and natural responses.

My foreign background, especially my perceived Britishness, played out in several ways during my fieldwork. Many research participants were interested in social and disability policy in Britain, which forced me to learn about developments in my own country. My nationality also established that I was probably wealthier than my respondents. Alone the fact that I was able to travel aboard to conduct research implied a level of income well above the average in Tatarstan. I was careful to answer questions about my ESRC scholarship, flat in Kazan and family home in England with reference to the higher cost of living in the UK. There was however an understanding that Western Europeans would have a higher level of material well-being than inhabitants of a regional city in Russia. I did not sense expectations or pressure as the result of my comparative wealth, certainly much less than when I had travelled to Russian villages or small towns. However, sometimes my younger research participants requested that I bring records from the UK for them by artists difficult to find in Russia or unavailable for download from unofficial websites. I did buy the occasional compact disc or small souvenir for research participants who had been especially helpful or whom I saw regularly, but this was the limit of my generosity.

During my research I was often faced with the issue of how to thank research participants for their time and frequently great hospitality. I generally took a box of chocolates with me to interviews. This was often appropriate as I would drink tea with them either during or after the interview, although it often did not balance the expenditure on food made by research participants who decided to feed me. Some were especially keen to treat me to several impressive feasts of Russian and Tatar specialities.

In the run up to New Year, calendars with photographs of Britain were also popular gifts that I gave. I rarely brought gifts for officials, with one exception being vodka purchased for the head of the blind association in Mari El on the advice of my local contact despite my own misgivings about encouraging consumption of alcohol. Most professionals were eager for information about legislation and policy in Britain, which I sent to them with the proviso that it was in English.

Despite not being disabled myself, my research participants never insinuated that I would be unable to understand their situation. Instead, they repeatedly condemned the idea that disabled people should only interact with their kind. It is also difficult to imagine a wheelchair user conducting the kind of research I did given the inaccessible built environment in Kazan. On my part, a lack of awareness about particular aspects of disabled life did sometimes affect my approach. For example, I did not always enquire into specific details of medical treatment or bodily processes for fear of embarrassing or offending people.

When deciding upon a fieldsite, I was often told by Russia specialists that Tatarstan would be a distinctive place to conduct social research due to its ethnic and religious profile and that I should be sensitive to this. I spoke to both Tatars and Russians with disabilities, including some people from mixed families, and only in very few cases did religion or language play an important role for them. For example, Damir was the only research participant to regularly attend religious services and he openly referred to Allah during his interview. Indeed, the influence of Islam on everyday life is very mild in

Kazan, which is a cosmopolitan and Russified city. Just as orthodoxy did not affect the lives of my ethnically Russian respondents, Islam was generally a cultural practice rather than a set of rules for life. So whilst I was working in a distinctive Russian region, its national and cultural specificities did not seem to affect how welfare provision supports social rights.

My status as a researcher did several times create expectations. For example, during a preliminary visit to Kazan in December 2006, the Presidential Advisor for Social Affairs ended our interview (attended by her public relations manager) by asking for my ‘professional’ opinion on how to develop philanthropic activities in the region in light of their upcoming ‘Year of Charity.’ Coming before my fieldwork, this question somewhat threw me. Similarly, I was asked by the director of the children’s rehabilitation centre in Kazan about my impressions of her institution; all I could answer was that the children seemed happy and that staff were obviously doing a good job within the confines of the special education system. My age was a positive thing in most cases; one research participant told me that she expected an older, senior academic and was pleasantly surprised to find a young researcher. Indeed, being 25 during my fieldwork was a particular advantage when talking to disabled students, for it meant that we had university experiences and life course in common.

Where my age and gender did intervene in the course of interviews was over questions about my own background, namely whether I had a girlfriend. This enquiry was often linked to leading questions about the attractiveness of Tatar and/or Russian girls depending on the nationality of research participant(s) in question. I generally deflected such comments by claiming that I was indeed attached and talking about one of my [platonic] female friends in England, or else suggesting that I could not support a girlfriend while I was studying, an answer that fitted well with Russian conditions of life and implied that I was responsible. My research participants may similarly have chosen not to reveal particular features of their personal lives. I did not however sense such deception, especially when directly discussing state welfare services.

Data analysis and revisit

Upon my arrival back in England in May 2008, I decided to analyse my materials by hand rather than with one of the software packages designed for qualitative data (Nvivo, AtlasTI). Such computer programmes are very useful when much of the raw data is in a similar format, for example responses to structured interview questions. However, I had moderate amounts of information in a wide range of formats. Furthermore, doing the analysis by hand – via annotations of fieldnotes and lists of references to interview transcripts and archival sources – meant that I did not dissect the narratives of my research participants, but could understand their points in context. When writing about a particular topic, I scanned my indexes and annotations for relevant material and then returned to the full texts. I did not look at the frequency of particular concerns or words, but rather at the range and nature of experiences, purposively selecting examples that best illustrated the nature of disabled people's social citizenship.

I returned to Kazan for two months in late 2008 in order to check facts and gain a sense of what, if anything, had changed in the lives and social provision of my research participants. I was also able to discuss my preliminary analysis with a fellow researcher at KSMU and several of the disabled people who had taken part in my research. Although I originally planned to show actual drafts of my work, it was not possible to produce these in time for my revisit, especially not in Russian. However, conversations about my initial findings did improve my work and show respondents what had been achieved with their interview narratives.

Conclusions

In this chapter, I have recounted the qualitative research strategy I used to investigate everyday experiences of disability, citizenship and social provision in Russia. I explained that qualitative information is important in my thesis to reveal the concrete formations of social citizenship available to a group of people that has historically been oppressed by state services in Russia. Focussing on the voices of people does not just provide important empirical materials, but also values research participants and their experiences.

In discussing my fieldwork in the city of Kazan, I emphasised the benefit of conducting research in regional Russia, especially in Tatarstan where politicians stress the social orientation of their policies and where there have been recent developments in state services for disabled people. My mix of qualitative methods enabled me to gather a great range of information on how disabled people negotiate local and national welfare systems. In reflecting on the fieldwork process, especially my interaction with people, I considered my own role in influencing the production of data as a young British male without a disability. While my background clearly meant I could not ‘go native,’ an open and empathetic approach did give me glimpses into how state organisations structure the social citizenship of my research participants.

I have woven quotes, observations and personal stories into the chapters that follow. I am perhaps proudest of my biographical interviews, each of which was a unique and fascinating account and yielded extremely useful information for my empirical discussions. The great respect I hold for my research participants underscores my rationale for a bottom-up approach that lets me present their experiences and concerns. The archives of *Gazeta Vybor* were valuable for understanding the changing social policy context and learning more about the frustrations, opportunities and problems faced by disabled people who make use of state welfare services. These have long existed, although their specific nature has changed over time, as highlighted in the historical overview of Russian disability policy given in the next chapter.

Chapter Three

Historical perspectives on disabled people's citizenship in Russia

* * *

In 1986, a Russian disability activist in exile penned a damning critique of Soviet disability policy called *There are no disabled people in the USSR!* (Fefelov 1986). The title was a quote from a Soviet apparatchik tasked with explaining why the Soviet Union would not participate in the first Paralympic Games. The spokesman's refusal to even acknowledge the existence of citizens with disabilities reflects the discriminatory attitudes and practices of the Soviet authorities towards this group. It is important to understand these antecedents of disability policy in Russia, for they scar the social citizenship of disabled people today. Chapter One highlighted that welfare systems may undermine citizenship and indeed the care provided by the Soviet state served to control and isolate disabled people. This chapter therefore looks at the historical development of ideas and practices underlying the citizenship and welfare provision of people with disabilities. I offer a largely chronological account of Russian disability policy that reveals how new approaches, including influences from abroad, have always been woven onto older institutional and ideological constructions in ways that result in considerable continuity. The increasing regionalisation of Russia's welfare state is an important part of this evolution and makes a research focus on local policies and practices extremely relevant. We ultimately find that disability provision in today's Russia is characterised by a combination of Soviet, post-Soviet and neoliberal elements that fuses ideas of social rights with notions of inability and dependency.

Soviet disability policies: paternalistic control

Disability policy in the USSR is best understood in the context of the ideal-type of society that the Soviet authorities sought to portray and build. Chapter One discussed how social polices affect the relationship between states and citizens by determining their rights, needs, entitlements and everyday life. The Soviet Union's notion of citizenship was strongly linked to Marxist-Leninist ideology, which prized labour and military service, and by extension physical health. Work was valued in itself as a form of self-realisation for workers and instrumentally as a means of supporting the Soviet economy. Indeed, the Soviet understanding of disability was an inability to work in line with one's professional qualifications.[13] Disabled people were not regarded as full citizens because they could not fulfil the expectation of [manual] work that accompanied rights and recognition in Soviet ideology. Sarah Phillips (2009: webpage) has described this as a 'functional' model of disability that stands in contrast to the 'individual tragic' model that dominated approaches in Britain, America and elsewhere until the early 1960s. She is correct that the Soviet conception drew attention to the social consequences of disability, even if it focused overwhelmingly on employment. However, I would refrain from her idea that this could be called a 'social model,' for the causes of disability were nonetheless located in individual health rather than social conditions.

The experiences of disabled people in the Soviet Union represent an important criticism of scholarly work that characterise state-society relations in the USSR as a 'social

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[13] See entry 'Invalidnost'', *Great Soviet Encyclopaedia*, available at http://bse.sci-lib.com/article053691.html [accessed 30 June 2011]

contract' in which the authorities guaranteed material sufficiency in return for political compliance from the population (e.g. Cook 1993). This interpretation has come under justified criticism for implying that Soviet citizens had a choice in acquiescing to the country's political and welfare systems and in light of regional differences in material provision (Ashwin 1999: 5). The analogy is furthermore flawed because it fails to account for how the Soviet state treated particular groups of the population. Mentally and physically disabled people, sexual minorities and certain ethnic and national groups were excluded from mainstream society and often subject to repression. The Soviet welfare state was therefore far from universal in its coverage and the 'social contract' made with citizens did not apply to the non-working population (White 1999: 30). Indeed, the Soviet authorities denied the existence of such social 'ills' as disability and poverty because they did not fit with their ideological interpretation of socialist society as consisting of healthy and productive citizens.

It is more accurate to view the Soviet state's relationship with its citizens as one of imposed paternalism, in which the state assumed almost full responsibility for public welfare and accorded individuals little scope to improve their well-being (cf. Zaslavksy 1982). I prefix the term paternalism with the qualifier 'imposed' to emphasise that individual Soviet citizens played a negligible role in defining their welfare need and eligibility for support (cf. Kittay 1999). Rather, disabled people and other vulnerable groups were seen as passive actors reliant on social assistance. Their presumed dependency and care needs thus overrode any notions of citizenship. The Soviet state was symbolically and legally seen as the guardian or 'good father' of these 'defective' people who knew how best to care for them (Zavirsek 2006: 186). The essence of the party state's paternalism was that 'it acted like a father who gives handouts to the children as he sees fit. The Benevolent Father Party educated people to express needs it would then fill, and discouraged them from taking the initiative that would enable them to fill these needs on their own' (Verdery 1996: 25). Such conceptions and practices of state support are evident in the institutionalisation and tight control of the disability movement discussed below.

The early Soviet period

By international standards, early Soviet approaches to disability were remarkably progressive. Scholars such as Lev Vygotskii made important conceptual developments with respect to disability, especially in the fields of child psychology and special education (Gindis 1995). As early as 1918, accommodation and vocational training were offered to disabled Red Army veterans with the aim of 'restoring' (*vostanovit'*) lost labour capacity (Phillips 2009). During the period of the New Economic Policy in the early 1920s, associations of disabled people (blind, deaf and physically disabled) were encouraged to establish companies to provide members with employment, housing and educational facilities. By the late 1950s, such organisations operated 4,200 enterprises employing 219,000 workers (Indolev 2000). These industrial cooperatives (*promkooperatsiya*) were largely closed, inward-looking institutions with their own infrastructure, enterprises and culture (Phillips 2009). Although monitored by state organs, they were officially independent organisations and greatly appreciated by members. Nonetheless these associations reflected a segregationist and work-based approach to disability that was to intensify after 1945.

By the advent of ‘High Stalinism’ in the early 1930s, a marked tendency towards the classification, categorisation and control of disabled people could be identified. In 1932, a classification of disabled people was introduced that remains today: Group 1 (those unable to work and requiring constant care), Group 2 (able to work in special conditions and not requiring full-time care), Group 3 (able to engage in part-time or casual work).[14] Disability pensions varied according to group as well as previous salary, work history and reason for disability. In a political context where work was posited as a citizen’s duty, this new categorisation created a negative image of disabled people as individuals with ‘a standard set of presumed qualities: social (exile), psychological (a loner fixated on one’s own misfortune), work (a low-qualified worker of limited skill and intellect) and economic (dependent, pensioner)’ (Phillips 2009: webpage).

The severity of the Second World War meant that the number of disabled Russians (especially injured men) greatly increased in the 1940s, prompting the expansion of provision for them. However, people who had previously been praised as soldiers and workers encountered a very different attitude from the state once they became disabled. Excluded from employment and free movement, they were often placed in remote residential institutions or isolated collective farms (*kolkhozy*). As elsewhere in the world, disability was conceptualised as a health-related condition of individuals and thus the preserve of medical experts. Very little attempt was made to provide the broader conditions in society that could ensure the participation of people with health

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[14] A similar classification system in relation to the ‘ability to learn’ was introduced for children with the result that some were condemned as ‘completely unable to be taught’ and thus excluded from any form of education (cf. Iarskaia-Smirnova and Romanov 2007).

impairments in work and social life. Extremely low pensions quickly made disability synonymous with poverty, an association that was bolstered by disabled veterans soliciting alms or publicly selling their belongings (Fieseler 2006). As a result, ‘disabled people were typically seen as awkward citizens – objects of pity or compassion who required charity and services’ (Tarasenko 2003: 1). Indeed, while Soviet social engineering and policy was used to redistribute property, reduce class divisions and achieve many other goals, it did not overcome the social factors that precipitated disability. Rather, provision increasingly isolated people with disabilities from broader society by using the care system to promote an image of Soviet society free from disability.

The later Soviet period

Somewhat paradoxically, disabled people were increasingly badly treated as the Soviet welfare state grew more comprehensive and provided greater services to the non-disabled, working population. Disability policy reflected a dual approach – ‘the provision of state support for the material needs of people with disabilities, but within a culture of stigma and social isolation’ (Phillips 2009: webpage). Opportunities to work were reduced, the use of residential care increased and various forms of control asserted over disabled people. Needs were defined in very narrow and exclusively physiological terms such that appropriate care just had to feed and shelter rather than develop broader capabilities and well-being. The very few attempts to facilitate the mobility of disabled people or allow relatives to care for them fostered reliance on the state.

One of the first policy changes reflecting outright hostility towards disabled people on the part of the Soviet state was the closure of their cooperatives in the late 1950s, when most of these enterprises were placed under the control of industrial ministries. This move effectively ended the employment of most people with physical disabilities because managers at general factories did not want to take on ‘unproductive’ workers for fear of not meeting tough production plans (White 1999: 45). Only the All-Russian Society for the Deaf (*Vserossiskoe obshchestvo glukhikh*, hereafter VOG) and All-Russian Society for the Blind (*Vserossiskoe obshchestvo slepykh*, known as VOS) were allowed to continue their activities, financing themselves by supplying finished products to state enterprises. Resigned to the fact that ‘only by separating themselves from the rest of the disabled could they hope for assistance in meeting their special needs’ (Madison 1968: 188), these two organisations grew to represent most blind and deaf people and played a significant role in the provision of employment, vocational training and social assistance. They were however subordinate to the Communist Party and often lacked disabled people in positions of authority (Pursglove and Komarova 2003: 251). Physically disabled people were however left without an organisation to represent their interests until 1988 and thus did not have collective forms of agency or voice.

The Ministry of Social Provision in Soviet Russia (popularly known as *Minsobes*) assumed responsibility for physically disabled people after the disbandment of their cooperative organisations. However, it had a highly negative attitude to disabled people and was primarily concerned with classifying and controlling them. One of its main roles was organising commissions of ‘medical-labour experts’ that assessed disability and rehabilitation needs (*vrachebno-trudovaya ekspertnaya kommissiya*, hereafter

VTEK). The *VTEK*s were allocated targets on the number of disabled people to register in line with practical and ideological requirements that disability should not be acknowledged and all citizens regarded as a potential work force. These commissions therefore monitored disabled people for improvements in health that would permit a reclassification of disability group. Anne White comments that ‘for disabled people, the *VTEK* seems to have embodied the most oppressive features of the Soviet state’ since its decisions were final and disabled people were not represented on the commissions (White 1999: 37).

In addition to determining the degree of ‘inability to work,’ the *VTEK* was responsible for recommending suitable employment and rehabilitation services. Despite a commitment to ‘socialist humanism’ in formulating rehabilitation services, they were poorly co-ordinated and often had contradictory aims (Madison 1968: 191). There was no counselling or psychological therapy and many medical treatments used in the USSR had ‘doubtful value from a Western perspective; difficult to understand, and possibly painful, even punitive (Bridge 2001: 6). Legislation and policy encouraged ‘work therapy’ through the creation of special conditions at work and a quota of two percent of disabled employees at all enterprises. Indeed, Soviet care espoused the idea that work was a natural desire and need for all people (Madison 1968: 186).[15] Despite this mythologisation of work, the Soviet economy did not provide suitable employment to disabled people, who were seen as capable of only a few occupations, generally unskilled and badly paid (Iarskaia-Smirnova 2001: 103). *Minsobes* had no inspectors or sanctions to enforce employment rules and often enterprises registered disabled people

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[15] More critically, the Soviet functional approach to disability can also be seen as a means of social control since schools and workplaces for disabled people were major platforms for Soviet ideological propaganda (Shek 2005: 391).

as employees, but requested that they stay at home. This practice calls into question the validity of official statistics that thirty percent of disabled people were employed in 1988. Thus, employment was not defined as a right of disabled people and consequently they were marked out as different from the rest of the population: not as full ‘worker citizens,’ but as ‘unable’ dependants on care.

Without an employment history that provided wages or work-based pensions, it was very difficult for disabled people in the Soviet Union to make ends meet. Their pensions varied between 21-32% of the average wages of blue and white collar workers (Tsivilev and Rogogin 1990: 185). The system of poverty benefits was poorly developed in the Soviet Union and support for relatives looking after disabled people was practically non-existent, thus preventing the development of informal care in the private sphere. The resulting low incomes of disabled people undermined their well-being and showed that the state conceptualised their needs in very basic and material terms.

The functionalism underlying Soviet social policy resulted in a rigidly differentiated classification system and wide variation in the services provided to disabled people, who received support not on the basis of an individual needs assessment, but rather their association with a particular group and impairment. The elevation of labour and military service in the Soviet Union created a hierarchy of disabilities that remains in Russia today. Soldiers who had been injured during military service were the most privileged in the social assistance system, receiving better pensions and access to separate medical facilities. Even within this group, support varied according to the conflict in which a disabled person had participated, so that veterans of the Second World War were better provided for than soldiers who served in Afghanistan. People injured at work also fared comparatively well, receiving a work-based pension on which to draw. In contrast, children with congenital disabilities were the lowest priority, only receiving financial benefits in 1967 and officially regarded as almost parasitical in their reliance on the state for support (Phillips 2009). Although Soviet culture and press rarely featured disability, contrasting images of disabled people as ‘spongers’ and ‘heroes’ (Iarskaia-Smirnova and Romanov 2009) revealed the alternate messages of disability promoted by the state.

The financial and employment problems of disabled people in the Soviet Union were exacerbated by the disabling nature of its architecture and planning. The inaccessibility of public spaces and resulting immobility of disabled people reflected a normalising ‘ablelist’ culture that alienated impaired bodies (cf. Imrie 2000). Soviet construction was characterised by great uniformity stemming from the top-down production of building plans. Whether in Moscow, Kazan or faraway Siberia, housing blocs, kindergartens, schools and many other buildings were constructed according to a very narrow range of models. In a modernist preoccupation with automobiles and large roads, residential areas were built with pedestrian underpasses and high pavements that highly restricted the mobility of those who could not use steps. The needs of disabled people were not taken into account in blueprints for buildings and public space. For example, bulky Soviet wheelchairs (conforming to a standard model reproduced across the country) were five centimetres wider than the lifts in many high-rise blocks of flats, virtually consigning disabled people living in these flats to isolation within their homes

(Tsiliev and Rogogin 1990: 186). Residents of the many five-floor *khrushchevka* apartment buildings built in the 1950s did not have the dubious luxury of such a lift. In all cases, once wheelchair users reached the street, they encountered many barriers in the form of high pavements, underpasses with steps and muddy areas. Ramps to allow access to and within buildings were virtually unheard of and pavements were not lowered to permit movement. Even such basic necessities as wheelchairs were in short supply – the 1989 economic plan included the import of 20,000 – while the quality of artificial limbs left much to be desired in comparison with international standards (Tsiliev and Rogogin 1990: 186). All this effectively confined disabled people to their homes, thereby perpetuating myths that they were dependent and incapable of activities and self-determination.

The approach of the Soviet state to disabled people can be seen as an attack on difference and deviation from the ideal of the 'new Soviet man,' for 'this was a state that insisted on universal content, anything 'different' was unwanted' (Kikkas 2001: 113). Indeed, disability was a taboo topic for the Soviet press and literature, television and culture had to adhere to the official position that disabled people did not exist in Soviet society. The social utopian slant of propaganda held that 'under communism there would be no disability and disability in the USSR was supposedly diminishing' (White 1999: 25). Disability was not allowed to become part of public knowledge or memory (Zavirsek 2006: 186) and the Soviet Union therefore did not participate in the United Nation's Year of Disability in 1981.

The official secrecy surrounding disability explains why the regime reacted very badly to disabled people who tried to assert their rights or build an independent life (Zavirsek 2006: 190). Not all disabled people were muted by the regime and a nascent disability movement did exist, whereby small networks of disabled people shared information, mutual help and moral support (Indolev 2000). Some circulated unofficial, handwritten publications known as *samizdat* and were occasionally successful in gaining official support at a local level (White 1999: 57). The most outright disabled activists became dissidents affiliated to the Helsinki Watch Group (Phillips 2009). Such activities reinforce the point made in the previous chapter that we must not underrate personal agency in the face of large structural obstacles to realising citizenship. Most activists were united in the larger aim of establishing a nationwide organisation for physically disabled people along the lines of *VOS* and *VOG*. However, the Ministry of Social Provision consistently squashed any proposals to provide disabled people with resources or representation (White 1999: 49). It also suppressed collective expressions of voice by disabled people by sending activists to closed residential institutions (Zavirsek 2006: 190), a tactic that openly reveals how the Soviet Union's social care system functioned as a mechanism of control.

Institutionalisation and defectology

A mixture of misguided care principles and political desire to conceal disabled people from the wider population led to the frequent placement of children and adults in residential homes. This was officially justified by arguments that specialist institutions offered the best provision for these 'defective' citizens. Such thinking was in line with state socialist beliefs in ‘modernisation, communal care and the responsibility of the state to care for the ‘needy’’ (Zavirsek 2006: 192-3). Particularly during the Stalinist period, the promotion of collectivist values meant that state homes and boarding schools were regarded as the best places to raise children and look after disabled people (Bridge 2001: 4). While pro-family policies later allowed for non-disabled children to be raised by parents, the relatives of disabled people were still told to abandon them to state institutions, a move that would begin a lifelong time in prison-like residential homes (White 1999: 32). It was common practice for disabled children living in institutions to be transferred to homes for adults upon their eighteenth birthday. In general, these were residential homes for older people in need of permanent care, so young people with impairments would be sequestered with residents three or four times their age. Having entered the system of institutions, it was very difficult to leave and disabled individuals or the families were given little say in choosing where they would be placed.

State residential care was a main tenet of the Soviet pedagogical discipline ‘defectology’ whose name reveals much about official approaches to disability. This approach was characterised by a philosophy that ‘invalids are “those who had to be cared for in a socialist society”’ (Zavirsek 2006: 189). It was highly individualistic, aiming to change disabled people rather than their social and physical environments (UNICEF 2005: 39). It promoted a separate system of educational facilities in line with the belief that the defects and special needs of disabled children were best treated in specialised institutions. While its combination of medical treatment and education possibly reduced mild and moderate impairments (Sutton 1980), defectology did not adhere to the social model of disability and focused on individuals’ inabilities.

Misdiagnoses of disability were also an acute problem despite the scientific rationale supposedly underlying Soviet defectology. Many children with cerebral palsy were assessed as ‘retarded’ (*oligophrenic* in Soviet terminology) even though their mental capacities were not affected by their condition (Dunn 2000: 161). This was especially harsh because children diagnosed with severe physical or mental disabilities were also pronounced ‘uneducable’ and thus denied a formal education.

While living in residential homes was officially promoted as a ‘right’ provided by a caring state, they in fact acted to remove disabled people from Soviet society (Shek 2005: 383). Firstly, residents of these closed institutions lacked opportunities to participate in society, for example visiting leisure facilities. Their right to employment (and therefore income and activity) was abolished in 1968 on the argument that people could not work and receive social assistance at the same time (White 1999: 37). Secondly, homes were generally located in geographically remote places away from built-up areas. The resulting restrictions on mobility and access to space ensured that disabled ‘inmates’ were neither seen or heard in public, and made it difficult for friends and relatives to visit them. Beyond a few well-known and well-loved sanatoria (for example, Saki in the Crimea), residential homes were overwhelmingly not adjusted to the needs of disabled people and wheelchair users. Residents were thus often confined to their own floors and could not easily move around or leave buildings. Within the institutions, strict time regimes and highly medical approaches often resulted in poor communication and interaction between residents and with staff. The autobiographical writings of Ruben Gallego (2006) paint a very gloomy portrait of life within various Soviet care homes, although other firsthand accounts mention some positive experiences (e.g. Rasiuk 2002, cited in Phillips 2009). Overall institutional care and its associated power inequalities (Oliver 1996) served to undermine the mobility and citizenship of disabled people.

Russian social policy since perestroika: continuity and change

To summarise, the Soviet Union's 'disability policy was paternalistic, segregate [sic] and promoted the social exclusion of disabled people' (Tarasenko 2003: 1). The authorities regarded disabled people as unproductive, shameful and ineligible for the benefits of citizenship. State care was tinged with attempts to control disabled people and decide what they needed. Medical and educational policy thus recommended institutionalisation as the best form of care despite poor conditions and opportunities in residential homes. Disabled people had limited independent resources with little state action to facilitate employment (despite the proclaimed use of work therapy) and mobility. The absence of disabled people in public discourse and public spaces meant that Soviet society had very little information or understanding of disability, which grew increasingly stigmatised. The political, social and cultural bases of disabled people's citizenship were thus very weak.

Like many other social issues, disability was only publicly acknowledged and discussed during the *glasnost'* period under Mikhail Gorbachev. Local groups of disabled people and their relatives were able to take advantage of the freer public sphere to establish self-help groups and campaign for day schools and rehabilitation centres to replace residential institutions (Tsivilev and Rogogin 1990: 181-2). In 1988 disability activists achieved their long-held goal of creating a national association for disabled people, the *Vserossiskoe obshchestvo invalidov* (hereafter *VOI*). Even here, however, *Minsobes* was reluctant to award the organisation full autonomy, trying to place its own candidates on the managing board and turn the association into a semi-state institution (Phillips 2009). Indeed, the organisation later became highly bureaucratic and top-down rather than a genuine vehicle of rights.

It is important to understand changes in Russian disability policy within the broader context of the socio-economic upheavals taking place during the 1990s, for they affected policy processes, state resources and public opinion. Russia's economic transformation away from state planning was more arduous than in many Central European countries due to stop-go policies that left Russia in a prolonged state of partial reform (Hellman 1998). Hyperinflation following the liberalisation of consumer prices in January 1992 reduced the real value of wages, pensions and savings to kopecks, thereby impoverishing large sections of the population (Milanovic 1998). Many enterprises went bankrupt in the face of competitive market conditions, causing unemployment and wage arrears. Coupled with the increased visibility of crime, corruption and inequality, these problems explain why the 1990s are frequently described in Russia as a period of *bardak* or chaos.

Russian social policy was largely unable to help vulnerable groups during these conditions, be they the 'new poor' or groups that had experienced deprivation during the Soviet period. Boris Yeltsin's administration did not have a coherent social model and policies were generally 'instruments for patching holes' in existing systems

(Smirnov and Isaev 1999: 44). It could not afford welfare provision in market conditions and therefore the infrastructure for public health and social care deteriorated. Proposals for social reforms were generally neoliberal in character, but they were often blocked by a hostile Communist-dominated parliament (Cook 2000). It was in these conditions of low funding and politico-economic transformation that the Russian government had to develop a new disability policy as part of the wider task of establishing social services and a social work profession from scratch (Thomson 2002b).

In spite of the inauspicious situation during the 1990s, certain breakthroughs were made in Russian disability policy. In particular, the 1995 federal law 'On the social protection of disabled people' marked a conceptual and legal watershed. This law explicitly stated that disabled people were equal citizens and outlined the rights and social services they enjoyed, adding detail to the throwaway reference to disability made in the country's constitution. A key characteristic of the 1995 law was that it gave a much wider definition of disability than had existed in Soviet legislation:

> The term 'disabled person' [*invalid*] means an individual who has a health impairment with a sustained disorder of bodily functioning caused by disease, injuries or defects, which limit everyday activities and make social protection essential.[16]

This phrase ended the Soviet-era equation of disability with an inability to work and focused attention on everyday activities, thereby adopting a stance more in line with World Health Organisation norms at the time. However, the assertion that health

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[16] Text of 'Federal Law on Social Protection of Disabled Persons in Russian Federation,' available from website of ILO InFocus Programme on Skills, Knowledge and Employability, http://wallis.kezenfogva.iif.hu/eu_konyvtar/Projektek/Vocational_Rehabilitiation/russia/rus_rap/leg_1.htm, accessed 15 August 2009

impairments limit daily activities is suggestive of a medical conception of disability. Indeed, disability is rooted in ‘bodily functioning’ and unequivocally associated with dependence on state welfare provision (cf. Fraser and Gordon 1994). Nonetheless, the 1995 law provided a legislative basis for disability policy that was progressive by Russian and perhaps even international standards (Tarasenko 2003, quoting Elena Iarskaia-Smirnova). It placed an onus on the state to ensure equal opportunities (*ravnye vozmozhnosti*) and the integration of disabled people into society, which were major changes to Soviet approaches.

The 1995 law was significant because it represented a deliberate attempt by the state to humanise state provision for people with disabilities and enshrine their rights to participate in society. However, the law was limited for two reasons: its declarative nature and limited focus on social inclusion. The law itself simply outlined general principles and required additional decrees and regional laws to detail the provision made for disabled people. The federal government programmes that followed the law lacked concrete implementation mechanisms and, perhaps more importantly, additional funding. For one, there were no procedures to enforce provisions relating to accessibility and employment (IDRM 2003). This meant that the 1995 law was largely a guideline document, setting out intentions that could not be fulfilled without requisite funding and policy initiatives. Although federal legislation provided important rights and protection for disabled people, it was ineffective because ‘the policy-practice link is often weak in contemporary Russia’ (Thomson 2002a: 36). The new form of citizenship offered to disabled people was thus largely fictional.

A key example of the failure of the 1995 law to promote an inclusive approach is in the field of education. Establishing that all children have a right to education was an important breakthrough given the purported ‘uneducability’ of some disabled children asserted in Soviet defectology. The establishment of day schools for disabled children during the 1990s was also a victory for parents. Although it was no longer state policy that families should entrust disabled children to the care of state institutions, the system of ‘special’ day schools that emerged in the post-Soviet period maintained the separation of disabled and non-disabled children. The teaching discipline of ‘defectology’ remained despite its reformulation as occasional ‘correctional pedagogy,’ thus continuing the professional separation of teachers of disabled and non-disabled children (Thomson 2002a). Families with disabled children were still confronted by a ‘context of decades of professional medical advice to parents that they place their children in state institutional care and “try again” for a child without “defects”’ (Iarskaia-Smirnova 1999: 69). Indeed, the proportion of disabled children in institutions increased during the 1990s as parents in material deprivation entrusted their children into state care (UNICEF 2005: 16). Deinstitutionalisation was a slow process since there were few programmes for fostering or adopting disabled children and no system of personal assistance to support independent living. This meant that most residents of state homes generally remained in them, be they children or adults. The changes in legislative discourse thus belied significant continuity in the operation of Russian disability services and everyday lives of disabled people, especially adults.

A combination of inactivity at the federal level and local pressures led to the increasing regionalisation of social and disability provision in Russia during the 1990s (cf. Stoner-

Weiss 1997). Local and regional authorities made varying progress in developing family and community-based care in line with their resources and political priorities. A handful passed their own laws on disability, thereby fleshing out points in the 1995 federal law. That this practice was not widespread is partly understandable given empty state coffers and inexperienced social policy makers, which means it is simplistic to claim that disabled people were not high on the government's list of priorities (Dunn 2000: 168). Nonetheless, the fact remained that there was no formal legal framework to underpin disabled people's citizenship, including policies on implementation and resources. Chapter Two explained that a regional legal framework for disability provision was not created in my fieldwork base of Tatarstan, but nonetheless several major projects and services were established such that provision there differs from that in neighbouring towns and regions.

In spite of significant activity of foreign donors and organisations in Russia during the mid-1990s (Wedel 2001; Henderson 2003), it is interesting that Russian disability policy was quite impervious to international influences. Symbolic moves such as adopting the United Nations' International Day of Disabled People (3 December) belied any significant change in the approach or practices taken to disabled people. Indeed, the strongest international actors in Russian social policy focused on the finances underlying welfare provision rather than the well-being of particular groups in society, especially disabled people (Cook 2007). Furthermore, Russian leaders lacked a strong international orientation, did not necessarily reject Soviet practices and tended to perceive few advantages from western-oriented reforms, all features that distinguished them from many countries in central and eastern Europe (Chandler 2001). Yet, this does not mean that there was no attempt to incorporate practices from abroad or that Western eyes were not trained on Russia's disability system (cf. Bridge 2001). Indeed, at a micro-level, attempts were made to build disabled people's organisations and NGOs as well as develop community-based rehabilitation services. However, it was often the 'hardware' of architectural plans and equipment that was adopted rather than broader ideas around how themes of inclusion and citizenship should be instantiated in state welfare. Some Russian disability organisations with an activist style were thus able to establish themselves on the basis of overseas funding (cf. Cook and Vinogradova 2006), although not in my fieldwork location of Kazan as explained in Chapter Seven. However, state structures at a local and regional level absorbed little discourse or practice from abroad with the possible exception of those in north-western Russia where Nordic governments and organisations were strongly involved (Kulmala 1999).

One of the main changes brought about by the 1995 federal law was the replacement of the *VTEK* with 'medical-social expert commissions' (*MSEK*) that are responsible for assessing disability and recommending rehabilitation measures. This change of name was intended to indicate that a new socially oriented approach would be taken to disability, with the inclusion of a social worker and psychologist on the boards. The new definition of disability adopted in the 1995 law meant that 'ability to work' was no longer a primary concern when classifying the disability faced by people, although it was still listed on the *MSEK* documents of individual disabled people. Commissions were instead instructed to focus their assessments on ability to perform everyday activities, which became the criterion on which pensions were awarded. The commissions were also responsible for designing 'individual programmes of rehabilitation' (hereafter IPR), a list of recommendations for medical, social and other forms of treatment and therapy. This innovation was initially heralded as overcoming the highly medical approaches that had previously dominated rehabilitation and disability provision. However, it soon became clear that the *MSEK* continued to operate in a similar fashion to their predecessors. As in the educational field, the same personnel remained in place and professional approaches to disability were not overhauled. Individual health and ability continued to determine diagnoses and existing classification procedures and categorisations of disability remained in place. The practices of the *MSEK* are discussed in greater detail in Chapter Four, which finds that they are a persistent source of frustration for people with disabilities in Russia.

Although some legal changes were made, it proved difficult to overcome the discriminatory attitudes and practices towards disabled people that developed in Soviet Russia. The notion that disabled people are active and equal citizens with full decision-making authority clashed with longstanding policy and professional beliefs that they are largely incapable and therefore dependent on state care. Indeed, 'political changes do not automatically change the social welfare order or the cultural images attached to stigmatised groups seen as "invalids"' (Zavirsek 2006: 189). For many Russians it was a shock to see disability shown and discussed on television since disabled people were almost never seen, heard or written about in the Soviet Union. The stigma around disability in socialist ideology – that disabled people are 'defective' and dependent on others – persisted. This was important since 'society has the power to name and define the identities of disabled people, to formulate and maintain definitions of normality' (Iarskaia-Smirnova 2001: 105). Indeed, hostile attitudes are likely to undermine the possibility of citizenship being inclusive given that rights are constructed and practised through webs of social relations (cf. Lister 2003). Public opinion has thus been a force undoing legislative progress in advancing disabled people's equality, for example in opposing the education of disabled children alongside non-disabled ones (Iarskaia-Smirnova and Romanov 2007: 92). This highlights the unfavourable relational influences on disabled people's citizenship.

Overall, there were mixed developments in the field of disability policy and practice in the 1990s. Following seventy years of Soviet institutional care, it was officially acknowledged that disabled people could and should live in family contexts. The impetus for new approaches to disability often emerged 'from below' as disabled people and their relatives came together to campaign for schools and day centres. However, it proved hard to overcome entrenched practices. Just as the end of the USSR did not fully abolish the Soviet economic and political systems, elements of pre-1985 disability policy persisted and were conjoined with newer influences, for example more socially-inflected laws and classifications. Although the legal bases of disability provision were overhauled, opportunities for achieving real change were however missed due to policy inertia, low resources and a lack of expertise in the social field. Inclusive approaches and ideas were thus not able to take hold and little progress was made in the fields of accessibility, employment or deinstitutionalisation. At the same time, local authorities and regional governments started to assume responsibilities for the social provision of disabled people in frustration at poor funding and guidance from the federal government, especially in the realm of services. Their different approaches and varying resources gave a patchwork effect to disability provision in Russia. This implies that a study of welfare provision should consider developments at a sub-national level, looking at how regional specificities in service provision affect daily life and social rights.

Reform and retrenchment: welfare reform under Vladimir Putin

Russian disability provision was tightened during the presidency of Vladimir Putin from 1999-2008. In contrast to the incremental and stopgap measures of the 1990s, his governments instigated policy reforms to restructure the entire welfare system. The changes were not primarily designed to improve the well-being of people with disabilities, but rather to resolve the chaotic federal relations and opaque state finances that had emerged under Boris Yeltsin, especially in the welfare sector (Cook 2007; Wengle and Rasell 2008). This is an important point, for it means that the interests of disabled people were never the prime focus of policy attention. Indeed, the economists placed in charge of welfare reform in Putin's government took a somewhat hostile approach to disabled people and other 'irrational' service users as summed up by Russia's former Minister of Healthcare and Social Protection Mikhail Zurabov, who asserted that 'there cannot be fifteen million disabled in the country. It's an unreal number,' implying abuse of the disability system (Utro 2005). As a result, disabled people lost out from various legislative changes and the intensification of control and scrutiny in *MSEK* procedures.

One of the early changes to disability policy came in 2002, when tax benefits for charitable organisations were abolished (Lupanova 2002). Before this date, Russian enterprises with more than 50% disabled employees were exempt from value-added and profit taxes as well as employee insurance contributions. This allowed enterprises belonging to disability organisations to survive despite competitive conditions of the market economy. However, these benefits were often abused by corrupt and illegal enterprises, some of which were connected to national disability organisations (Pursglove and Komarova 2003). Rather than improve the monitoring and distribution of tax breaks, the federal government decided to tackle such abuses by cancelling all such benefits. The resulting burden of taxes and employee insurance payments forced many companies with disabled employees into financial difficulties and greatly reduced the employment opportunities for disabled people (Cherkesova 2006). The federal government promised to compensate official disability organisations for this change in tax status, but was very slow in passing the appropriate legislation and awarding remuneration (*Gazeta Vybor*, 18.08.2006, p.2).

The cancellation of the financial privileges of factories and organisations employing disabled people exacerbated what was already a severe problem of unemployment. It is estimated that just ten percent of disabled people in Russia work (Martz 2007). As well as being more likely to be unemployed, people with disabilities endure longer periods without work (MTZSZ 2007: 9). Employment quotas for companies are generally not enforced and often it is cheaper and simpler for employers to pay the requisite fines (if imposed) instead of actually taking on workers with disabilities. In 2005, legal changes meant that quotas of disabled employees only applied to firms with more than a hundred workers rather than the previous thirty. While the quota system is not adhered to in practice, this nonetheless represented a symbolic blow and further reduced the possibilities for disabled people to obtain work.

Another work-related setback came in 2003 when amendments to the pension law delinked disability pensions from a person's overall group of disability that is based on the ability to perform everyday activities. Pension levels were instead related to 'inability to work.' As explained in Chapters Four and Five, the upshot of this law was that disabled people were no longer officially allowed to work while claiming a disability pension. This represented a return to Soviet-era practices and prompted a mass of re-examinations by *MSEK* as disabled people tried to get their inability to work certified with the hope of receiving higher pensions. It is unclear why this policy was introduced, but the fact that it goes against the grain of social interpretations of disability suggests that it originated in the financial ministries of the federal government. The policy change perpetuated the Soviet prioritisation of work and ideas that state care is not about equal citizenship, but basic survival. Indeed, economists dominated Russian social policy during this period (Cook 2007: ch. 4). A proportion of disabled people stopped working as a result of the change, preferring a pension to low wages (Cherkesova 2006). This change was particularly detrimental because it was not accompanied by efforts to improve the employment opportunities of disabled people by reducing the social barriers and obstacles they face. Nor were *MSEK* diagnostic procedures made more humane or realistic; instead, they continued to reflect discriminatory and medicalist interpretations of disability. As discussed in future chapters, the designation that certain disabled people are 'unable to work' undermines their citizenship in several ways and causes them many problems in attempting to make a living.

The 2000s also saw additional changes to procedures for classifying disability and issuing rehabilitation aids. For one, the rules for *MSEK* re-examinations were made tougher, requiring people with permanent health impairments to repeatedly undergo what Chapter Four illustrates is a drawn-out process. There is much evidence to suggest that *MSEK* commissions face pressures to restrict the number of people officially registered as disabled and therefore claiming state assistance (Gazhev 2007). Another development was the stipulation in 2002 that treatment (medical and social rehabilitation) would only be issued on the basis of an 'individual programme of rehabilitation' (IPR) determined by *MSEK*. Before this date, family doctors were able to prescribe assistive aids and arrange various courses of rehabilitation. Following the change, *MSEK* is the only body with such powers and therefore has significant control. This change caused some difficulties for people who had been diagnosed with permanent disability before 2002 and thus did not have an IPR document. In 2007, a law increased the official usage periods for prosthetics and equipment for disabled people, thereby reducing the frequency with which they are replaced at the state's cost (*Gazeta Vybor*, 29.06.2007, p. 7). Wheelchairs, crutches and nappies must now last for longer regardless of how actively or frequently they are actually used. All these moves sought to prescribe the behaviour of disabled people, introduce greater scrutiny and reduce the generosity of state support.

The above-mentioned changes to tax and pension law were made to improve state finances and there was little pretence about considering the interests and well-being of disabled people. However, Vladimir Putin’s re-election in 2004 was swathed in powerful rhetoric about reducing poverty and raising living standards, even if disability was rarely mentioned as an issue. Gaining a large majority in the federal parliament, his government had carte blanche to implement virtually any reform they proposed. One of its first actions was to introduce major social reforms that radically changed the delivery of social benefits and triggered mass protests across the country (Wengle and Rasell 2008).

Law 122 was designed to regulate federal-regional relations in the sphere of public services, including welfare policy. Its 200-odd pages outlined the responsibilities of each tier of government and their funding sources and sought to rectify the administrative and budgetary disorder that developed during the Yeltsin years when the central government often mandated local authorities to provide services without providing the requisite funding (Solanko and Tekoniemi 2005). One of the consequences of the law was that social benefits for disabled people became the policy and financial responsibility of the federal government. Other dimensions of disability policy, for example accessibility, schooling, rehabilitation and social care, became regional tasks, thus increasing the pattern of regionalisation that emerged de facto in the 1990s. The outcome was not necessarily positive for disabled people since the federal government restructured and reduced support while regions were rarely prepared to develop services for them.

The most controversial element of Law 122 was that it replaced many social benefits (free public transport, medicines, sanatoria stays and discounts on utilities) with cash payments. Whereas many groups of the population had previously used these services for free or at discounted rates, after 1 January 2005 they were given cash payments with which they had to pay in full for the services they used. This was known in the country as ‘monetisation’ (*monetizatsiya*) and affected close to thirty million inhabitants, including disabled people, military veterans, pensioners and Chernobyl victims. In line with the differentiation underlying Soviet and, by extension, post-Soviet social policy, the new monthly cash payments varied between different categories of the population and disabled people. For example a person classified as fully ‘unable to work’ received 3,120 roubles (approx. £62) per month in early 2008 on top of their 1,855 rouble (£17) monthly pension (MTZSZ 2007: 2). The state move towards providing cash rather than services was designed to improve the financing of public services, which had deteriorated during the 1990s due to incomplete government funding of the discounts granted to various groups of the population. All categories of disabled people affected by the reforms strongly opposed monetisation due to fears that the new payments would be insufficient to cover the services that had to be paid for upfront (Klimov 2006). Poor explanation and information about the changes exacerbated these fears, showing a lack of care on the part of the state in providing useful material. The reforms prompted spontaneous bottom-up protests, but disabled people found it difficult to participate in them due to accessibility issues.

The monetisation reform was tempered slightly in that people were given the option of retaining a small ‘social package’ (*sotspaket*) of in-kind benefits in return for a reduced cash payment (513 rubles less). This package covered prescription medicines, annual sanatoria trips and local transport. Politicians lauded the option as enhancing consumer choice and making the welfare system more flexible to the needs of different people. In 2006, 50.5% of benefit-recipients across Russia opted to receive higher cash payments instead of the social package, although there is high variation in these numbers by group and region (MZSRRF 2007: 4). Disabled people, for example, were overwhelmingly likely to choose the ‘social package’ and reject the cash option, showing the importance of certain in-kind services for them. However, administrative and financial problems have caused widespread shortages of medicines and sanatoria places each year since the new reform came into effect (Parfitt 2007). Chapter Four discusses how the 2005 reforms affected my research participants, explaining that the theoretical attractiveness of being able to choose between cash and prescription medicines is greatly limited by the latter’s unavailability. Monetisation was thus very much a second-best solution and its botched realisation meant that the reforms did not raise well-being, especially its subjective dimensions. Instead the changes undermined an already weak relationship between state and citizens, as will be discussed in Chapters Four and Seven.

Experts widely hold that disabled people suffered the greatest losses as a result of monetisation (Volchkova et al 2006). Although federal politicians were keen to emphasise that Law 122 replaced rather than cancelled social benefits, one particular aspect of welfare provision for disabled people was abolished outright: free automobile transport. Before 2005, disabled people were eligible to receive small cars adapted to hand-drive fully financed from the state budget. This benefit was scrapped as part of Law 122’s cost-cutting and compensation was not envisaged for disabled people. The consequent termination of state orders for small *Oka* cars was one reason for the cessation of their production by Russian car manufacturers. The government did promise to honour deliveries for all those on waiting lists before January 2005, but very few cars have been provided, with the largest share going to elderly military veterans upon the sixtieth anniversary of the end of the Second World War. Chapter Six will discuss how these cars were crucial to the mobility and livelihoods of my research participants and therefore the type of citizenship and everyday life they enjoyed.

Notwithstanding the developments discussed above, the Putin presidency generally paid little attention to the needs of people with disabilities. Mention of disability was for example absent from the welfarist rhetoric during the 2007-8 election cycle, during which ‘national priority projects’ to improve living standards in the country were announced. None of the four projects (Healthcare, Education, Housing and Agriculture) made specific provision for disabled people, pointing to their invisibility in policy circles. Perhaps the only positive developments were several increases in basic pensions, particularly in the run-up to the 2008 elections. The cash benefit paid to full-time carers of disabled people was more than doubled to a nonetheless meagre 1200 rubles (£60 per month) from 1 July 2008. While improving financial well-being, these moves represent a very narrow approach to disability, implying that disabled people have mainly material needs rather than the inclusion and mobility implied by the concept of social citizenship. Indeed, the absence of moves to encourage social inclusion and participation was striking, with very little policy innovation or development in the fields of education, employment and accessibility.

Conclusions

Overall, the chapter shows that tropes of paternalism, control and hierarchy have long run through state provision and approaches to disabled people in Russia. It is clear that disability policies in Russia today can only be understood with reference to the Soviet past. Soviet state care undermined rather than supported disabled people's citizenship in its core belief that impairment was abnormal, shameful and something to be 'treated' by medical professionals (cf. Marks 1999). Much of the care provided by Soviet state organisations was designed to reduce disabled people's mobility and connections to society, ostensibly in order to help them, but also as a form of social engineering (Phillips 2009). Relations between the state and disabled people as well as between disabled and non-disabled citizens were neither positive nor equally balanced. Current practices are complex evolutions that draw on previous discourses and systems, but rework them in light of more recent conditions. So whilst the *MSEK* may seem to work in the same ways as their Soviet predecessors, 'individual rehabilitation programmes' and the ostensible focus on social rehabilitation are recent developments. A different Soviet policy – the definition of disability as 'inability to work' for pension purposes – was in fact resurrected under Vladimir Putin despite having been abandoned during the 1990s. The continued privileging of people with disabilities resulting from work and military service represents a more straightforward legacy. It would therefore be inaccurate to think that Soviet-era policies have been directly maintained since the collapse of the USSR.

Arguably the most crucial change in Russian disability policy is that a right to live in the community has been recognised. Care and support for disabled people has thus been transferred or ‘privatised’ so that they are now likely to live with their families instead being placed in state institutions on the basis of professional advice. This means that social relations, especially within the family, strongly influence disabled people citizenship (Tronto 1993; Kittay 1999), especially in the absence of professional personal assistance and homecare services. In addition to this ‘neofamilialisation’ of care (Teplova 2007), the role of local and regional actors in disability provision has also increased since the 1990s due to a mixture of official decentralisation and federal government inertia. These changes strengthen my arguments for a bottom-up, local study of citizenship in Russia that captures the diversity on the ground and the frequent discrepancies between proclaimed rights on paper and lived realities.

With Soviet practices and policies continuing to inform current approaches to disability, it is unsurprising that disability policy in Russia pays little attention to social inclusion, mobility and participation. The 1995 Law on Disabled People was mainly declarative, which undermined its achievements of asserting the equal rights of disabled people and introducing a socially informed concept of disability. It did nonetheless represent the first buds of equal citizenship for disabled people. There have however been few wider developments to tackle social barriers and provide a genuinely inclusive form of citizenship. Recent policy changes have concerned financial payments, disability classifications and healthcare provision. As such, disabled people remain characterised in Russian policy as passive ‘receivers’ of assistance rather than potential beneficiaries of policies designed to change the social conditions that cause disabilities. Instead of widening the opportunities and societal participation of disabled people, policies continue to assume that they are dependent on the services and support provided by state organisations. The nature of this dependency has changed – from the state residential care of the Soviet period to the provision of basic benefits – but opportunities for disabled people to live as they wish and build up their own assets remain very limited. Indeed, policy seems far away from the equality and inclusion discussed in Chapter One as the foundation of truly ‘social’ citizenship.

The considerable continuity in welfare practices related to disabled people points to the weak influence of international actors on disability policy, especially at a federal level, but also in terms of local service delivery. Although World Health Organisation definitions were adopted in the 1995 law on disabled people, the creative energy of politics and society in the early post-Soviet period was not utilised to drive change on the basis of foreign knowledge. Some ‘elite’ disabled people’s organisations slowly established strong foreign links and thus had to maintain a balance between meeting local needs and acting as wider advocates (cf. Wedel 2001; Henderson 2003; Hemment 2007), but major reforms in the state sector have not drawn on international practices. Thus, positive models of rehabilitation and community care, for example in Britain or the Nordic countries, have not underpinned the broad development of *MSEK* and welfare provision. As a result, broader discourses about inclusion and equality, which are especially strong in EU and UN circles, have barely shaped how the Russian welfare system works with disabled people.

It is in the context of these powerful structural forces that I conducted my study of how welfare provision affects the everyday social citizenship of disabled people. The themes of my four empirical chapters – needs interpretation and classification, livelihoods, mobility and agency – resonate with the discussions above in that all are affected by distinctive Soviet and post-Soviet heritage. Focussing on personal experiences and perspectives helps us to understand these dimensions of citizenship in the context of disabled people’s lives.

Chapter Four

Classifying disability, rehabilitation and the medical gaze

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This chapter explores official understandings of disability in Russia by examining how my research participants experienced bureaucratic procedures for classifying disability and their needs. I thereby show how the ‘politics of need interpretation’ developed by such care theorists as Fraser (1987) and Tronto (1993) functions in Russia. As discussed in Chapter One, policy concepts and classifications of disability make normative assumptions about people with health impairments and thereby influence the ways in which their needs and rights are understood by state organisations and wider society. Processes of classification and labelling are infused with power inequalities, not least in how they establish the lens through which persons with impairments are regarded and treated by official structures. In view of how the Soviet state regarded disabled people as having largely medical needs arising from their ‘defective’ physiology, as discussed in the previous chapter, I am interested in personal experiences of disability classification in today’s Russia.

I start this chapter by discussing the dominance of the negative term *invalid* in Russian legislation and policy documents and how my research participants sought to challenge its use and implications. I then use firsthand accounts to trace the steps by which medical commissions judge individuals to be disabled and therefore entitled to welfare provision, focusing on personal responses to official labels and definitions. My analysis identifies a strong medical tinge that roots disability in individual bodies and frames welfare services in terms of ‘rehabilitation’ rather than support to reduce the social determinants of disability and exclusion. I also examine how material and rhetorical support for disabled persons in Russia varies according to their supposed ‘contribution’ to society, thereby creating a hierarchy based on a particular understanding of ‘deservingness’ (cf. Kay 2011a). The second part of the chapter focuses on the policy implications of the narrow medical gaze underlying official conceptions of disability in Russia, thus beginning a discussion about how the Russian state ‘takes care of’ disabled people that will run throughout the rest of this thesis (cf. Tronto 1993: 106). I discuss the unfortunate irony that the provision of medicines, equipment and medical treatments is extremely patchy even though disabled people’s needs are largely defined as health-related. Legal entitlements to state support are poorly met and disabled people increasingly use their own resources to obtain services that by law should be provided by state organisations. The conclusion surmises that the official focus on health and impairment – as opposed to social causes of disability – promotes the idea that disabled people are inherently (biologically) different from non-disabled citizens, an understanding that results in exclusionary and unequal policies.

Official discourses about disability

Legislation and policy documents in Russia use a variety of terms to refer to people with bodily impairments, of which the most common remains *invalid*, which is also the word frequently heard in ordinary conversation. The term was widely used during the Soviet period and has singularly negative and health-related connotations, although it is less demeaning than such words as *kaleka* (cripple). In addition to the all-encompassing word *invalid*, other terms describe more specific forms of disability, for example wheelchair user (*kolyasochnik*) or person with spinal injuries (*opornik*).

The word *invalid* appears prominently in the main piece of federal legislation concerning disabled people: the 1995 law '*O sotsial'noi zashchite invalidov v Rossiskoi Federatsii*' (On the Social Protection of Disabled People in the Russian Federation, Law No. 181, 24 November 1995). It is also used in the names of all the disabled peoples' organisations that I met during my fieldwork, including:

- *Vserossiskoe Obshchestvo Invalidov* (All-Russian Society of Disabled People)
- *Samarskaya Obshchestvennaya Organizatsiya Invalidov-Kolyasochnikov "Desnitsa"* (Samara Community Organisation of Disabled People and Wheelchair Users "Desnitsa")
- *Obshchestvennaya Organizatsiya Invalidov "Vera"* (Community Organisation of Disabled People "Vera")
- *Regional'naya Obshchestvennaya Organizatsiya Invalidov "Perspektiva"* (Regional Community Organisation of Disabled People "Perspektiva")

Even though some of these organisations actively promote principles of independent living and human rights (especially *Desnitsa* and *Perspektiva*), they have adopted the official terminology of *invalid* to make their activities clearer to outside parties, including governmental structures (cf. Desnitsa 2007: ch. 4). They do however pointedly use a different formulation in their daily activities and publicity materials. Indeed, in the 1990s the word *invalid* was joined by the phrase *chelovek s ogranichennymi vozmozhnostyami*, which translates as a person with 'restricted' or 'limited' abilities.[17] While *vozmozhnosti* can also be translated as opportunities or

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[17] Interestingly, the term *chelovek s ogranichennymi vozmozhnostyami* is not a literal translation from English (as is often the case with Russian terminology in the welfare sphere), but a term that developed within Russian-language circles. Some activists do speak of *chelovek s invalidnost'yu* (person with a disability), which represents a direct translation from English, but is linguistically awkward.

possibilities, the ways in which health-related qualifiers can be added suggest an individualistic discourse where the problem in located in health and bodies:

s ogranichennymi fizicheskimi vozmozhnostyami ~ with restricted physical opportunities
s ogranichennymi vozmozhnostyami zdorovya ~ with restricted health opportunities

The occasional use of the word 'limited' as a noun (e.g. *s fizicheskimi ogranicheniyami* – with physical limitations) confirms the medicalist undertones of this expression for disability. Nonetheless such formulations are widely regarded in Russia as the most politically correct way of referring to disability and often used in documents produced by federal government agencies (although not the 1995 law on disability). They have also permeated political discourse at the regional level, cropping up in policy documents issued by government departments in Tatarstan, for example:

> The changes taking place in Russian social policy have cardinally altered the stance of society to the problem of disability. People with disabilities (*s ogranichennymi vozmozhnostyami*) are not regarded as simply needing material provision, they are recognised as members able to make their own contribution to the economic and socio-political life of society.
>
> MTZSZ 2007: 5

As should be clear from Chapter Three, such a conceptualisation of disability is worlds apart from the Soviet approach that regarded disabled people as dependent and unproductive. Interestingly, such inclusive formulations acknowledging the importance of societal participation are absent in official reports from regions where less progress has been made in modernising social provision. Thus, ministerial reports on disability provision in the region of Mordoviya that neighbours Tatarstan speak only of *invalidy* (e.g. MTSZRM 2007), suggesting that policy discourses around disability in Russia are very localised and not necessarily responsive to developments at a federal level or in major cities.

My research participants were quite adamant that the term *invalid* cannot be construed as positive in Russian language since it implies weakness, inability and a need for help. As one disabled interviewee commented, ‘I don’t like the word invalid, because ordinary healthy people believe that we are somehow different’ (Damir, law student, 24). Damir’s use of the word ‘healthy’ (*zdorovyi*) to signify non-disability reaffirms that Russian linguistic practice is not particularly tolerant or sympathetic towards disability, which is seen as a negative ‘other.’ In general, the younger people to whom I spoke were unhappiest with the word *invalid* whereas older ones accepted it as an official term despite its negative associations. Masha, a business studies student who used a wheelchair, carefully referred to *chelovek s ogranichennymi vozmozhnostyami* throughout our interview in order to actively disassociate herself from the term *invalid*. Anton, a 26 year-old law graduate, pragmatically noted that ‘you can say *invalid*, but this offends some people, in which case it’s better to say person with disabilities (*chelovek s ogranichennymi vozmozhnostyami*). But an invalid is an invalid. I use the official term.’ His attitude highlights that the newer formulation is somewhat unwieldy in Russian language and not universally accepted in society and policy circles.

Among my research participants, the term ‘person with restricted abilities’ was regarded as preferable because it gives a people-first definition akin to ‘person with disabilities’ in English. Indeed, Damir, the law student who took issue with the term *invalid*, commented that the phrase is positive because all people face some restrictions in what they can do. For him, the term reflects natural human diversity and does not posit that disabled people are inherently different to the wider population. He therefore did not see term as creating an 'other' or positing the inadequacy of impairment. The only person opposed to the phrase that I met was the head of Tatarstan's disabled sport movement, who has publicly criticised what is an awkward expression in Russian and advocated the term *invalid* because to her the former has implications of limitations (*Gazeta Vybor*, 30.11.2007, p.3). It is true that the phrase does not address whether the 'restrictions' on disabled people result from their own impairments or are imposed by a disabling environment. However, this interpretation of the phrase is quite rare and I did not hear similar concerns from other research participants. In the Russian context, *chelovek s ogranichennymi vozmozhnostyami* represents a progressive if awkward phrase to talk about people with disabilities. Yet, it is not fully understood, even among top policymakers, as demonstrated by the fact that the federal government's 'Plan for Socioeconomic Development until 2020' spoke at several points of creating policies for both '*invalidy*' and '*lyudi s ogranichennymi vozmozhnostyami*' as if they are two separate groups (e.g. MERT 2007: 59).

Official discourse on disability in Russia is therefore permeated by the rather hostile and unsympathetic language of *invalid* that reduces disability to impairment and therefore implies that it is something abnormal. Attempts to develop a more neutral term have only patchily been realised at both federal and regional levels. This places disabled people (and their organisations) in the difficult position of having to publicly identify with a term that has negative connotations and meanings stemming from Soviet-era interpretations of disability as inability and dependence. Such terminology others disabled people and thus undermines their status as equal citizens. This is however just the outset of difficult relations between state institutions and disabled people. The following discussion of procedures for classifying disability in Russia finds that they apply a narrow medical lens and do not accord disabled people a role in making decisions that have important ramifications for the definition of their needs and thus their entitlements to welfare provision.

Classifying disability

Before a Russian citizen can receive state support related to their disability, they must obtain official confirmation that they are eligible in the form of a disability certificate (*spravka*). The classification of disability is not just a bureaucratic issue, but has real consequences for disabled people's life chances and entitlements to welfare provision, not to say their personal identity and confidence. This is because classification into a particular 'disability group' determines the financial benefits and welfare services available to a disabled person in Russia. As will become clear in later chapters, the label 'invalid' also shapes the options and pathways open to disabled people by promoting particular images and stereotypes of disability.

The authority to award disability status lies with offices and commissions of 'medical-social expertise' (*byuro mediko-sotsial'noi ekspertizi*, hereafter *MSEK*).[18] The *MSEK* have a variety of diagnostic tasks: establishing individuals' overall degree of disability, determining their abilities to perform various everyday activities (including the all-important ability to work that determines pension levels) and devising 'individual rehabilitation programmes' for each person assessed as disabled. These assessments

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[18] More details about the *MSEK* can be found on the Russian-language webpage 'Organizatsiya deyatel'nosti byuro mediko-sotsial'no ekspertizi,' available at http://www.invalid.ru/expert/buro.htm, accessed 30 June 2011

determine the medical, financial and social support available to disabled individuals, often in a mechanical fashion from predetermined lists of available services (cf. Beckett 2007: 371). The organisation has a hierarchical administrative structure extending from boards in small districts and settlements up to a federal head office. Each commission consists of at least three doctors, a medical rehabilitation specialist, a social worker and a psychologist. They thus represent a reformed version of the Soviet medical-labour committees (*VTEK*) that operated until 1995, retaining the predominance of medical personnel, but distinguished by the presence of a social worker and psychologist as compared to the trade union member and representative of the social welfare administration who participated during the Soviet period.

Before an applicant for disability status can attend the *MSEK*, they must be examined from head to toe by a series of specialist doctors, involving visits to multiple clinics, long queues and much time. These check-ups were regarded as frustrating and taxing by the disabled people to whom I spoke since they are organised to suit medical personnel rather than 'patients.' The focus is purely on bodily functioning rather than the social and contextual factors that actually support or disable people (for example housing or informal care provision). The resulting medical reports are submitted to the *MSEK* for official consideration of the level and type of disability experienced by an individual, with final decisions being made at meetings of the *MSEK* board with individual applicants. Relatives, family doctors or personal social workers are not called to offer information or reports and there is no element of self-assessing needs, further promoting the clinical gaze. The *MSEK* assesses the extent to which individuals are ‘able’ to perform seven everyday activities using a 1-3 scale, with 3 being the most severe level of restriction:

Ability to perform daily living activities
Ability to move independently
Ability to orientate
Ability to communicate
Ability to control behaviour
Ability to learn
Ability to work

The focus in the *MSEK* assessments on these criteria suggests a very medical interpretation of disability focused on an individual’s perceived inabilities rather than the restrictions imposed by a discriminatory external environment. On the basis of these results, the *MSEK* awards the applicant one of three ‘groups’ of disability, corresponding to ‘very significant’ (Group One), ‘significant’ (Group Two) and ‘moderate’ (Group Three) in a classification system that has survived largely intact from the Stalinist period, as discussed in the previous chapter. Confusingly, the degrees of limitation on everyday activity have reverse rankings to the disability groups, in that the ‘third degree’ represents full inability to perform a certain task, but usually applies to people with Group One disability. All disabled people under 18 years of age receive the blanket status of ‘disabled child’ (*rebenok-invalid*) without a group.[19]

The experiences I heard concerning the *MSEK* process suggest that actual examinations are often cursory and mechanical. The disabled ‘applicant’ is largely passive in the process since diagnoses are based mostly on medical assessments of bodily functioning rather than a dialogue about individual circumstances and priorities. Venera, a pensioner whose health has been deteriorating since the early 1990s, told me that the

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[19] Whilst I look at adults in this thesis, it was clear from my research participants’ stories that the label of ‘disabled child’ is very powerful in pushing children down particular pathways, for example the separate schools discussed in the next chapter.

first time she tried to register as disabled, ‘some doctors entered the room, didn’t glance [at me] and before even sitting down offered me Group Three’ (the lowest degree of disability that provides only minor benefits). Others said that the *MSEK* process was ‘simply about people sitting there and asking questions about whether I can do everything at home by myself, things like that’ (Damir, law student, 24), which further suggests that the focus is on individual ‘abilities.’ The participation of disabled people is therefore limited even though the *MSEK* assessments greatly affect the welfare provision later provided by state organisations. The voice, preferences and knowledge of disabled people are thus disregarded and the ideas of professionals privileged as ‘expert’ (cf. Oliver 1996).

In addition to the assumptions of inability made by MSEK, the inconsistency of their classifications aroused much exasperation among my research participants. Decisions by *MSEK* boards often seem too harsh or the opposite as a result of the fact that they are made on physiological criteria. Thus, wheelchair users are almost exclusively defined as Group One disabled with third-degree inability to work**,** deeming them to be wholly reliant on state provision due to a presumed inability to support themselves independently. Without wanting to condone the logic underlying *MSEK* decisions, it seems contradictory that people with other forms of disability rarely receive such assessments. Anton’s mother recalled how ‘they didn’t give him Group One because he can just about walk. But all the same I have to go everywhere with him. He orientates badly, gets lost.’ To her, Anton’s classification was too lenient.[20] *Gazeta Vybor*

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[20] Anton’s mother also confirmed the widely known problem of misdiagnosing disability in the Soviet Union (cf. Dunn 2000: 161). Anton, who has mild cerebral palsy, had been diagnosed with ‘oligophrenia’ in his childhood, which was the Soviet medical term for mental disability (‘retardation’).

similarly reported on a fully blind person who was assessed as having only second degree ‘inability to work’ since the disability commission felt he could hypothetically complete simple manual tasks or work from home (11.01.2008, p.1). That wheelchair users are regarded as unable to perform such tasks suggests that discriminatory ideas about the inability of physically disabled people (especially with spinal impairments) exist within the Russian medical bureaucracy.[21] This reduction of disability to impairment misses the social context of disability and focuses on defects rather than strengths, personhood and holistic needs.

In addition to complaints about classification into the three disability groups, I heard much dissatisfaction with *MSEK* assessments that many disabled people are partially or completely ‘unable to work’ (*netrudosposobnyi*). The degree to which *MSEK* evaluate disabled people as ‘able to work’ is very important, being the basis on which pensions and social benefits are awarded and determining whether they can legally be employed. As discussed in Chapter Three, since 2003 disability pensions have been awarded as a replacement salary rather than as financial compensation for social barriers to well-being. This makes it legally untenable for someone who is classified as ‘completely unable to work’ (degree three) – as most wheelchair users automatically are – to receive both a disability pension and a salary.[22] Although the prejudices of many employers in Russia do make it very hard for disabled people to work, the power accorded to medical

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Only through the efforts of his parents was he permitted to receive a school education and sit exams allowing him to study at university, where he obtained the highest grade in his law degree.

[21] Indeed, some of my research participants (including young adults) used the Soviet-era abbreviation for the medical commissions, *VTEK*, rather than the term *MSEK* that has been in place since 1995. Such linguistic continuity suggests that they saw little change in the approach taken to classifying disability or the institutions making the assessments.

[22] The next chapter shows how some people manage to navigate around this restriction by engaging in informal work or finding sympathetic employers willing to disregard their official status as unable to work.

commissions to *a priori* write off wheelchair users ignores the few cases where they work very successfully, if illegally. It significantly shapes what it means to be a disabled citizen of the Russian Federation by barring people with impairments from employment. Here we see the huge impact of medicalist thinking that relates impairment to broader inabilities.

As Chapter Five discusses in more detail, this equation of disability with an inability to work creates difficulties for disabled people who manage to obtain employment. The only time one of my research participants declined to answer an interview question related to my enquiry about her classification as ‘unable to work.’ The person in question was employed by a local disability organisation and seemed to be concerned about possible ramifications if the authorities discovered this. Indeed, disabled people risk losing their pension and rehabilitation entitlements, while employers face administrative penalties (low fines) in the highly likely event that they are prosecuted for illegally employing a person classified as completely ‘unable to work.’ Another respondent, Lena, spoke of how she had been given permanent ‘unable to work’ status, but was trying to prove that she could in fact work, especially since she was able to walk and use public transport independently. Although she holds several vocational qualifications, Lena was frustrated that she was prevented from employment: ‘it’s difficult to get a job since I am officially ‘incapable of work.’ I go to *VTEK*, but there they say that I cannot work.’ Masha, a 22-year old student who uses an electric wheelchair, was offered a full-time job as the coordinator of disabled students at the private university where she studied. She told me how the *MSEK* board would remove her status as disabled if they found out that she was working. This would deprive her of a disability pension, which she felt unjust because she faced significant obstacles in holding down a regular office job: ‘they [the *MSEK*] don’t understand that my mum takes me to work and that they also help me at the university.’ She also related how *MSEK* decisions that disabled people cannot work create negative attitudes in other sectors: ‘when they make the classification they completely cannot understand why I would want to study at university if I won’t be able to work due to my disability.’ Such testimony reveals that the authority of the *MSEK* commissions to proclaim that people are ‘unable to work’ creates an image of disabled people as incapable not just in the field of work, but in other areas as well. When combined with the negative term *invalid*, we thus see that official understandings of disability are both harsh and narrow, seeing disability as something inherent to an individual’s biology.

The unpleasantness associated with the protracted *MSEK* process is exacerbated by requirements to undergo periodic re-examination by the disability commissions. Permanent disability is only awarded to adults of pensionable age (55 for women, 60 for men) and those with ‘irreversible anatomic defects.’ Otherwise, diagnoses of disability are valid for either one year (Groups Two and Three) or two years (Group One). After these periods, the whole array of medical tests, examinations, paperwork and *MSEK* meetings must be repeated. Maksim, a wheelchair user in his mid-twenties, told me of his relief at receiving permanent disability status: ‘they torment us every two years. Literally a year ago they gave me permanent status, so I don’t have to suffer all this anymore. Not all doctors make home visits, so you have to go there, constantly bother people, stand in queues.’ The official justification for these re-examinations is to monitor changing health and social circumstances that affect disability. However, in practice even people with permanent impairments, for example a missing limb or paralysed spine, have been required to appear for re-examination despite no possibility of their condition changing (*Gazeta Vybor*, 18.04.2008, p.1). Masha, who moves around in an electric wheelchair due to a spinal condition, was outraged that ‘they force us to repeat the assessments every year, but it’s impossible that a person’s leg might grow back … I also have to undergo this every two years, have to travel and wait in queues.’ Indeed, the frequency of re-examinations suggests that the *MSEK* operates to control access to state provision rather than to support people with health impairments, thus supporting arguments that disability provision and needs interpretation are politicised resource issues (e.g. Stone 1984).[23]

Many of the frustrations with *MSEK* procedures are encapsulated in the following letter from a mother to *Gazeta Vybor* seeking information about how disability is classified (23.02.2007, p.7):

> “My 22-year old son was diagnosed as disabled during his childhood. However, his disability status was cancelled at his last re-examination. His left arm does not function and is shorter than his right by 7cm. He found a job with a salary of just 3,500 rubles [approx. £70 per month]. I was told that his disability status had been cancelled because he works. But surely he did not stop being disabled because of this? Now he has been deprived of his 1,300 rouble pension and social package. Please advise what I should do.”

The *MSEK* representative who answered this letter for the newspaper cited long regulations and laws to argue that her son was not sufficiently ‘limited’ to be regarded

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[23] Such an impression was borne out in an interview I had with the Deputy Director of the regional *MSEK* office for the region of Tatarstan. She spoke at length of the checks that her office conducts when disability rates turn out to be higher than average in particular districts or in particular commissions. While allowing for different healthcare and environment conditions, she strongly implied that it was useful to ensure that classification rates meet a ‘golden mean’. She was very proud that no classifications made by *MSEK* branches in Tatarstan had been overturned on appeal to the head office in Moscow. This is further evidence that the balance of power in making decisions overwhelmingly lies with the *MSEK* commissions rather than disabled people.

as partially ‘unable to work’ and therefore could no longer receive a disability pension. However, the mother’s letter asked a broader question about how disability is conceptualised in Russian law and policy, in particular the basis for considering disability and employment as mutual opposites. Just like Masha, Damir, Lena and other research participants discussed above, she questioned procedures and classifications that fail to correspond with actual experiences of disability. Her letter highlighted that the official conception of disability in Russia does not resonate with the concerns and experiences of disabled people themselves. The fact that it ignores the social construction of disability is not simply an issue of stigmatising labelling, but affects material well-being by shaping welfare entitlements, which is an important consideration given the poverty of many disabled people.

Hierarchies of disability

That the Russian state tries to determine the extent to which people with impairments are disabled is not unusual, being an important and politically controversial task for all welfare state bureaucracies. Yet, in addition to health-based classifications, Russian law establishes a number of hierarchies and inequalities within the disabled population. These distinctions relate to the cause of impairment and person’s employment history and affect the rhetorical and material support granted by state organisations. They establish a state-sanctioned spectrum of deservingness that creates divisions among the disabled population.

Individuals with a military past, especially one connected to the Second World War, are by far the most privileged group of disabled people in Russia's welfare system in line with the elevated status of the military in Russian public culture (Sapper 2005). This is reflected in the size of disability pensions awarded to former military personnel. Disabled veterans with Group One disability receive a monthly pension that is three times higher than civilians if they were injured during service and two and a half times higher otherwise.[24] This means that military veterans receive an income just under the average wage in Tatarstan, while their non-military counterparts must struggle on pensions very close to the region's 'minimum subsistence' line. Artem, a severely disabled former officer with a comfortable material standard of living, acknowledged the better financial and medical support he received due to his military background during an interview with me. In addition to a higher pension, he receives access to special hospitals and sanatoria (health resorts) for military personnel where equipment and standards often far exceed those in institutions serving the general population. Neither he nor a middle-aged veteran I met in Samara's housing complex for wheelchair users complained to me about the welfare provision they received. They certainly did not mention shortages of equipment, medicines and sanatoria places, which are a real bane for many disabled people, as will be discussed later in this chapter. Military status therefore seems to bring priority and greater attention in the welfare system and means that disabled people are not all treated equally by state organisations, but differentiated according to a criterion of deservingness based on contribution.

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[24] Information taken from the website of the Pension Fund of the Russian Federation, http://www.pfrf.ru/disability_pension/, accessed 30 June 2011

Along with former military personnel, people who become disabled at work also receive better-quality welfare provision. Vladimir, a middle-aged man injured at his workplace, frequently noted the advantages that came with his status as *proizvodstvennik* (a difficult-to-translate term referring to a person with a work-related injury): 'they give me sanatoria stays without problem' and 'a *proizvodstvennik* can choose the wheelchair he wants … whereas those with general disability get whatever wheelchair is available.' Together with higher pensions, this group enjoys far better services than disabled people without a work record since support comes from a separate fund financed by employers' contributions. Indeed, his income was very important to his family's budget given that he and his wife had two children of school age to support.

Despite their relative privileges, it is important to note that disabled people with military or work-related status (overwhelmingly men) are still affected by the connotations of legal status as *invalidy* and related designation as 'unable to work.' Indeed, the inequalities between different groups of disabled people relate mostly to traditional forms of state support such as pensions and medical assistance rather than the official conceptualisation of disability. They do however reflect additional state recognition and create a hierarchy based largely on the association of physical labour with deservingness.

People who have been disabled since childhood are last in the hierarchy of disability that underlies Russian social provision. In the eyes of the Soviet state, these people had little status or value as citizens since they were supposedly economically and militarily unproductive. They were not valued for themselves and hidden away as truly abnormal rather than the victims of accidents. As a consequence, they received the lowest pensions of all disabled people and lacked access to the same health and leisure facilities available to former workers or service personnel. Very high rates of institutionalisation in the Soviet period excluded many members of this group from mainstream society. Most of my research participants fell into this category of 'general disability,' which forces them to accept poorly designed services that do not always meet their needs. Even if they are assessed as having the same level of [medically inflected] needs, members of this group will be officially regarded as less deserving and a lower priority compared to former servicemen and workers. It is mostly their experiences and stories that I relay in my subsequent chapters, which show that disabled people are still a low policy priority and that ideas that they have not 'earned' state support remain embedded in the welfare system.

Defining need as rehabilitation

The medical thinking underlying classifications of disability in Russia means it is unsurprising that welfare policies define the needs of disabled people largely in terms of treatment to restore or support physical health. State support for disabled people is framed as 'rehabilitation' (*reabilitatsiya*), a strongly medical discourse that asserts the need to restore or approximate a particular bodily norm. Indeed, the Great Soviet Encyclopaedia defined rehabilitation as 'a series of medical, pedagogical, professional and legal measures directed at the restoration of health and ability to work.'[25] This focus on health (with the assumption that health and employment are related) seems to

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[25] Entry 'Reabilitatsiya,' *Great Soviet Encyclopaedia*, available in Russian at http://bse.sci-lib.com/article095789.html, accessed 30 June 2011

represent a continuation of Soviet approaches to disability that assert a particular norm of biology in which being non-disabled is seen as healthy (*zdorovyi chelovek*).

The emphasis on rehabilitation arises out of the responsibility of *MSEK* committees to devise an 'individual programme of rehabilitation' (IPR) for each person with health impairments. This is a document listing the various services and support that the person in question is assessed as needing. The 'individual' in the name is a misnomer since there is no element of self-assessment and very little personalisation of treatment plans, which are major principles in many western European countries. Introduced in the late 1990s, the programme has three sections covering medical, social and professional rehabilitation. It is an important document since a disabled person can only receive wheelchairs, crutches, sanatoria stays, counselling and other forms of 'rehabilitation' explicitly listed on their IPR form.[26] This list of services sounds focused on health precisely because other services are not offered. Medical services and treatments dominate the thrust and delivery of the IPR, which focuses on an individual's health rather than the broader settings and surroundings in which they live.[27] Thus, support is rarely specified or given for adjustments in the home or workplace and indeed very few of my research participants had them. Indeed, occupational therapy and personal assistance services are poorly developed in Russia and the 'social' rehabilitation mentioned in the IPR generally refers to prosthetics and technical equipment. Furthermore, as discussed below, rehabilitation is not delivered in community settings,

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[26] This is one reason why the official number of disabled people increased following the introduction of the IPR (*Gazeta Vybor*, 25.05.2008, p.3).

[27] The prioritisation of medical rehabilitation is borne out by statistics about the implementation of IPR recommendations: 85% of recommendations for medical rehabilitation were fulfilled in 2007, but only 47% of prescriptions for professional rehabilitation and 79% for social rehabilitation, which generally means prosthetic aids (*Gazeta Vybor*, 25.05.2008, p.3).

but in such specialised institutions as rehabilitation centres or schools catering exclusively to children with one particular form of impairment. Despite lip service to notions of ‘social rehabilitation’ in policy documentation, the actual focus thus remains fixed on the individual’s body, thereby failing to recognise that disability and citizenship are constructed by environmental and social conditions.

Many of the professionals to whom I spoke questioned the effectiveness of the rehabilitation diagnoses made by the *MSEK* commissions. For example, the director of Kazan’s adult rehabilitation centre told me that the document was so general that they conducted their own assessments of rehabilitation needs when accepting new patients. While the IPR forms have gone through several changes since the system was first introduced, the documents that I was shown by one research participant simply stated that he was ‘in need’ (*nuzhdaetsya*) of particular forms of rehabilitation, for example social or medical. It did not specify concrete treatments or their recommended duration, except in listing the equipment and technical aids that should be provided. Nor is there space in the document for disabled people to make their own assessment or suggestions, with their role in the process limited to a signature accepting the diagnosis. This reduces the IPR to a proof of entitlement to welfare services serving bureaucratic requirements rather than a vehicle for empowering and supporting people. There thus seems to be little room for disabled people to have their voice and knowledge considered, suggesting that state structures are not open to bottom-up and personal interpretations of needs.

Medical services

Given the strongly medical flavour of disability classification and rehabilitation in Russia, I was interested in how my research participants evaluated the medical services they used. Although they often praised medical staff, I heard a barrage of complaints related to the provision of prescription medicines, technical aids and sanatoria places. As I discuss in this and the next two sections, there was general dissatisfaction with healthcare services even though the needs of disabled people are overwhelmingly defined by state structures as health-based.

Most of the people to whom I spoke had undergone operations or significant periods of hospitalisation. I rarely heard negative comments about these experiences and do not have the medical expertise to judge whether the large number of operations endured by some research participants were justified (in some cases they were viewed unfavourably). In mind of widespread stories about out-of-pocket payments in the Russian healthcare system, I often asked whether treatment was provided completely for free. I always received positive answers and no hint of pressure to provide gifts or financial rewards to staff in hospitals, polyclinics and rehabilitation centres. There was instead often admiration for individual doctors or nurses, pointing to the positive relations that developed with medical staff. People did however feel that it was normal for family members to provide food and even bedding for their relatives in hospital. Such practices were not regarded as particularly vexing, but rather as a normal part of the hospital experience.

Research participants occasionally told me about difficulties in persuading doctors to undertake operations or provide particular treatments. Thus Vladimir, who received a spinal injury at work during the Soviet period, fought a long battle to receive an operation: 'my father travelled to Moscow to speak to the Burdenko hospital … they told him that I would die in a few months. The head of the Party Committee at my workplace also made a trip, but they told him the same: it's no use to me, that I would die a few days after the operation. It was still the Soviet Union then and they refused to do it.' After a couple of years, Vladimir's father eventually managed to persuade the institute in question to operate. While perhaps an isolated case, it reveals the historically unsympathetic stance towards disabled patients in Soviet Russia discussed in Chapter Three. While none of my research participants mentioned being refused particular medical care, there were high-profiles cases during my fieldwork period in Kazan of disabled people needing money for expensive operations that could not be conducted through the state hospital system. The case of a toddler called Bogdan who required a bone marrow operation in Germany due to its unavailability in Russia was particularly well-advertised during Tatarstan's Year of Charity (2007) through billboards, leafleting and fundraising volunteers in prominent shopping centres. Such a focus on a single individual seemed to ignore wider questions about provision for other disabled people in the region and even this campaign did not raise sufficient funds for the infant's treatment.[28]

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[28] Further information about Bogdan's case can be found in the article 'Kazan' spasaet Bogdana,' *Izvestiya Tatarstana*, No. 27 (285), 19 June 2007, available at http://www.tatarnews.ru/?page=9&article=396 (accessed 30 June 2011). Interestingly, no newspapers in the region reported on the failure of the government-backed campaign to raise sufficient funds for the child's operations.

That I discuss health and medical services in my first empirical chapter must not be taken to imply that I regard health as a defining dimension of disability. However, it is a major, if not dominant, element of state provision for people with bodily impairments in Russia and I came across very few social and psychological rehabilitation services for disabled people in Kazan. For example, there is no occupational therapy (although the child and adult rehabilitation centres in Kazan have mock kitchens and bathrooms) and no system of professional carers. One exception to the predominance of medical provision was the adult rehabilitation centre in Kazan, which employs two psychologists who were highly praised by patients and residents of the adjacent housing complex. The organisation also has impressively equipped rooms for relaxation and sensory therapy. However, the centre's programme of psychological support seemed to focus on using simple computer programmes to assess clients' moods or their aptitude for particular kinds of work. Such schemes may not necessarily help with emotional strain that requires counselling, for example after trauma or accidents. Indeed, several of the disabled people I interviewed mentioned experiencing depression and shock after injuries that led to wheelchair use, but not being offered any psychotherapy. One male respondent in his forties was intensely frustrated that his recent spinal injury prevented him from working as an engineer and that he could not even look after his young children since he could only stand for short periods. Whilst he found some solace and support from other disabled patients in the rehabilitation centre, he received little professional assistance to deal with his mental burden. Yet, my research participants did tell me that staff of the rehabilitation centre were eager to help 'patients' where possible. For example, its director translated a German book into Russian on sex for disabled people in order to help a husband and wife who both had physical disabilities.

Still, I did not hear of many disabled people using psychological services offered by state organisations in contrast to the frequency with which my research participants underwent medical forms of rehabilitation.[29] Professionals and disabled people thus have little scope to challenge the health-focused official conception of disability and disabled people's needs whose narrow lens cannot be mitigated by the general satisfaction with medical services.

The non-provision of medicines

One of the most frequent criticisms of state provision that I heard concerned the unavailability of prescription medicines and equipment. The system for funding and supplying medicines was overhauled during the 2005 monetisation reforms, when various groups of *l'gotniki* (people eligible for benefits), including disabled people, were given the option of foregoing their entitlement to free prescription medicines in return for a monthly cash payment. Whilst the cash payments were paid on time to the few disabled people who opted for them, a series of mistakes and miscalculations on the part of the government led to severe problems with the supply of medicines that should be available for free to those choosing the package. The resulting shortages were frequently mentioned during my interviews and came out strongly in letters and articles in the newspaper *Gazeta Vybor*. Complaints were directed at the lengthy bureaucracy involved in obtaining prescriptions for free medicines, the unavailability of medicines in chemists and the narrow list of medicines that could be prescribed for free.

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[29] One disabled people's organisation in Kazan ("*Nika*") recognises that state services do not meet the psychological and emotional needs of disabled people, especially young adults, and tries to fill this gap by organising seminars, for example on confidence building, teamwork and problem solving. However, they receive little official support in such work and find it difficult logistically to organise their events, as Chapter 7 will discuss in greater detail.

During my conversations and interviews, I often heard that people were discouraged from trying to obtain free medicines due to the drawn out procedures for issuing prescriptions. Visitors to Russia will be aware of the many chemists (*apteki*) in the country. The overwhelming majority of these are commercial enterprises that sell medicines, while prescriptions for free drugs can only be redeemed at state chemists, usually one in each local district. Indeed, prescriptions do not represent medical authorisation to receive particular medicines since Russian chemists generally dispense any drugs upon request, including antibiotics. Rather, the documents signed by the doctor are proof that patients do not need to pay for medicines. Yet, the difficulties of receiving and then redeeming these prescriptions mean that people often prefer to purchase medicines privately.

A letter to *Gazeta Vybor* (12.10.2007, p.4) from an elderly inhabitant of a small town in Tatarstan explained the difficulties and obstacles placed in the way of disabled people receiving free medicines. In his words, ‘it’s not easy to be a disabled person in Russia and paradoxically all the problems start in the polyclinic’ as if he expects the medical presumptions underlying disability policies in Russia to mean that doctors’ surgeries would be responsive to disabled people’s needs. Although procedures vary between medical clinics, his description rang true with other tales of frustration I heard. He described the need to wake up extremely early in order to queue outside the polyclinic doors well before they open at 7am. When inside there was then a push and struggle to obtain a numbered ticket to see a doctor with no guarantee of being seen on the day in question. However, the real problems began when obtaining a prescription for free medicines. Individual doctors do not have the authority to issue such documentation; rather, their recommendations must be approved by a commission within each polyclinic, necessitating another long queue and wait. Once permission has been given, the original doctor can issue an official computerised prescription, but this piece of paper must be signed off by the commission, stamped by the polyclinic administration and, in the case of the small town where the man lived, receive an official stamp from the central hospital two kilometres away. It is generally the patient who must trek between the various offices and wait to obtain the requisite signatures, stamps and paperwork. As well as being highly inconvenient, the number of checks suggests an institutional distrust of the claims of disabled people for free medicines.

The time and effort required to have a prescription issued can discourage people from claiming free medicines. When discussing the procedures for receiving free medicines, Anton’s mother emphasised that they were so laborious that she preferred to purchase them herself in commercial chemists: ‘It takes so much time to see a doctor that it’s easier for me to buy his medicines and administer them myself. I don’t drag him to doctors and they only make house visits to disabled people in Group One’ (Anton had Group Two). I often heard that relatives collected prescriptions and medicines on behalf of their disabled kin in order to spare them the frustrating queues and travelling. Indeed, bothersome arrangements within polyclinics and transport problems meant that many of my respondents only visited doctors when absolutely necessary. They certainly did not view medical treatment as readily available and helpful, even though their needs were generally defined by state organisations and policies as health-related. Thus, their legal entitlements as citizens, moreover as disabled citizens, to health services are not fully instantiated and the organisation of provision in fact serves to discourage its use.

The process for receiving prescriptions is made even more frustrating by the fact that medicines may be unavailable in chemists due to erratic funding by the federal government. In such cases, people are either forced to wait for their medicines or to purchase them from their own funds, which will be necessary if the drugs need to be taken immediately or at regular intervals. Delays in receiving medicines are especially vexing because medical prescriptions in Russia are only valid for a limited period of time. The prescription loses validity if the medicines are not supplied within this time frame and must then be issued again, necessitating the repetition of the bureaucratic procedures described above. The same is true when medicines are only available in a dosage different from that stated in the prescription. Although such problems sound almost preposterous, they were regularly encountered by my research participants. Like many of the disabled people I met in Russia, Damir had taken to buying his own medicines even though he was supposed to receive them for free because ‘by the time you’ve waited for the free medicines, the validity of the prescription may have expired, so you are forced to buy them privately anyway.’

Another concern was that the government’s list of drugs that can be prescribed for free is relatively narrow. There was widespread feeling among my research participants that only cheap or ineffective medicines were available for free. Ksenia’s mother, a qualified nurse, recalled how a doctor initially refused to issue a free prescription for a course of injections that would have helped her daughter’s cerebral palsy. When pressed upon to issue a prescription, the doctor prescribed an unknown drug that turned out to be vitamins retailing in chemists for nineteen rubles (approximately forty pence). She was insulted by this and purchased the required drugs commercially. Damir had in fact given up hope of receiving free medicines: ‘there are drugs that really hurt the wallet of ordinary people. I need expensive injections so that my spinal cord develops, but when your turn comes in the waiting list for free medicines, there might not be any left. You could call it a really painful (*bol’naya*) problem.’ This fear was borne out by official statistics; in 2005, only 20-30% of prescriptions for expensive medicines were filled against an overall average of 70%, which is still low (*Gazeta Vybor*, 17.02.2006, p.3). Instead of solving the supply problems, the federal Minister of Health even criticised benefit recipients in Russia for demanding expensive or heavily advertised medicines and doctors for prescribing them (ibid.). Entitlements to welfare provision have thus become sites of struggle and negotiation.

Shortages and laborious procedures also affect the supply of what in Russian official parlance are called ‘technical means of rehabilitation,’ referring to prosthetics, wheelchairs and other aids. In 2007, it was estimated that 100,000 disabled people did not receive prostheses due to the same funding problems that affect the provision of free medicines and sanatoria places (*Gazeta Vybor*, 16.11.2007, p.2). As mentioned in Chapter Three, official usage periods for various pieces of equipment (the minimum intervals after which they are replaced) were extended in 2007. However, such rules do not consider that the lifestyles of disabled people vary greatly. Masha, the young student and wheelchair user who was working in a private university at the time of my fieldwork, complained that ‘wheelchairs are given for five years, but they break quickly if you have an active lifestyle. For example, I get on and off the bus, there are curbs everywhere and I go into the countryside where the roads are uneven, so of course my wheelchair will wear out. If I sat at home all day, then it would last five or even ten years.' However, inflexible administrative norms that a wheelchair should last a specific length of time mean that disabled people are forced to repair their wheelchairs as best as they can (although there is no specialised wheelchair repair shop in Kazan) or purchase new ones privately, something that is complicated by the lack of a sales outlet for such equipment in the city. Very little attention is therefore paid to individual needs, especially as they may be defined and enunciated by the disabled individuals in question, who are placed in a passive role vis-à-vis the medical bureaucracy.

The upshot of the multiple problems with the provision of free medicines and technical equipment was that many research participants had stopped expecting state healthcare services even when they had opted for the 'social package' that gave them an explicit entitlement to these items. Some had therefore cashed out their entitlements to free medicines, in which case monetisation represented a second-best solution in the form of partial compensation for a system that did not function properly.[30] Other people retained hope that they might receive the medicines and equipment to which they were entitled, although they often ended up buying medicines themselves. The supply problems promoted an idea that disabled people should manage on their own and not expect state assistance. Those lucky enough to have sufficient resources therefore tried avoid state provision. Indeed, although disability is conceptualised in Russian law and

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[30] Monetisation was more clearly positive for the [few] disabled people I met who did not regularly take medication and had therefore willingly cashed out their entitlement to free prescription drugs. However, a nuance in Law 122 on monetisation means that opting for the cash payment also involves relinquishing the possibility of a state-funded sanatorium stay, which few people want to do.

bureaucracy as highly medical and connected to the body, the consequent policy response – medical treatment – is only patchily realised, suggesting the low political priority of disabled people. This unfortunate irony also extends to sanatoria places, which were also affected by budgetary problems following the introduction of the 'social package' that supposedly guarantees provision.

Sanatoria as social institutions

The inadequate funding afflicting the supply of medicines also affected sanatoria (health resort) provision for disabled people after 2005. Russia has a strong tradition of sanatoria, which are seen as offering health benefits through rest, medically influenced spa treatments and an unpolluted environment away from cities (Bihari-Axelsson and Axelssson 2002). They were a major element of Soviet healthcare and social policy, becoming a longstanding social right in the eyes of the population, if not the government as well.

Receiving a *putevka* (sanatoria stay) was seen by my research participants as a very positive thing because it involved a change of scene and provided opportunities to meet new people. The value of sociality was emphasised in many interviews and especially important for disabled people who are largely restricted to their homes. Ksenia's mother explained to me that when they visit a sanatorium 'we rarely stay in the room, we walk in the woods and along the Volga river. We spend most of the time outside and after a while Ksenia literally blooms.' As I discuss in Chapter Six on housing, Ksenia rarely leaves her family's highly inaccessible flat, meaning that a sanatorium trip is very novel and highly cherished. Vladimir, a middle-age man injured at work, told me that when he first visited a health resort after his accident, he ‘met lots of people there and understood that I was not alone, there are lots of us [disabled people].’ Indeed, health was often not the main motivation for going to sanatoria. Olga explained to me that ‘I have kept the option to have a free *putevka* because I want to travel to a sanatorium, not for treatment, just to relax. Sometimes you have to get away from studies and everything else.’ This somewhat subverts the official logic of visiting sanatoria to maintain or improve health, suggesting that my disabled people were able to rework dominant representations of their needs in daily practice. Indeed, Olga was sceptical that the treatments offered could improve her health. She felt that ‘it’s a shame to waste time and energy on treatments, they’re just a burden,’ but one that in her opinion was compensated by the opportunities for unwinding and social interaction at a sanatorium. This highlights that the relationality underlying citizenship – as discussed in Chapter One – is often experienced very positively and as a means for social interaction and participation.

Given the very positive associations with sanatoria, it is not surprising that the poorly organised system for funding sanatoria places aroused almost as much frustration among my research participants as the problems with prescription medicines. By law, disabled people who opt for the ‘social package’ of in-kind benefits and services are entitled to a state-funded visit to a health resort every two years. However, inadequate resources and organisational problems following monetisation meant that in 2007 the number of people eligible for and requesting sanatoria places was three times higher than the number of available trips (*Gazeta Vybor*, 03.08.2007, p.7). This was borne out in the interviews I conducted. For example, Maksim, a 22-year old computer specialist with cerebral palsy, explained that ‘the waiting list for sanatoria places is very long, so it’s very difficult to get a place. There isn’t enough money for the many people who want to travel.’ Indeed, while research participants can afford to purchase some medicines privately, funding a sanatoria stay would be beyond the means of most.[31]

A further complaint that I frequently heard was that sanatoria places were generally limited to one’s home region, marking a change from Soviet times and the 1990s, when trips to the Black Sea and warmer or mountainous southern areas of Russia were common. Indeed, several older research participants fondly remembered travelling to the Crimean health resort of Saki in what is now Ukraine. Such expectations also existed among the younger disabled people to whom I spoke, sometimes based on childhood travels. Maksim told me that ‘for example, I want to travel to the South, it’s nothing out of the ordinary, within the borders of Russia. I’m entitled to this on paper. According to the legislation, I have the right to choose which sanatorium I visit, but it doesn’t happen like this. In reality, they only give places in Tatarstan and that’s all.’ Similarly, I overheard parents at an event for disabled children in Samara excitedly discussing rumours that their local social protection office was awarding places in sanatoria outside the region. Natalia told me that she had always opted for the ‘social package’ instead of a higher cash benefit, but had not yet visited a health resort because ‘I would like to travel to a sanatorium, but so far I’ve only been offered places where I don’t want to go.’ As a child during the Soviet period, she had frequently visited

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[31] Interestingly, Ksenia’s mum told me that their sanatoria stay was in fact funded by their local social services department rather than the federal agency that should provide them as part of the ‘social package.’ They were therefore lucky to have found a way around the shortages, although it meant that their official entitlement to a free stay was still fictional.

sanatoria in Georgia and made strong friendships with other patients there. While travelling to another country was understood to be unfeasible, the geographic expectations of research participants (in part bolstered by entitlements enshrined in law and memories of past trips) were nonetheless wider than the options offered to them by a state system suffering from insufficient resources and poor planning. This naturally caused frustrations and feelings of being ignored similar to those that the problems with free medicines aroused.

Another reason for not travelling to sanatoria was that disabled visitors, especially those in wheelchairs, need to be accompanied by a companion due to limited staffing and facilities at health resorts that produce immobility. Ksenia revelled in telling me how the lift in the sanatorium she had visited in summer 2008 only operated during working hours, confining residents to their rooms on upper floors at weekends. Non-disabled companions were needed to collect food from the ground-floor canteen and help the official residents to negotiate stairs and other barriers. While such problems arguably reflect inadequate resources, they also are suggestive of the treatment-based philosophy underlying sanatoria in which the aim is to tend to damaged bodies rather than facilitate wider social goals. Even reaching the sanatoria was a problem for many guests since no special transport was organised to its remote rural location even though it was poorly served by public buses. Similar situations at other sanatoria mean that a wheelchair user or person with mobility limitations can find it difficult to visit on their own, thereby missing out on the social interaction and relaxing environment offered by a *putevka*. Indeed, Ludmila, a very isolated women in her forties who contacted me through *Gazeta Vybor*, told me that she had long abandoned hope of visiting a sanatorium since she could not ask anyone to accompany her, having no relatives or close friends. The problem was not financial since the costs of travel and stay for a companion of a person classified with Group One disability are covered within their ‘social package.’ Rather, Ludmila did not know anyone who could spare two or three weeks for the trip and organise private transport for her. This affirms that the use of some state services is dependent on having social connections, highlighting the importance of social relations for the utilisation of care, even state welfare provision.

Overall, sanatoria places were highly valued by my research participants who applied their own interpretations of their value over their official medical connotations, making the problems with their provision extremely vexing. As with medicines, sanatoria places are supposedly guaranteed for all disabled people who opt for the ‘social package’ of benefits instead of a cash payment. The failure of state organisations to deliver this strongly cherished entitlement was regretted for several reasons related to the novelty of new surroundings and social contact for people very isolated in society rather than official health reasons. My respondents were aware that these problems stemmed from inadequate funding and implied that they were a low priority in the state system, a theme that will be discussed more directly in the final empirical chapter.

Conclusions

This chapter has examined the messages underlying official concepts of disability and procedures for assessing the needs of disabled people in Russia. It showed how they are forced to accept the official label *invalid* based on a medically tinged discourse whereby disability is viewed as an individual bodily affliction requiring ‘rehabilitation’ rather than a socially constructed phenomenon (cf. Oliver 1996). Disabled people are thus presented as inherently (biologically) different to other citizens and construct their needs as largely health-based. Such narrow views are perpetuated in the official assessments of disability made by medical ‘experts’ with little input from disabled people. The power of professionals to assign the legal status of *invalid* even though it is rejected by disabled people places them in strong positions over their clients and indicates how power imbalances within state services deny people voice and control, as discussed in Chapter One’s section on agency. The people to whom I spoke often riled at the way they had been classified as disabled, especially if their *MSEK* assessment implied a complete inability (and therefore legal barrier) to employment. Indeed, the notion of physically disabled people being ‘unable to work’ is intensely normative, downplaying the role of the social environment in disabling people and sharply reducing opportunities for disabled people to contribute to society and their own well-being.

A major theme in this chapter was how entitlements to state support vary among people with disabilities. Disabled people are not just officially conceptualised as biologically different to the non-disabled population, but their needs are differentially assessed based on criteria of deservingness and worth that privilege military service and employment. For all disabled people, access to social provision is rigidly differentiated according to the health-related classifications of ‘disability group’ and ‘degree of inability to work.’ However, these divisions are intersected by considerations of previous work since military veterans and former workers receive comparatively generous services and financial benefits. Certain groups of disabled people are therefore materially and rhetorically privileged in the welfare system although even they will be affected by the negative connotations of their status as *invalid*. In contrast, children and young adults with disabilities are by default disadvantaged in the support they can receive from state organisations since they are not deemed to have made a contribution to society. Such a hierarchy of disability suggests that welfare provision in Russia is partly something to be ‘earned’ rather than an inherent right. Welfare entitlements are not allocated according to needs (however they may be defined), but distributed in ways that allow for the unequal treatment of people based on a supposed ‘contribution’ to society. As we will see in the next chapter, the moral economy around such notions of ‘deservingness’ (cf. Kay 2011a) is especially pernicious since disabled people are not encouraged or supported in making such an input through employment and indeed actively discouraged from working by the assumptions underlying the disability system.

The discussions above identified a paradox in state provision: while disability is overwhelmingly constructed as an individual health problem, the medical services available to disabled people in Russia are lacking in many ways. Although sociological understandings of disability do not reduce it to biology, they equally do not deny the importance of medical care and the embodied experience of impairment (e.g. Thomas 2007). The monetisation reforms clearly established that people classified as disabled can choose to receive free medicines and sanatoria places or a cash benefit. Those that opt for the former – the ‘social package’ – are therefore legally and arguably morally entitled to various forms of medical provision. However, the present supply of prescriptions and sanatoria does not satisfy these claims. Shortages and intense bureaucracy mean that formal entitlements on paper are of little practical use and many people acquire medicines out of their own pocket. Choosing cash instead of medicines is an option, but it cannot fully replace a system of free services and is often seen as a second-best solution. Disabled people's official assessments of health-related needs and resulting entitlements to medical provision thus do not seem to place firm obligations on state organisations, which consequently disempower people with impairments through shortages and poor resource provision.

At the outset of my study, it appears that Russian state institutions offer disabled people little scope to make themselves and their concerns heard. There is little role for personal voice and knowledge, which were identified as key dimensions of agency and social citizenship in Chapter One. Many of my research participants were critical of official terms and understandings of disability that did not fit with their personal experiences, indicating how 'needs are contested and renegotiated between individuals within the context and the course of ongoing lives' (Watson et al 2004: 344). However, personal agency is limited since disability classifications are almost never adjusted upon appeal, indicating how power within the welfare system is located with professionals such that countervailing messages about disability are not heard. In light of the lack of redress if medicines or sanatoria places are unavailable, the most common response of my research participants was to reduce interaction with state structures, thereby weakening a state-citizen relationship already strained by classification criteria that conceptualise disabled people as unable in many areas of life. The next chapter considers whether such limited state support, constraints on voice and unequal power relations vis-à-vis professionals also affect the instantiation of disabled people's rights to education, employment and livelihoods. These are key arenas shaping social participation and inclusion, but also ones in which messages about disability are perpetuated and state structures may work to control disabled people and limit their options.

Chapter Five

Shaping livelihoods: education, employment and money

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'Why do you need an education?' This provocative question was posed by an admissions officer at a technical institute that one of my disabled research participants wanted to attend. It underlines how access to education and employment is shaped by professional attitudes as well as messages about disability enshrined in law and policy. More broadly, this derogatory comments raises questions of how needs are defined and how policies try to address them, thus moving us from the framing of needs to the 'taking care of', 'giving' and 'receiving' aspects of care and citizenship discussed in Chapter One (cf. Tronto 1993). Education, employment and material well-being are all bases for livelihoods and major themes in disability and citizenship studies since they affect a person's position in society, raising questions of resources, relations and power. They also have crucial emotional and representational dimensions concerning societal image, self-identity and the lived experience of policy practices. In this chapter, I consider how relationships between disabled people and state institutions as well as interaction between disabled and non-disabled citizens are structured in these sectors and what this reveals about official approaches to disability. In looking at the relations underpinning education and employment trajectories, I reveal the dynamics of inclusion and exclusion produced in the discourses and practices of state welfare systems that supposedly address need (cf. Knijn and Kremer 1997).

This chapter therefore interrogates the nature of societal participation underlying disabled people's citizenship in Russia, focusing on education and employment while the next chapter will look at mobility and access to space. I start by looking at the dilemmas faced by disabled children and their parents in choosing between what they see as imperfect forms of education. Their main concern is exclusion from mainstream schools and society, but this must be understood in a nuanced fashion, for there are various ways in which disabled children may be isolated from wider society by the education system. This section highlights the value put by research participants on social interaction and educational quality in contrast to official understandings of ‘special education’ as protective and health-focused. The second part of this chapter discusses the legal and social barriers that frequently deny disabled people the right to satisfactory employment and consequently objectify them as unable to work and dependent on state welfare. Exclusion is again a key theme here since state organisations do very little to support disabled people in finding employment and adapting workplaces. I finish this chapter by exploring how my respondents made ends meet and regarded their material situation in light of barriers to work and their resulting reliance on low state pensions. The conclusion surmises how education and employment policies promote the idea that disabled people are unable and thereby perpetuate the dependency, exclusion and poverty of this group. Such a position is however not accepted and disabled people often draw on social relations to challenge and rework these dominant conceptions of their livelihoods in ways that reveal the presence of agency even in the face of powerful structural constraints (cf. Lister 2007: 37-42).

The educational dilemma: ‘choosing’ how to be excluded

In this section, I discuss the uncomfortable task faced by disabled children and their parents in choosing between three forms of education that are all regarded as unsatisfactory: home education, special schools and boarding school. My research participants used a range of criteria to evaluate educational options, including perceived quality, accessibility, opportunities for social interaction and stigma. Above all, they enunciated a preference for inclusive approaches in which disabled children could attend mainstream schools. However, state provision in the education sector is premised on the need for ‘special’ education and therefore works to separate children with impairments from society, thereby giving them a distinctive and arguably disadvantaged experience of the right to education.

The educational trajectory of disabled children diverges from that of their non-disabled peers at a very early age. Indeed, I did not hear of a single kindergarten in Kazan that accepts disabled infants. In part this refusal relates to the inaccessibility of nursery buildings, but more fundamentally it stems from teachers believing that only specialists in the field of ‘defectology’ (now sometimes called ‘correctional pedagogy’) can look after children with disabilities, be they mental or physical. During my time in Kazan, the only pre-school care that I came across was a nursery group in the combined school and children’s rehabilitation centre located in the southern part of Kazan. However, it was too far to reach for parents living in other areas of the city and pre-school children would be too young to send on school or public buses. Such factors explain why almost none of my research participants mentioned kindergarten when talking about their education and life histories.[32] This lack of care for young disabled children creates a range of problems. For one, someone has to be at home to look after child(ren) who would otherwise be in kindergarten. This naturally prevents the parent(s) or relative(s) in question from working and performing many other activities with consequent implications for their income and lifestyle. Secondly, not going to kindergarten creates an educational disadvantage because Russian nurseries offer lessons in basic arithmetic, writing and the alphabet. Children without this education will automatically be behind when they start school. For example, Maksim (a university computing student, 24 years) in fact started the first year of junior school when he was eight years old, which is one or two years later than usual in Russia. Not attending kindergarten also means that disabled children have fewer opportunities to play and make friends with their peers. The unavailability of pre-school care thus triggered social isolation and educational disadvantage as well as additional care responsibilities for parents, representing a very early beginning to the separation of disabled children from their non-disabled counterparts that was to continue throughout their lives.

At school level there is no direct denial of educational provision as with kindergartens, but forms of exclusion and unequal treatment still affect disabled children. Several of my research participants had started their education at local schools catering for non-disabled children. Their parents had persuaded the directors to accept disabled pupils in line with a law that lets families select their children's school.[33] Parental time and

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[32] It is also important to note that the kindergarten group of Kazan's special school had not been created when my youngest research participants were children in the early 1990s.

[33] Kindergarten provision does not fall within the framework of this law and directors can therefore reject disabled toddlers with impunity. At school level, many teachers will also override parental wishes by refusing to teach disabled children, feeling they should be taught in special schools by defectologists (cf. Iarskaia-Smirnova and Romanov 2007).

effort were crucial in supporting attendance at local schools because the children needed to be carried or transferred between rooms in highly inaccessible buildings. Masha (a wheelchair user who was undertaking a distance-learning university course in management when we met) was able to go to the local primary school for the first four years of her education because all her lessons were on the ground floor and therefore she did not have to be carried up or down stairs. Masha's mother sat through classes with her daughter in order to help her move around, thus supporting Chapter One's theorisation of mobility as strongly influenced by social relations. Even so, she stayed at home for the three winter months of the year due to the problems of navigating icy roads. Her teachers then visited her occasionally with homework and mini-lessons. From Year Five, Masha changed to home education – which in Russia refers to local teachers visiting pupils at home to offer tuition – because her classes took place on various floors of the school building and it was impossible for her to move between floors in her wheelchair in the absence of a lift. Here teachers' attitudes were not the problem, but rather the built environment and how school architecture was designed around a [Soviet-era] image that did not include disabled children.

Ksenia, who needs support when walking due to the effects of cerebral palsy, similarly started her school life by attending the local school in her area before transferring to home schooling. Her mum explained that in the first school year 'I carried her there in my arms every day. A lesson lasted 45 minutes, after which I would lead her into the corridor and we slowly went to the next classroom. I could only manage half a year of doing this.' Ksenia's parents then sent her to the special day school in Kazan for physically disabled children, where she stayed for three years before transferring to home education due to concerns over the quality of instruction being provided, a story that will be discussed below. Her case of changing schools several times is not uncommon and quite a number of my respondents had moved schools several times due to problems of accessibility, transport and educational standards. This highlights the difficulty of choosing between various second-best forms of schooling and how state policymakers and services may not define needs in the same ways as they are experienced.

Masha’s and Ksenia’s experiences show that parental efforts can sometimes overcome the barriers to educational inclusion and that this is some scope for bottom-up agency to refashion citizenship. However, this demands much time and energy to cope with inaccessible architecture and possibly hostile views on the part of teachers. Educational inclusion is nonetheless only possible for children at primary school level who have a parent who can accompany them. That some relatives try to support their children in local schools reveals a preference for inclusive education where disabled children could study, interact, learn and play with their non-disabled counterparts living locally. However, the fact that the burden of providing the required assistance falls to parents suggests that state organisations do not see inclusion as an important element of the right to education for disabled children. This creates a space for the contestation of official interpretations of needs, which the previous chapter suggested is largely focused on biological impairment and supposed ‘defect.’ Such messages are borne out in the options open to disabled children of secondary school age, who face an unenviable choice between two different forms of exclusion from the wider community: special schools and home education.[34]

Roughly half of my research participants who were disabled during their childhood had attended the ‘special’ day school or *spetsskola* in Kazan for physically disabled children. Others had been taught at home by a teacher from a nearby school who spent several hours with them each week. Finally, a few had been educated in a boarding school on the outskirts of Kazan for children with cerebral palsy, sometimes going home at weekends. The three available options all involve teaching disabled children separately from their non-disabled peers, which chimes with earlier research on ‘special education’ in Russia, indicating that little structural change within the education system has taken place in a decade (cf. Thomson 2002a).

Special schools

Kazan’s day school for disabled children opened in 1994 and was one of the first such institutions in Russia. It was a prestigious project for the regional government, which was keen to demonstrate that Tatarstan was socially innovative. Indeed, the Russian president Boris Yeltsin visited the school during a trip to Kazan in the mid-1990s, where he praised it as an example of Tatarstan’s progress in social affairs. He subsequently allocated additional funds for its renovation and a second building to house a swimming pool and properly equipped medical rehabilitation section.

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[34] There is in fact a third form of exclusion: boarding schools, of which there are several on the outskirts of Kazan. Statistics suggest that 28% of disabled children in Russia live in boarding schools and residential institutions (UNCIEF 2005: 16). I unfortunately do not consider their experiences in this thesis given my focus on state support for disabled people living alone or in family settings (i.e. outside the state care system).

However, this construction is still ongoing and the school's auspicious start belied serious problems related to the accessibility of its buildings and the quality of education provided.

The criticisms I heard of Kazan's special school focussed on its limited curriculum and the experience of being taught separately with other disabled people. As a *spetskola*, the school offers twelve years of education in contrast to the standard eleven that it usually takes in Russia to complete school, reflecting a slower pace of delivery. Ksenia, who had started education in her local primary school until her mum grew exhausted from providing the necessary support, changed to home-based tuition after a few years in the special school due to her dissatisfaction with receiving an incomplete education that would have made it difficult to achieve a full high-school qualification and enter university. She was especially vexed by the absence of regular English classes. I asked the director of the school in question about the breadth of the curriculum; she explained that they technically did offer tuition in all subjects required for a Russian high school diploma, but that some of them were taught at weekends in the form of additional classes that not all pupils attended. When Maksim studied there, the twice-monthly Saturday classes covered English, history, IT and Tatar language. Some of these subjects are compulsory in Tatarstan's schools, resulting in incomplete school certificates if students do not study them. Ksenia's mother usually worked at weekends and therefore could not help her daughter catch the school bus on Saturdays. Indeed, the school is located on the southern edge of Kazan and is therefore difficult for people living in other districts to reach, especially by public transport. Ksenia's mother told me that it was tiring and frustrating to bring Ksenia to and from the bus stop, especially during winter months, echoing Masha's experiences of receiving home education from December through to February even though she officially attended the local school. So whilst the special school fulfilled its mandate to offer a full educational programme, it did so in ways that were incompatible with how families organise their lives. This is indicative of the broader point that state services may not be designed to fit with users' priorities, (Tronto 1993: 108; Beckett 2007).

Another problem was that the special school for disabled children is in fact poorly designed for wheelchair users. Like many social services opened during the 1990s, the *spetsskola* is housed in the building of a former kindergarten.[35] The only lift is located in the kitchen and people with even mild walking difficulties may find it difficult to ascend the narrow staircases, although convenient handrails have been installed. The director told me how older pupils often helped to carry smaller children between rooms and floors, but this became unfeasible as the latter grew older and heavier. Maksim had this very experience. As a child with cerebral palsy that necessitated use of a wheelchair, he started to attend the special school as soon as it opened, when he was in the second year. However, by the fifth year he changed to home education because the building was completely inaccessible to him. In contrast to Ksenia, he stayed affiliated to the school (which was very close to his family's flat) and therefore its teachers visited him at home to give lessons. That a major city's only school for physically disabled children is in fact poorly accessible – with rooms spread over two floors and no lift – reflects how physical barriers can impede mobility and inclusion, as will be discussed in greater detail in the next chapter.

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[35] Budgetary cuts and a low birth rate meant that the high number of kindergartens operating in the Soviet period to enable mothers to work was reduced in the 1990s. Newly emerging social services and non-governmental organisations were often offered premises in the vacant buildings.

My conversations with the staff of special schools in both Kazan and the Siberian city of Tyumen suggested that they understood the flaws of their system, including the stigma that affects children by being associated with 'special' education. In Kazan, the day school was co-operating with a nearby general school and even awarding diplomas in the name of the latter. Indeed, one research participant asked me to note that the school was technically not a 'special school' because the educational programme was the same as everywhere else, albeit on paper rather than in delivery. The school directors were aware of inclusive practices and seemed prepared, even expectant, of my questions on this subject, suggesting that global discourses were circulating in Russian special pedagogy. Interestingly, one claimed that the problems of her pupils were essentially health-related. On first impressions, this might suggest a medical understanding of disability of the kind that underlay the Soviet pedagogical branch of 'defectology.' However, her view was in fact a frustration that so little was being done to tackle the social determinants of disability in Russia. To her, improving the health of pupils through medical treatments and physiotherapy was one of the few things that her special school could achieve that would make a real difference to disabled children's living standards. It was thus a pragmatic, if somewhat defeatist and potentially problematic, response in her role as a professional trying to promote the well-being of her pupils.

Indeed, I did at times feel as if physical health was over-prioritised in special schools. In the primary school for disabled children I visited in Tyumen the headmistress proudly singled out the children who would be moving to general schools in view of their reduced impairments, generally better walking or control of their hands. Such actions perpetuate an expectation that good health is to be rewarded and that disability has shameful dimensions, thus giving moral shades to questions of need. This is not to underrate the medical support offered in the special school. For example, Damir's fluctuating health meant that the medical care offered at the special school in Kazan was very useful to him since it is unlikely that he would have been able to successfully study in a general school. He therefore praised the school and also noted approvingly that the school was specifically for children with physical disabilities; pupils were not put together with those with learning difficulties, which often happened in Soviet residential care. He praised the mix of education and medical treatment, comparing it positively to home education 'because studying at home isn't the same as in a collective group. If I had stayed at home, it would have made communicating with other people more difficult and I wouldn't have been as talkative as I am now. Probably I would have retreated into myself.' He thus saw the special school as an opportunity for social interaction with other children that he would otherwise have forfeited. In his eyes, the special school was positive since 'there are institutions where they just teach and those where they just provide medical treatment, but from the start everything was together there.' Despite these warm words for a system that segregates children from society, Damir was nonetheless a 'supporter of equal rights for people with disabilities (*lyudi s ogranichennymi vozmozhnostyami*), like it's written in the constitution of European countries.' Although he did not directly comment on fully inclusive schools, his support for social interaction, equality and not 'simply sitting in your wheelchair and not going out' suggests that the overall idea of disabled and non-disabled children studying together was positive for him.

Several former pupils of the *spetsskola* in Kazan told me that they would have been unable to cope in a general school due to the stigma attached to disability, not least among teachers. Anton's mother was especially forthright in this respect: 'at least in the boarding school there wasn't the pressure he would have felt in a standard school. When we tried to enrol him in the first year of a usual school they asked me, what are you doing, the other kids will trample all over him.' That teaching professionals rebutted the attempts of a mother to enrol her son suggests the continuation of Soviet pedagogical principles that disabled children need separate education and care in specialist institutions due to their purported difference, inability and weakness. This is a clear example of purported concerns about 'protecting' disabled children overriding other considerations, especially those related to questions of rights, for example the right to choose which school to attend or learning alongside non-disabled children (cf. Rioux 2002: 214). This example also shows how anxiety over the stigma associated with disability can influence the instantiation of rights to education if it is feared (by teachers and parents alike) that disabled children would not be accepted by their non-disabled counterparts in general schools. Interestingly, my respondents who were home-schooled did not mention such fears, perhaps suggesting that they arise within the special school system. Such fears highlight the importance of looking at how emotional responses, especially self-esteem and self-identity, are shaped by particular representations of need (Lister 2007: 39-41).

Home schooling

In Kazan, the alternative to attending the special school was home schooling. In Russia this does not refer to parental tuition, but to being taught at home by teachers from a local school, generally the nearest one to a child's home and not necessarily a special school for disabled children. Children are officially enrolled in this school and receive its graduation certificate even though they are taught separately and largely through self-learning. Disabled children and their parents who opted for home schooling did not regard it as an ideal form of education and understood the high risks of children being socially isolated. Some were compelled to accept it due to the special school's inaccessibility, while others felt home education offered a better, but not optimal, experience and quality compared to the special school.

As mentioned above, Masha was taught at home for most of her childhood after it became difficult for her to attend the local school in her wheelchair. She was very critical of special education and her case shows that home schooling does not necessarily have to be negative and isolating. This is because formal affiliation to a local school gives disabled pupils the chance to take part in its various events and thereby make friends. Masha explained to me that although she studied at home, she turned up in school fairly often for parties, competitions, games and drinking tea during breaks between lessons. It is important to note that this regular attendance was only possible because her family lived in an accessible housing bloc and her mother, who did not work, could support Masha in these activities. The upshot was that Masha had a wide range of friends even though she did not attend lessons in school. Indeed, she only came into contact with other disabled people when she started to work as the co-ordinator of a distance learning programme targeted at disabled people. Similarly, Maksim and Ksenia had a number of close friends from school despite having been educated at home. Perhaps ironically, home schooling can thus facilitate inclusion and interaction in society and with non-disabled people even though it means they are not a full part of a school community. Access to social relations rather than physical location is the key factor in inclusive citizenship here.

Although she did not fully experience it herself, Masha was a strong supporter of inclusive schooling in which disabled and non-disabled children study together. Working with disabled students across Tatarstan in her role as a university coordinator, she felt that there was a large difference between those who had attended boarding or special schools and those who went to schools where they mixed with non-disabled children. To her, the two groups were 'completely different people. I think that when you study altogether, you are more emancipated, talkative, you're not embarrassed about anything and more active. In a boarding school, you just stew in your own juices. The same people are around you and this is not good, they are more withdrawn and dependent.' She also felt that inclusion at school level was 'useful for society, the population gets used to disabled people and then they don't stare so badly on the streets.' Certainly, home and special education isolate disabled people from the wider population and thereby maintain attitudinal and social barriers to their inclusion by implying that 'special' and separate approaches are needed for these fundamentally different people.

Anton's mother had reservations about home education, but more related to its quality than to issues of group interaction: 'home education … that means they learn how to write their name and count money, Anton wouldn't have got anything more.' Certainly, one teacher is often expected to cover most core subjects with some foreseeable quality issues. In Kazan, Maksim mentioned to me how the Maths teacher also offered him geography. Based on her personal experience of home education from her fourth school year onwards, Nataliya was also sceptical of its quality:

> 'teachers would visit me at home, but I began to understand that I was learning differently from all the others. I knew that more stayed in my head when I attended school. It stayed with me more than when teachers visited and explained things to me at home. That's because single teachers had to give me all the core subjects, but they didn't always teach them themselves. For example, there was a super English teacher in the school who had to teach me geography. The quality of education was naturally not very high.'

Although her critique mostly concerned standards of education for children who are home-schooled, Nataliya also told me that 'you can tell when talking to me that I didn't interact much with people' during childhood. Home education can certainly reduce opportunities for communication and interaction. Thus, while Masha's parents acted to ensure that she used home schooling as an opportunity to engage with other students and pupils, Nataliya's links were more limited. She was isolated socially and also in terms of educational experience and outcome. Context, particularly constellations of social relationships, is therefore very important to whether particular educational structures can be said to be inclusive or exclusionary.

Both special schools and home schooling instantiate the right of disabled children to education, but do so by excluding them from the mainstream. Parents often make great efforts so that their children can attend local schools for at least the first years of education, implying strong support for community-based education. However, disabled pupils almost inevitably end up in separate programmes that are generally seen as second-best solutions forced on children for whom local schools are architecturally and attitudinally inaccessible. Fears over the quality of education and interaction available to disabled children suggest that this group receives a disadvantaged school experience compared to non-disabled counterparts. These inequalities confirm the evolving argument in Chapters Three and Four that Russian policies define disabled people through their bodies rather than as citizens holding equal rights. Indeed, the 'special' structures for educating disabled children seem to be underpinned by the broader message reminiscent of deficit approaches to disability that 'to be cared for is to be in deficit and to have one's competence as a social actor denied or questioned' (Hughes et al 2005: 261).

Higher education: distance learning

Although children with physical disabilities living in Kazan have some choice over how they are schooled, albeit imperfectly, options for vocational or higher education are very limited. Most universities in Russia expect their students to attend classes at least part of the time, but do not create accessible conditions for wheelchair users or those with mobility problems.[36] Choice in higher education is thus reduced to distance learning through textbooks and online courses. Indeed, the several higher education schemes for disabled students I encountered were all based on correspondence courses with very little face-to-face contact time. Unfortunately I cannot give much information on vocational education for disabled people because I met very few disabled people who had received such training. Most of the disabled students I knew were completing

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[36] This makes a mockery of the fact that most Russian universities, including the classical and medical universities in Kazan, have formal policies to admit disabled students without entrance examinations and exempt them from tuition fees.

university degrees, while the older adults had generally become disabled as a result of accidents or deteriorating health after finishing their education. The one exception was Lena, who had completed courses at two different technical colleges. While the accessibility of the built environment was not a crucial issue for her since she is not a wheelchair user, she still encountered significant professional opposition when trying to study as a disabled person, having been asked the hostile question that opened this chapter. Such attitudes reaffirm how mobility and access to space is largely conditional on social relations and representations of mobility among the population and policymakers.

In Kazan, only one university offers higher education courses specifically targeted at disabled students. Other institutions have part-time or distance programmes, but they require some class attendance which is problematic for disabled people due to inaccessible buildings and transport. Masha explained to me that she originally wanted to study psychology, but there was no distance learning course in this subject. It was the same situation with journalism at Kazan State University, the most prestigious university in the city. She did find a business studies course that required lecture attendance for just two months a year and her mother enquired whether she could visit lectures with a dictaphone instead of Masha, who would have attended just to sit exams. However, this was not allowed and no special allowances or measures were considered. This means that disabled students in Kazan must choose from a very limited range of courses and universities if they wish to receive higher education, thereby placing constraints on the agency and freedom of disabled people.

Like other research participants in Kazan, Masha found that the private university TISBI offered her the only opportunity to obtain a degree. TISBI is a commercial 'academy' that started to provide distance learning to disabled students in three subjects (law, computing and management) in 2000.[37] This initiative was initially supported by the regional Ministry of Social Protection in Tatarstan, which paid the fees of disabled students. The distance programmes are taught via textbooks, online courses and occasional consultations with lecturers. Assessment is online in the form of multiple-choice tests, structured answers and essays to be submitted by email.

The several people studying at TISBI that I met felt that distance learning was positive in helping them to get a university degree, but very much a second-best solution. Firstly, there was almost no interaction between students, with everyone sitting at home in front of a computer. Students rarely saw or communicated with each other and therefore could not make friends. Indeed, I attended a 'confidence building workshop' for young people organised by a local disability organisation with the support of a psychology lecturer from TISBI. Participants were especially enthusiastic at meeting fellow students and sharing experiences because it was the first time in their five-year course that they actually come together as a group. Secondly, the courses are essentially self-study; students have consultations with lecturers by telephone, at home or at TISBI, but nonetheless 'this type of study is difficult … you're forced to learn 95% of it yourself, with books. It's especially difficult with hard sciences, for example maths, when you need someone to explain an example or how to solve a task,' as Ksenia told

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[37] In addition to distance learning for disabled students, the academy has a special group of deaf students who attend on a daily basis, but are nonetheless taught separately from non-deaf students.

me. Motivational and pedagogical concerns were therefore associated with the distance learning in addition to the rarity of interacting with other students and academics.

Another concern of disabled students in Kazan was the cost of tuition. Originally the Ministry of Social Protection in Tatarstan paid the fees of disabled students. However, this funding was cancelled following the 2005 reorganisation of governmental responsibilities at federal and regional levels (the infamous Law 122). Disabled students at TISBI are now responsible for finding the 14,000 rouble (£280) fee charged for each of the ten semesters of their five-year degree. TISBI offered a ten percent discount to its disabled students following the cancellation of state funding, but nonetheless the payments represent a large financial burden given that the maximum disability pension in 2007 was 3,120 roubles per month and average wages in Tatarstan were 12,000 roubles per month. Indeed, as a private sector institution, TISBI cannot provide state-funded scholarships (commonly known as ‘budgetary’ places) for any of its programmes. As coordinator of its group of disabled students, Masha was well-placed to tell me that TISBI noticed reduced demand for its distance-learning courses among disabled people after ministerial funding was cancelled, as indicated by smaller intakes.

As with schooling, disabled people are not formally denied university education, but its format is highly prescribed. Distance learning is the only real possibility open to them due to the refusal of universities to adjust their regular courses or buildings to include disabled people, indicating the powerful issue of attitudes equating disability with individual responsibility and health rather than social discrimination. Potential students are therefore forced to accept a form of exclusion if they want to continue their studies after finishing school. Sometimes they also have to study subjects that would not be their first preference due to the limited range of distance learning courses on offer. The provision offered in TISBI undoubtedly expanded the education options for disabled people in Kazan and was greatly facilitated by the development of the internet. However, its atomising and isolating format is not regarded as useful educationally or socially by those who experience it. Indeed, the lack of comprehensive state support or intervention to support disabled people in higher education suggests that attending university is seen as the problem of disabled individuals rather than an element of the societal participation connected to citizenship that state organisations should facilitate. Participation in higher education and the resulting mobility and social interaction it promotes therefore does not fit with official conceptualisations of disabled people's needs.

Overall, none of the educational options available to disabled people provide similar experiences to their non-disabled peers, undermining the claim in the Russian constitution that all are equal. State policies define disabled children's needs and rights to education very narrowly in terms of receiving formal instruction. In so doing, they consider neither the quality of this education nor its role in shaping disabled children's broader opportunities, social interaction and place in society. Indeed, the practices of educational institutions and personnel create an exclusionary form of citizenship that channels disabled children and students down separate pathways. Whilst the possibility to receive education while living at home is an important breakthrough for disabled children compared to the Soviet period, current practices are nonetheless premised on a ‘special’ approach that constructs disabled people as different and needy. Whilst these dominant representations are often challenged, at least discursively, relatives find it very difficult to overcome the multiple hurdles to educational inclusion with the result that state institutions and personnel are powerful actors in disabled people’s lives. Similar conclusions can be made about the field of employment and the next section examines how policies either wilfully prevent disabled people from working or else do very little to overcome the discriminatory attitudes and infrastructural inaccessibility that make this difficult.

Employment: state-sponsored exclusion

My fieldwork diaries and interview transcripts reveal that finding work was simultaneously a large problem and great hope for my disabled research participants. Their concerns highlight the saliency of work for livelihoods and citizenship and how employment is a way of interacting with society as well as providing activity and material resources. The nature of official support in this field offers an important insight into state conceptions of what it means to be disabled and the appropriate role of disabled people in society. The experiences and stories I heard suggest that the process of getting work is complicated by great legal and social obstacles. The first subsection below considers why very few of the disabled people I met worked while the second discusses how available work does little to increase social participation. A noticeable lack of proactive state activity in this sphere suggests that disabled people are not conceptualised in state circles as workers who can independently shape their own lives.

Official and informal barriers to work

Underlying the problems of finding employment is the legal status of many disabled people as completely 'unable to work' (*nesposobnyi k trudovoi deyatel'nosti*) which state medical commissions (*MSEK*) generally award automatically to wheelchair users, as discussed in Chapter Four. According to Russian law, disability pensions are granted because people are officially classified as 'incapable of working' and therefore in need of funds as a substitute for wages that supposedly cannot be earned. Pension levels thus vary with the three degrees of 'inability to work' that *MSEK* may award. This represents a very narrow definition of need that conflates work and physical competence, thus ignoring social barriers in the construction of disability. This logic means that the [low] pensions of wheelchair users – who almost universally are regarded as 'completely unable to work' – should be officially cancelled if they find work. Conversely, employers are legally prevented from employing people classified as disabled and could be fined in the [admittedly very rare] case that their infringement of this administrative rule is unearthed and prosecuted. This means that disabled people have four options if they wish to find work (cf. Lupanova 2002):

1. Hide their disability when applying for jobs (if possible)
2. Find an employer willing to hire them illegally despite their classification
3. Request a change in their classification that may either be refused due to the medicalist assumptions underlying *MSEK* thinking or else result the cancellation or reduction of pensions
4. Undertake unrecorded work in the informal economy

As wheelchair users, many of my research participants faced this legal hurdle about being classed as 'unable to work.' Thus, Masha knew that by law she should not be working: 'I'm classed as unable to work, but I have a job. If they [the *MSEK*] find out, then they will immediately stop my pension.' She was lucky that her employer – the private academy TISBI that runs the distance-learning programme for disabled students discussed above – was willing to ignore the law to employ her and did not believe the condemnation of her abilities and potential listed in her MSEK disability certificate.[38] In this case, Masha could take advantage of the holes in her country's legal-administrative systems for monitoring the population to challenge dominant discourses about her abilities to work. Indeed, people who officially declare that they work may risk losing benefits (World Bank 2008: 10).

Whereas Masha had been offered work by an employer willing to disregard the interpretation of disability as inability to work in Russian law, twenty-four year old Lena found that potential employers refused to consider her for vacancies due to her status as 'unable to work' even though she held several qualifications and was prepared to accept low wages. She felt that her largest problem in life was 'work. I really want to work, I would work indefatigably, I am trying to find work, but I don't know where else to turn.' Lena told me that 'I want to be needed by someone, to contribute my expertise. I have many skills, but no work. I always joke about myself that I will retire,

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[38] The Moscow-based disabled people's organisation *Perspektiva* tries to work with employers to solve the legal questions surrounding employment of disabled people who officially are not allowed to work and assumed to depend on pensions. There was no such scheme in Kazan and even in Moscow significant effort and time is needed to place a small number of disabled people in jobs. More information on these schemes and employment issues is available on Perspektiva's website at http://rabota.perspektiva-inva.ru/ (accessed 30 June 2011).

get an old-age pension and then find work. Of course if you really try, then you can find it.' Lena's determination was reflected in her long efforts to obtain qualifications that would give her an advantage on the job market. When I first met her, she had already completed two vocational education programmes: following boarding school, she trained in a nearby city as a seamstress and later received separate training as a teacher of home economics. Finding work in either field proved impossible, with the most realistic chance being a post in the boarding school she had attended as a child together with Anton. She found the director to be very encouraging, but funding pressures prevented the school from employing new staff. Just before I left Kazan, Lena told me that she had signed up for a course in basic computer maintenance – one actually targeted at deaf teenagers – in the ever present hope of gaining employable skills.

As in the case of TISBI offering work to Masha, it is practically possible for employers to circumvent (i.e. ignore) the legal formulation of 'inability to work' attached to wheelchair users since they are unlikely to be investigated and prosecuted for infringements. However, unfavourable attitudes towards disabled people among employers, especially in the private sector, mean that enquiries for work are very unlikely to be met with sympathy even if the applicants are allowed to work (first and second degree 'inability to work' allows part-time employment or jobs with reduced responsibilities). Indeed, anyone with a disability *spravka* will be tarnished by the association with inability made in law and policy. This reinforces the message emerging in this chapter that social relations and societal representations of disability – themselves framed by official discourses – are very important to citizenship. Labour market discrimination is poorly policed by state agencies and in any case would not help Masha and many other disabled people due to their official classification as 'unable to work.' Before being offered work at TISBI, Masha had responded to several job advertisements by telephone and been told that she was very well-suited to the posts in question. However, this enthusiasm ended when managers found out she was disabled. In one case, she called regarding a job as a telephone dispatcher. She did not mention her disability and the potential employer did not seem to react to it when he delivered a contract to her at home. Yet, she never heard from him again, which highlights the social stigma around disability in line with the negative messages about disabled people's employability promoted at an official level by state institutions, especially *MSEK*. Similarly, the head of the disability organisation *Vera* in Kazan recollected to me how a factory personnel director at a job fair had openly told him that his firm would not countenance the employment of disabled people so there was no point in trying to place members in that particular enterprise. Such prejudiced attitudes and practices are perpetuated by the image of disabled people as 'incapable' contained in Russian law and the consequent ineffectiveness of state schemes to support employment rights for the disabled people whose 'abilities' to work are not fully dismissed.

It was striking that none of my research participants who were legally permitted to engage in employment had benefited from the state employment service in Kazan, which runs an annual job fair for disabled people. This event generally presents vacancies for poorly paid and unskilled work in such fields as security or cleaning. Beyond this event, the city's job centres do little to support or promote disabled-friendly policies and conditions among employers.[39] For example, it poorly enforces formal quotas on large enterprises to employ disabled people. Fines for breaking these laws are rarely imposed and in any case so low that employers often prefer to pay them rather than actually take on disabled staff. Furthermore, the unskilled and poorly paid quota posts generally offered to disabled people are in low demand, not least in the wake of the 2002 social security that made it illegal to work while drawing a disability pension. State actors thus play a negligible role in supporting the employment of disabled people, be it preventing discrimination in the labour market or providing information on available vacancies. This policy inaction serves to perpetuate negative images of disability by failing to highlight that barriers to employment and inclusion are largely socially constructed.

Disability organisations in Kazan were also largely unsuccessful at improving the employment chances of people with impairments, which may reflect the relative underdevelopment of this subsection of the city's third sector (discussed in greater detail in Chapter Seven). Connecting disabled members with potential employers looking to hire workers was one of the few forms of support about which I heard during my fieldwork. Thus, the former military officer Artem received a well-paid telephone sales job after his future employer phoned the Kazan branch of the national disability organisation *VOI* to enquire about suitable staff. He was lucky both in obtaining lucrative work and being put in touch with a manager willing to employ a person with severe spinal paralysis. As a military veteran with a relatively high pension, he had

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[39] A rehabilitation centre focused on employment was opened in 2007 in Tatarstan's second city of Nabarezhnye Chelny as part of an EU programme on the social inclusion of disabled people. I visited the impressive building just before its opening, so cannot report on its actual activity, although several experts later told me that its services were quite formalistic and that its success at finding work for disabled clients was limited.

been able to invest in computer equipment to help him work despite his impairment, indicating how appropriate support can be extremely facilitating. Very few of my other research participants had obtained work through disability organisations, which in any case tend to facilitate poorly paid unskilled work, as will be discussed in the next section. In 2008, the Kazan-based disability organisation *Vera* was in the process of opening a workshop in central Kazan that would generate employment to its disabled members by offering various services to local residents, for example shoe repair and legal consultations. The fact that its premises in the basement of a social services department are not accessible to wheelchair users was not an immediate concern for the organisation since most of its middle-aged members can walk and use public transport without assistance (and are therefore unlikely to be classed as completely ‘unable to work’). Although the jobs were for *Vera* members only, the organisation’s attempts to create employment opportunities should not be underrated since employment would provide important income, activity and social interaction for some members. This makes it unfortunate that I did not come across any news in 2009 or early 2010 that the workshop had opened even though the renovations I had observed during my visit two years ago were nearly completed. Nonetheless, the realisation of these plans represents a group-based challenge to the inaction of state structures around disabled people’s employment and reflects how a collective form of agency can try to rework dominant ideas of citizenship from below.

Due to the scarcity of state and non-governmental sources of support, most of my research participants found work through personal contacts. Whilst finding a job through *svyazi* or social connections is common across Russia (Yakubovich 2005), it has particular significance for disabled people because their social networks may be smaller as a result of their social and spatial isolation. Furthermore, the attitudinal and legal barriers to employment faced by this group can often only be overcome through the intimacy and trust associated with personal intervention. Masha was studying in TISBI when she was offered work there, while Maksim had found data processing work through an online acquaintance who asked him whether he worked once she learnt he was disabled. His virtual friend forwarded his details to a company that six months later offered him work inputting data. These cases are strong evidence that social connections fashion opportunities for social inclusion and livelihoods through employment as posited by the relational interpretations of citizenship discussed in Chapter One. Conversely, they suggest that having few social contacts will greatly reduce the chances of finding work given the absence of well-functioning state services in this field.

The multiple barriers to obtaining work underlay all my conversations with disabled students, for whom the chance of finding graduate employment is very low due to societal discrimination, legal issues around their MSEK classification and the inaccessibility of the built environment. Anton (26 years old, second-degree ‘inability to work’) was one of the first students to graduate from TISBI’s distance learning programme in 2005, where he managed to surprise himself and his parents by receiving excellent marks in his law degree. However, paid work has not been forthcoming. He volunteered at the Kazan office of Russia’s national disability organisation *VOI* for a few months in order to gain experience and occupy his time, but grew frustrated at not being paid. The organisation could not find him work or even an internship and in 2008 he embarked upon the same basic computer maintenance course that his friend Lena was completing. When I was in Kazan, Ksenia was in the penultimate year of her law degree and starting to worry about finding work. The real fear of not being employed following her studies sorely undermined her motivation to complete her course at TISBI, which her parents financed following the end of support from Tatarstan's Ministry of Health and Social Protection. Like Anton, she found it hard to imagine what work could realistically be forthcoming. As will be discussed in the next chapter, Ksenia rarely leaves the highly inaccessible residential building in which she lives. It was therefore doubly difficult for her to envisage a regular office-based job since she did not know any employers willing to accept disabled legal staff and she would find it extremely difficult to enter and leave her family's flat to travel to and from work each day.

Staff at TISBI are attempting to address the dire employment chances faced by their disabled students. The plan I heard in 2008 concerned opening a print shop that would employ graduates from its distance-learning courses. The discrepancy between having a university degree and operating a photocopier was blaring, but I was told that it was difficult to create a coherent and financially viable proposal around other activities. Many disabled TISBI graduates seemed willing to accept a lower-skilled job – in Anton's words, 'in principle I don't care what I do, the main thing is having work.' Although TISBI did not manage to launch the scheme during the fourteen months I spent in Kazan, the scheme was apparently to include special buses to bring employees to and from work. Staff therefore recognised that mobility is an important determinant of labour market participation since not all disabled people have cars (especially not young adults) and public buses are inaccessible to wheelchair users, as the next chapter discusses in greater depth. Such forward thinking indicates that barriers to employment do not just concern laws and attitudes, but also the built environment.

Work as exclusion

Although TISBI's plan to open photocopying shops represents a rare attempt to provide disabled people with some form of employment in the face of large social, physical and legal barriers, it would not facilitate their inclusion in society. Exclusionary tendencies underpinned the employment experiences of most of the disabled people I met who had found work. Their jobs varied from the unskilled tasks traditionally offered to physically disabled people in Soviet times to more novel forms of work that could bring in significant income. With a few exceptions, work was generally based at home and thus did not further social interaction or participation.

The resulting isolation was a major reason why segregated workplaces were not viewed positively by my research participants. Such feelings were expressed well by a young blind man interviewed by *Gazeta Vybor* about work in a factory for people with visual impairments that has existed since Soviet times: 'I don't want to work with people like me. The eleven years I spent in a boarding school for blind children were more than enough! I want to work among non-disabled people' (21.12.2007, p. 3). As with special schools and home education, there is a danger that policy solutions to disabled people's unemployment will continue to separate this group from society either for logistical reasons or deeper policy ideas that separate programmes offer the best support. Such schemes would not promote an inclusive citizenship for disabled people where they can work alongside non-disabled people in Russia. The image of disabled people as requiring ‘sheltered’ workplaces would instead be perpetuated with the unpleasant connotations that they have lower abilities and are intrinsically less useful to society (Oliver 1996).

During one visit to the special housing complex for disabled people in Kazan (discussed in the next chapter), I had two back-to-back interviews that accentuated the different employment fates of people with physical disabilities in Russia. My first meeting was with a married couple, both disabled since childhood, who lived very humbly, with little furniture and few consumer electronics in their flat. Tatyana worked as a telephone dispatcher while Aleksei’s job consisting of folding large stacks of thin cardboard into files and folders. Tatyana earned just 1,500-2,000 roubles (£30-£40) a month, while her husband’s piecework was extremely badly paid and monotonous to say the least. Both jobs had come through the Kazan branch of the disability organisation *VOI* and represent the unskilled tasks traditionally allocated to disabled people in Russia to do at home.

The second person I met that day was a military veteran who is paralysed from the neck down, although he has control over his hands and lower arms. As briefly mentioned a few pages earlier in this chapter, Artem worked as a salesperson for a company selling construction materials and made a two percent commission for each sale he processed. He was remarkably successful at this, earning 10,000-15,000 roubles per month during the construction season (£200-£300, which is roughly the average salary in Tatarstan).

Together with his military pension and cash benefits, this income allowed him to acquire impressive computer and music equipment. Artem understood that some disabled people were extremely badly paid, referring directly to the long hours and little pay endured by Aleksei and Tatyana. Artem was extremely proactive and had various ideas for the employment of disabled people, suggesting that they could offer competitively priced computer services advertised in local newspapers. He bemoaned the fact that the vocational training available to disabled people was limited and did not focus on employable skills, citing the lack of courses on computer programming and website design. To him, education, especially in the forms provided by the state employment service and vocational colleges, did not answer market needs and was therefore largely useless to disabled people looking to find work. The lack of such provision confirms the strong message emerging in this chapter that disabled citizens in Russia are officially regarded as incapable of work and therefore having no need for professional education or employment.

Before he obtained work as a data processor, the 24-year old computing student Maksim made some money on the side by repairing and refurbishing computers that people dropped off at his home. When I confirmed that his work was home-based, he exclaimed that he could not work in any other way since it was very difficult for him to travel around the city: ‘there’s no way for me to travel on public transport. I would need someone to drive me in a car since the state hasn’t modified anything at all!’ His statement is interesting for directly blaming the state for poor transport and its impact on his employment prospects; how my research participants talked about their relationship to the state will be considered in more detail in Chapter Seven. Maksim currently works at home as a data processor, which involves labouring twelve to fourteen hours every other day in front of the computer. He told me that his eyes suffered from the long periods spent in front of a screen, but that he tolerated this discomfort because it was hard to find any type of work and his job paid relatively well. That Maksim was forced to accept work with unpleasant features is a prime example of the limited employment choices available to disabled people.

While studying at TISBI, the university offered Masha a job as co-ordinator of the distance learning programme for disabled students in which she was enrolled. Although she had shorter working hours, she was the only wheelchair user I met in Kazan who had a regular job in an office and team setting. I first met her when she had been there for almost a year. She was very complimentary about the adjustments made by her employer to her workspace, including installing ramps, providing a larger desk and equipment so that she can type and use a telephone at the same time. Although she felt valued at work and had good relationships with colleagues and students, she expressed a desire to work in the sphere of banking and economics in line with her university education. At the same time, she feared that other employers would not make special provisions for her or even consider her as an eligible candidate. This would include overlooking – or not even asking about – her MSEK certificate. Her major concern was feeling ‘unneeded when I finish university … of course I work now, but it would be nice to receive higher wages and get a promotion, to work in my specialist field.’ Yet, it can be extremely difficult to obtain highly skilled work and indeed I met no disabled people who worked in professional fields matching their qualifications. The constraints on employment therefore had clear implications for feeling useful and valued as making a contribution, which relate to the emotional dimensions of citizenship theorised in Chapter One.

Several male research participants told me that they occasionally earned money by using their cars to operate as black market taxi drivers in Kazan. In this case of informal employment, disabled people are able to avoid engaging with assumptions of being unemployable and passively relying on pensions. Unofficial taxis are a common part of life in Kazan; one hails any car on the street and negotiates the fare to the destination required. Although generally seen as a spontaneous decision by the driver to accept paying passengers, certain car owners operate 'professionally' by driving around the city looking for clients. For example, it is well-known in Kazan that a small group of 'deaf and mute' drivers operate in such a way and even have an unofficial taxi rank in a specific part of the train station's car park. Obviously this type of work is not without risk, for example if passengers are dangerous, drunk or refuse to pay. Some disabled drivers therefore preferred to work by taking telephone orders from people they know. Still, such work is stressful and not reliable in terms of income and schedule. It is generally an option open only to men since gender norms and fears over personal safety prevent female drivers from taking on such work. Nonetheless, this use of Kazan's informal taxi economy represents an interesting way of partially overcoming the barriers to work that exist in the state and private sectors. The use of informal practices to build livelihoods in a broader setting of official discouragement to work indicates a considerable degree of agency in shaping citizenship from below.

Overall, state policies in Russia do not posit disabled citizens as workers, but rather as unable to work and thus dependent on state financial support. The official equation of disability with incapability discussed in the previous chapter means that people with impairments are generally offered low-skilled work, if any at all, and left to the vagaries of a poorly regulated and discriminatory labour market. There is no state support to find work and challenges to classifications are rare, not least because people fear losing financial and healthcare benefits if their disability classification is reduced. While personal connections or good fortune can present valuable opportunities for work, such ephemeral conditions are not a strong basis for building a livelihood, as shown by the high unemployment among disabled people both in my study and in the country more widely. Agency in shaping one's life is therefore not impossible, but it is certainly constrained by the messages about disability contained in policies and legislation. Such a situation has important consequences for inclusion, social relations and self-identity by promoting feelings of being unneeded in society and regarded as dependent by state organisations. These emotional dimensions of being prevented from working are also aroused by the low financial income and material resources of many disabled people, which is the topic of the next section.

Material well-being

The difficulties of finding work raise the question of how my research participants made ends meet. Income is undoubtedly an important issue for citizenship since money can facilitate certain options and opportunities, including a feeling of equality that comes through enjoying living standards similar to other citizens. Indeed, the satisfaction of basic needs and broad equality in resources form the essence of social citizenship as formulated by Marshall. At a normative level, Margaret Somers has written that all people have the right to a 'citizenship livelihood' that 'cannot be stigmatised by means testing, or the epithets of "dependency," "charity-case" and other words of social exclusion' (2008: 44). This mention of stigma highlights that livelihoods are not just about activities to support material well-being, but bring meaning to people's lives and affect their relationships to the state and other citizens.

As explained in the previous chapter, welfare provision in Russia is differentiated according to the cause and degree of disability that a person is diagnosed as having. This is especially true in the pension sphere, where the size of financial support awarded depends on the group and nature of a person's disability. Thus, Vladimir was very aware that his industrial injury and resulting support from the social insurance fund provided him with far better treatment and financial privileges than colleagues who had been disabled since or in childhood. He received two pensions – one for disability and the second from workplace insurance – on which he felt he could 'definitely live' (*zhit' na eto vpolne mozhno*). However, he noted that some of his neighbours in Kazan's housing bloc for disabled people had to work extremely hard for little money. Similarly, Artem's military pension together with his wages helped him to acquire expensive home technology and orthopaedic equipment. Although diverse incomes do not necessarily indicate a differentiated hierarchy of citizenship, the fact that disabled people with a work or military record receive far better material support from the state than their counterparts who are officially denied the right to work and earn money strongly implies that support is linked to notions of contribution rather than equal rights.

Indeed, people with disabilities since childhood are in fact prevented by law from gaining a work record and therefore confined to a life of low pension income. The livelihoods and support that they have as supposedly equal citizens thus greatly differ from disabled veterans or workers, not to say people without disabilities.

Although I did not always ask for concrete information about the amount earned by my research participants, I obtained impressions from their lifestyle and observations in their rooms and houses. Disabled people are statistically one of the poorest groups in Russian society given that even the maximum pension for those without a military or work record barely meets the government's official poverty line. Yet, it is important not to typecast all disabled people and their families as poor, for there was considerable diversity in income and financial needs among my research participants. As I mentioned above, Artem had quite a high level of material well-being thanks to his lucrative sales job. His income was however exceptional among my research participants and, in any case, money is not always a panacea for the problems facing disabled people and their families. It cannot overcome the disabling built environment and social attitudes that prevent employment and participation in many fields of societal activity and life. Nataliya, a 35-year old employee at *Desnitsa* in Samara, fully understood that money was not a complete solution: 'of course I would like more money, but it doesn't solve everything. I would still need help at home with everyday tasks.'

The emotional dimensions of financial deprivation and ill-being were a common theme in my discussions with disabled people and help to illuminate the lived experience of disabled people's citizenship. Olga, who had grown up in a family with three disabled children and dilapidated housing, expressed how tired she had been of saving money:

> 'You sat there and always restricted yourself … we could put some money aside, save up for something, but it would have been nice to buy the jacket that we liked, that we wanted to wear, and not the one that matched our low budget. It was already great when you could buy some CDs and pay for the internet, but of course without wages it was very difficult.'

When she and her disabled brother and sister started to work in the disability organisation *Desnitsa*, their wages meant they could 'gradually save a little and buy a computer, a microwave and some other things, a DVD player … we couldn't have bought those things on our pension, getting a computer was really something for us.' In a similar vein, Maksim told me of his dream to 'live nicely like everyone else, get a good salary, and do my favourite things.' Such comments show how money can generate feelings of independence and enjoyment through material consumption. As Maksim's remark suggests, it can also promote an important feeling of being like other citizens. Material resources and the resulting capability of acquiring things could therefore boost self-esteem and emotional well-being through a shared experience with wider society.

Only in a few cases were salaries the main source of income for my disabled research participants; all others relied on their pension. Thus, a middle-aged wheelchair user called Nikolai explained how 'I live mainly on my pension and don't earn much with the car [as an unofficial taxi driver]. When my pension runs out and I need to buy something, then I get into my car. I really enjoy driving and even tried to get work as taxi driver. However, I have problems with my car, I need a bigger, better one.' In this case, his small car was both a source and limitation of income. Maksim was open with me that he earned 7,000 roubles per month (about £140) for working every other day from morning to late as a data processor. This represented a nice supplement to his disability pension of 3,800 roubles and brought his income slightly under the average wage in Tatarstan. This amount compared very favourably to the income of research participants who relied solely on their pensions and even some who worked, for example Aleksei and Tatyana, whose badly paid jobs gave them little additional money.

While the low income of many disabled people reveals that they are not highly prioritised in state policy, it is often wrong to focus on the income of disabled individuals rather than the overall income of their families. This is because the incomes of various people living in a household are often shared, at least in part. Thus, Masha paid her portion of the family's utility bill and much of her university tuition fees from her wages at TISBI. Nikolai, the army veteran who enjoyed his black market taxi work, officially lived separately from his mother in a special housing project for disabled people, but they pooled their pension incomes. Combining funds can be important because families receive little financial support for caring for a disabled relative, just 1,500 roubles per month (approximately £30). This clearly does not cover the lost wage income of a parent (overwhelmingly mother) who stays at home in order to provide care. Other financial benefits for families with a disabled member are similarly meagre. Until a disabled person is eighteen years old, a fifty percent discount applies to the household's entire bill for housing services and utilities. However, in adulthood this discount only reduces the individual's share, completely ignoring the fact that most disabled adults do not leave home and continue living with their relatives. When speaking to Lena, I was surprised that she dismissed her housing discounts as 'a trivial sum.' However, her sentiments became clearer when Anton's mother showed me the utility bills for her household. With one disabled member in a household of four adults, the family received a 163 rouble discount on their overall bill of 1,767 roubles. This suggests that state provision does not recognise the interdependence of citizens and the various ways in which resources might be shared within families such that policies for disabled people affect the people with whom they live. Policy instead considers adults as separate individuals, seemingly assuming that they live in a social vacuum.

Conclusions

The accounts in this chapter reveal that the negative images and representations of disability underlying education and employment policies work to place physically disabled people in Russia in a very marginal position in society. Disabled people's livelihoods are shaped by the official association of impairment with inability and difference that was discussed in the previous chapter. The Russian welfare state therefore constructs needs around an assumption of inherent difference and dependency that undermines notions of equality (Fraser and Gordon 1994). As a result, state institutions and policies prevent people with impairments from participating in education and employment in ways open to other citizens. They are barred from regular schools and most workplaces through a mixture of legal precepts, hostile professional attitudes and inaccessible settings that all arise from the state's equation of disability with defect. Opportunities for social interaction and relations are constrained by school and job options that do not seek to bring people into mainstream settings, but rather offer separate settings that isolate people from wider society, often in their own homes.

The material and social deprivation that result from the official undermining of opportunities to build livelihoods further contribute to the symbolic, financial and spatial exclusion of this group.

Disabled people receive little control and say over how their livelihoods are influenced and instantiated, reaffirming the conclusion of the previous chapter that disabled people are not accorded a role in defining their needs. Decisions about ‘taking care of’ are rather made externally by experts and policymakers in powerful positions due to their control of discursive and material resources (cf. Tronto 1993). My research participants were therefore unable to challenge the powerful discourses about special education and inability to work circulating within politics and society. As a result, personal choice and equal opportunities fail to be major elements of this group’s interaction with the Russian welfare system, suggesting that their citizenship is largely fashioned ‘from above.’ Indeed, the barriers to inclusive education and employment represent the strong and disabling exertion of power by state organisations over people with impairments, who are not regarded as ‘able’ or ‘similar’ enough to be part of the mainstream. In this respect, it is clear that state structures for care can function as mechanisms of ‘limited social engagement, partial citizenship, disempowerment and exclusion’ (Hughes et al 2005: 261).

It would however be wrong to suggest that there was no role for agency or refashioning social citizenship from below. The empirical discussions above indicate a striking disconnect between policy practices and my research participants’ own preferences and I did encounter many attempts to challenge official ideas about appropriate forms of social provision for disabled people. Several parents thus worked hard to ensure that their children attended general schools when they were young enough for this to be possible. Similarly, a small number of adults refuted the assertion in their *MSEK* classification that they were ‘unable to work’ by engaging with the informal economy or securing positions with sympathetic employers willing to ignore *MSEK* pronouncements of ‘inability to work.’ While difficult, state policies positing that disabled people are incapable of building their own livelihoods can therefore be challenged discursively and in practice since ‘people can be, at the same time, both agents in their own lives and the victims of oppression or inequality’ (Lister 2007: 86).

The support of other people, especially parents and relatives, is often crucial to such contestations of need, highlighting that social connections strongly mediate the livelihoods and social position of individuals (cf. Bowlby et al 2010). The influence of other people may be positive – for example the dedicated mothers of Masha and Ksenia discussed above – or negative, as in the cases of prejudiced employers and university administrators. The citizenship of my research participants is therefore shaped by personal agency embedded in social relations as well as the practices and values of state personnel and organisations. The importance of these ephemeral factors confirms the importance of examining how citizenship rights are realised in everyday practice by multiple actors who may have divergent views of citizenship and appropriate state assistance. Yet, the very exclusion from schools and workplaces that disabled people try to resist is likely to reduce the number and range of contacts they have, suggesting that the obstacles which prevent their participation in society are self-perpetuating and hard to overcome.

Chapter Six

Mobility and access to space: housing, the built environment and transport

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This chapter explores how state provision affected my research participants' mobility and therefore the ways in which they could take part in wider society. It is concerned with the facts, representations and experiences of movement that affect the dynamics of inclusion and exclusion underlying citizenship (cf. Cresswell 2010). Chapter One highlighted that state policies influence social interaction by shaping the mobilities and moorings of everyday life. Policies around transport and the built environment promote messages about the place of different groups in society by creating 'mobile subject types' through the interface of hardware, discourses and regulations (Richardson and Jenson 2008). The political construction of disabled people's mobility is an important question in post-Soviet Russia, where state policies and organisations have historically discouraged people with disabilities from living and taking part in community settings. Chapter Three discussed how the dominance of medical interpretations of disability reduced the policy impulse for access to space and inclusion in the Soviet era while Chapter Four found that disability is still largely equated with a 'defective' physiology. Given this unfavourable context, I focus this chapter on the actual and potential mobility of my research participants, especially as they relate to questions of agency and freedom implied by citizenship.

I use the mobilities paradigm to discuss three policy areas where the use of space is a crucial theme: housing, the built environment and transport. I start by examining the accommodation options available to my research participants and how they cope with life in buildings and flats built without consideration of their needs. In line with work on the lived experience of mobility (Imrie 2004; Freudendahl-Pedersen 2009), I consider the emotional and social implications of being isolated at home as well as the ways in which my research participants tried to challenge policy practices that prevented them from leaving their homes and moving into public spaces. I then use the cases of two new housing projects for disabled people in the Volga region to highlight that architectural accessibility is not a sufficient condition for inclusive citizenship if wider social practices are still rooted in negative and paternalistic approaches towards disabled people. Later in the chapter, I look at the relations between disabled people, other citizens and state institutions entailed by transport provision and policies to make public spaces accessible, pointing out that barriers to moving around are not just physical, but also social, organisational and temporal (cf. Cass, Shove and Urry 2005). I also flag up a very poignant concern of my research participants: the obstacles to mobility caused by sharp Russian winters, which draws attention to the contingent and contextual nature of mobilities (Adey 2006). Throughout the chapter we learn that social relations and related imbalances of power greatly influence the mobility and thus citizenship of disabled individuals.

Isolation at home

Like most physically disabled people in Russia,[40] the majority of my research participants lived in flats built to the highly disabling standards of Soviet architecture. Chapter Three discussed how the presence and needs of people with physical impairments were completely disregarded in the USSR's highly functionalist planning and construction. Official representations of society and concrete urban planning did not allow for impaired bodies and the inaccessibility of the built environment perpetuated government claims that there were no disabled people in the Soviet Union by confining them to their homes if they were not sequestered in residential institutions. Architecture thus reflected wider ideas about how Soviet society should be and was an important element of the immobility and exclusion that underlay disabled people's citizenship (cf. Imrie 1998).

Immobility arising from the legacies of Soviet architecture was most acutely experienced by my research participants who lived on the upper floors of apartment blocks without lifts. These are typically five-storey *khrushchevka* buildings that were built in the 1950s and 1960s. The lack of a lift means that disabled residents require substantial assistance to enter or leave their flats, effectively in the form of several people who can carry them up or down the stairs. Bringing adult wheelchair users up several flights of stairs is a complicated task since narrow staircases reduce room for manoeuvre and Russian wheelchairs may weigh in excess of thirty kilograms. The

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[40] As mentioned in the introduction to my thesis, it is estimated that 72% disabled children in Russia now live with their families (Unicef 2005: 13). This is likely to be higher than the proportion of adults since very few people leave the system of state care.

upshot for disabled people living in such buildings is virtual confinement to their flats, which understandably arouses powerful feelings of isolation.

This was certainly the case with Ksenia, a twenty-two year old student in TISBI's distance learning programme for disabled people. Her family of four adults have a two room apartment[41] on the top floor of a five storey building without a lift. She rarely leaves this flat – perhaps once every three or four months – due to the difficulties of moving up and down five flights of stairs. Indeed, her parents together cannot provide Ksenia with sufficient physical assistance to descend and ascend her housing block's staircase. When I asked her to describe her daily routine, which amounted to reading, computer and television, she answered that 'to be honest, my typical days are very boring, everything is very banal … it's incredibly monotonous.' I also had the impression that she felt powerless to arrange her social life: most events and meetings involving her have to take place at her home, making her dependent on other people's timetables, movements and priorities in a way that highlights how 'some mobilities depend on the relatively immobility of others' and vice versa (Cresswell 2006: 739). Spending most of the year in her flat meant that she cherished any activity that let her leave home, be it going to the cinema, visiting friends or just walking in the neighbourhood. She had thus had to wait over a year before finally being able to visit a Western-style café to try a latte macchiato, the drink of her favourite musician. Indeed, Ksenia positively glowed when recounting how some summers she travelled to a sanatorium or to stay with relatives in other towns. Mobility thus had many positive associations for her related to freedom and choice (cf. Sager 2006; Urry 2007) with the

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[41] In Russian terms, a two-room apartment does not refer to the number of bedrooms, but means a total of two rooms for living *and* sleeping plus a small kitchen and bathroom.

result that the physical barriers which prevented her from leaving the house were extremely frustrating. Indeed, her immobility and isolation meant that her family's home was 'a place of confinement and, far from being a haven, was, in part, a signifier of a life' upon which she was missing out (Imrie 2004: 754).

Ksenia's family had tried hard to obtain a flat from the housing authorities from which it would be easier for her to go outside. Her mother railed at the many letters and appeals they had written to various agencies without luck:

> 'We have been on the waiting list for fourteen years, but are still stuck in the same place. God knows which authorities I didn't visit to ask for a three-bedroom flat, even if just a *khrushchevka*. But it was useless. I was even ready to exchange apartments, but that didn't come to anything. They promise everything, but nothing happens and it will probably stay like that.'

The family wanted a larger apartment in which Ksenia and her older brother would not have to share rooms, ideally on the ground floor or in a building with a lift so that Ksenia could exit onto the street. Since they live in public housing, Russian law entitles the family to living premises appropriate to their family size and composition. Yet, the lack of suitable accommodation meant that this entitlement was largely fictional, leaving Ksenia stranded within the four walls of her flat, one of the reasons she had been home schooled and was pursuing higher education through distance learning when I met her.

The difficulties of obtaining accessible housing were also apparent in the city of Samara, where Olga had lived with two siblings and her parents in a dilapidated wooden house. Her mother worked full-time, which meant that:

> ‘I could not go anywhere on my own. There weren’t any care workers then … I was therefore always at home, but it’s hard to be at home all the time and not go anywhere. We didn’t have a telephone and it was a private house, there wasn’t piped water, our mum would carry water from the well. The toilet was on the street without heating and you can imagine what that was like in winter. To put it short, it was very hard.’

In this quote Olga expresses very similar frustrations to Ksenia about having her mobility severely restricted and therefore not feeling independent, pointing to the crucial importance of the subjective experience of (im)mobility (cf. Imrie 2000; Cresswell 2010). She also mentions that she had to rely on others to help her move around, be it social workers or parents, which would greatly detract from a feeling of freedom or ‘potential mobility’ (Kaufmann 2002).

What makes Olga’s case interesting is not the poor housing conditions – in which a considerable number of Russians live – but the fact that her family received little support from the state to solve their housing problem even as her brother and sister also became disabled because of a degenerative health condition. Multiple requests and letters to various authorities for better housing were unsuccessful over an eight year period. Eventually the disabled members of her family were offered places in the housing complex for wheelchair users that will be discussed in this chapter’s next section. They were lucky that this facility opened in Samara since it seemed unlikely that they would receive other assistance to solve their housing question. Indeed, the immobility arising from restrictions on movement between home and public spaces does not appear to have been sufficient grounds for awarding state housing. This suggests that inclusion and mobility are not officially regarded as important features of disabled people’s citizenship and therefore obligations to be fulfilled by state organisations.

Ludmila, a woman in her mid-fifties, was even more socially and spatially isolated than Ksenia and Olga, living alone in a flat that she had not left since 1997. She walked very slowly with the aid of a zimmer frame and often had attacks of breathlessness. Her very small studio apartment is on the second floor of a five-storey apartment block situated on the outskirts of Kazan. The space of her single room is almost completely taken up by a bed, large table, old television and several cupboards. The building technically has a lift, but residents on her floor voted to end its service in order to avoid paying the associated service charges. She is essentially confined to the apartment since she finds it difficult to use stairs and has no social ties that could help her to overcome the physical barriers preventing her independent movement. Her attitude towards this situation varied from resignation to despondency and inevitably created much pessimism. She gloomily joked that she could only tolerate her daily activities of watching programmes on her small television and re-reading her many books because it took her so long to perform everyday tasks like bathing or preparing a meal, meaning that she did not have much time to kill.

Although her apartment is cramped and becomes extremely hot when the sun shines through her large window, Ludmila's main concern was a sore lack of social connections to overcome her confinement and lack of social activity. Whilst Ksenia's family and social network could arrange occasional opportunities to leave her flat, Ludmila does not have any close family, being estranged from her sister who lives in another city. Her closest friend is Tatyana, who works in the local chemist and occasionally pops by to chat and help with small domestic tasks. However, Ludmila expressed slight concern to me that their relationship is driven less by personal affection and more by her friend's affiliation to a spiritual organisation that encourages charity work. She is also visited by a care worker twice a week who performs basic chores like cooking, cleaning and shopping for groceries, but does not support – and indeed is not instructed to support – social participation like going to the shops or chemist. Here a 'politics of need interpretation' from care theory (Fraser and Gordon 1994) is revealing: local welfare services have paternalistically defined Ludmila as dependent and consequently requiring help with basic household tasks. By assuming that she is a passive 'receiver' of care, there is no consideration that Ludmila may want and benefit from engaging with society – visiting shops and running her own errands – rather than having teabags purchased and vegetables chopped on her behalf. Social inclusion and mobility are therefore not officially recognised as basic needs and rights that state social provision should facilitate.

Ludmila told me that several years ago a former colleague – who she knew from the time before her health deteriorated to the extent that she could no longer work as a laboratory assistant – had suggested going to the countryside for a day trip. This was already a few years after she had stopped leaving her apartment. She agreed, but became very stressed about what to wear and take with her in the build-up to the event. She was trying on various dresses the evening before the planned trip when she fell, hurting her leg and falling unconscious. Her acquaintance found her the next morning immobile on the floor. Since then Ludmila has had no opportunities to leave her flat and very mixed feelings about mobility, which for her is at once frightening, enticing and almost unimaginable given her long isolation at home. Significant physical obstacles thus combined with a lack of social ties to involuntarily immobilise Ludmila, who consequently could not even envisage any possibilities for being mobile. Her self-image thus did not incorporate mobility or social connectedness such that, like Ksenia, she saw the home as ‘a place of captivity and isolation’ (Imrie 2004: 747).

Ludmila’s case highlights that mobility is greatly shaped by the presence or absence of kin and friends who can help to navigate physical barriers and provide the necessary emotional support that underpins movement (cf. Imrie 2000; Urry 2007). Many disabled people cannot move independently around public spaces in Kazan due to their housing situation or the physical and social obstacles discussed later in this chapter. It is personal contacts rather than state organisations that make environments accessible for them and thereby facilitate participation in society. The rare occasions when Ksenia leaves her home are only made possible by the help of her family and friends whereas Ludmila does not have anyone to provide such assistance. This highlights how mobilities, inclusion and ultimately citizenship are ‘about relationships’ (Urry 2007: 13) and certainly not individual bodies, which is the assumption that seems to underlie the provision and allocation of state welfare.

Although the lack of a lift was certainly a major problem for Ksenia and Ludmila, an elevator is just the first stage in a drawn-out process of exiting onto the street.[42] This is because there are often steps to negotiate between flats, corridors, lifts, building

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[42] This is assuming that the lifts in question actually function. Having myself once been stuck between floors in a faulty lift in Russia, I experienced both immobility and the results of a thankfully quick though very amateur repair by a longsuffering caretaker. Such failures are a common part of life in Russia and were mentioned by several people as vexing. The chairman of a district disability organisation was particularly scathing that disabled people are left at the mercy of erratic lifts and poor maintenance (*Gazeta Vybor*, 21.09.2009, p. 3). My research participant Masha was more accepting, noting positively that lifts were often repaired within an hour. Such delays can nonetheless upset plans and are certainly unnerving, especially if lighting within the lift simultaneously fails.

entrances and streets. Adjustments or modifications are needed to make these areas traversable by people using wheelchairs. One means of reducing the barriers posed by steps within and around housing blocs is the installation of narrow metal tracks on flights of stairs to make it possible to smoothly push or pull a wheelchair. Such rails can also be attached to staircases in buildings without lifts to facilitate movement up and down in a wheelchair. While in a minority, a number of my disabled research participants had received assistance from their district's social protection department to install such equipment over the stairs between their apartment, lift and building's main entrance. They were very happy with this support, notably Artem, whose authoritative status as a former military officer and readiness to insist on his entitlements probably explains why his local social protection office had organised the construction of ramps and a protected space in his building's stairwell where he could leave his wheelchair. Maksim lived in a high-rise apartment block with a lift, but it operated from a hall located roughly ten steps up from his building's front door. The social protection department in his district therefore erected an additional lift to cover most of these steps, although a friend or relative still had to help him negotiate his wheelchair over three steps that the lift could not reach. In offering such help, there seems to be nascent recognition at an official level that immobility relating to the built environment undermines citizenship and well-being.

Yet, far from all my research participants received assistance from state organisations to reduce the obstacles to mobility within their apartment buildings. Ksenia told me that the local authorities had refused to install tracks that would have greatly eased the task of reaching her fifth floor flat. This was ostensibly because the modifications would have bothered neighbours, although it is unknown whether they were even consulted about this. This purported concern for neighbours was also cited when Masha's family were refused a ramp to help her move from her building's lift to its main entrance. Her father was exasperated by this administrative unwillingness to make such provision and built the necessary ramps and tracks himself even though he did not have official permission. She explained to me that 'he made them himself because it's impossible to get anything out of the housing services.' They heard no complaints from the neighbours and this example shows how official decisions about welfare support and appropriate access to space may be circumvented by agency and action from below.

The varying willingness on the part of social protection offices to adapt living spaces means that disabled people have no firm entitlement to adjustments that would facilitate mobility. When coupled with the non-provision of accessible ground-floor or lower-floor flats, we see that mobility is not officially conceptualised as central to disabled people's citizenship with the implication that they are not supposed to be part of public space. Instead of being a firm right, mobility 'becomes a function of the state's benevolence and the possible provision of fixtures, fittings and welfare payments to facilitate some form of mobility and movement' (Imrie 2004: 1645). So whilst living in family settings rather than residential homes has become a crucial element of disabled people's citizenship in the post-Soviet period, this does not necessarily mean that they are included in the wider community.

Housing complexes: new buildings, old approaches

Despite the limited state support to include disabled people in society by making it possible for them to enter and leave their own homes, it would be wrong to say that there is no state housing provision for this group. In recent years, special residential complexes for disabled people have been constructed in several Russian cities and accommodation in them was the only housing solution offered by local authorities to many of my research participants. As purely post-Soviet developments, they give an insight into how this group's needs and social citizenship are conceptualised at an official level. I was able to make several visits to two such projects during my fieldwork, one in Kazan and the other in the Volga city of Samara. Each has its own format, but both represent an awkward fusion of accessible architecture with management principles more suggestive of a medical and paternalistic approach to disability.

a) The Samara 'village'

When visiting the disability organisation *Desnitsa* in the city of Samara, several activists invited me to see their accommodation in the special housing 'village' for wheelchair users that opened in 2005.[43] The complex is located at the bottom of a hill on the outskirts of Samara and is completely surrounded by wire fencing with a security

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[43] Pictures and information about the village for disabled people and labour veterans can be found on its official website http://www.poselok.mt.ru/ (accessed 30 June 2011).

guard at the only entrance.[44] The complex itself is a set of individual white bungalows that are strikingly different from typical housing in Russia because instead of grey blocks of flats there are low painted buildings with well-tended gardens. Each of the bungalows has a gentle ramp up to the front door, which opens into a large living area with access to several bedrooms and a bathroom. The entire space is built with the interests of wheelchair users in mind with wide entrances, large rooms and specially equipped bathrooms. Residents of the village do not live completely on their own: while each has a private bedroom, they share a living area and bathroom with two or three other residents.

Residents of the complex are a mix of older ‘labour veterans’ (retired workers with a distinguished employment record) and physically disabled adults of working age. Bearing in mind this group of residents, it is interesting how the purpose of the complex changed from its initial conceptualisation to realisation. Originally designed as a model for ‘independent living,’ the housing complex was turned into a residential home or *pansionat* just before its opening. This change in ethos is reflected in the care regime of the complex. For example, a central canteen provides three meals a day, with staff delivering food to all residents in their homes even though the centre’s accessible build would make it easy for residents to collect their food. The provision of meals obviously promotes a certain regimen and daily timetable within the centre and such ‘care’ offers an opportunity for professional discipline and surveillance of residents (cf. Hughes 2005: 263). It also explains why residents were not given full kitchens in their homes. Some have acquired a fridge or microwave, but they are essentially reliant on the

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[44] I was unable to ascertain whether this perimeter fence was built to ‘protect’ residents or simply reflects a common feature of most state organisations in Russia, including universities. A high brick fence similarly surrounds a residential home for mentally disabled children located on the outskirts of Kazan.

centre’s catering, especially for cooked food. Indeed, there is no on-site shop where groceries could be purchased, while the centre’s location at the bottom of a hill precludes wheelchair users from travelling to the kiosks and small supermarket located seven hundred metres outside its fence. The implication seems to be that the complex is designed to offer complete care to its residents even if this is defined very narrowly in terms of meeting basic material needs.

Facilities at the complex include a first aid station manned by a nurse and leisure activities including a library, games room and well-equipped television room. This provision of special amenities for residents of the village could be viewed critically as undermining efforts to include disabled people in broader society. Indeed, non-residents, be they disabled or non-disabled, do not use them and in fact only visit the village when they wish to see specific people. However, providing amenities that wheelchair users find it difficult to access in the rest of the city could equally be a pragmatic decision. For example, one resident told me that it was difficult to find an accessible cinema in Samara since the few premises with step-free entry were located far away from the housing village: ‘at the moment it’s a problem to go to the cinema. There are no accessible conditions, but sometimes you really want to go and watch a film.’ The film room in the housing complex was therefore perceived as positive, although the same person felt that it offered a vastly inferior experience compared to attending a ‘proper’ cinema with a full audience, café and large screen. Furthermore, this particular ‘mooring’ promoted the exclusion of disabled people from society by addressing an immediate need (watching films) rather than the broader issue of undertaking activities in society.

Residents of the village pay seventy five percent of their disability pensions for their accommodation. This is a considerable sum for those who do not have other sources of income and little remains for additional expenditure, for example car maintenance, telephone calls and internet bills. Although the last chapter found that financial income is not a key priority for my disabled research participants, money can support feelings of independence and equality. The complex's relatively high charges reinforce the idea that it is officially regarded as meeting the full needs of disabled people, in this case defined as accommodation, food, basic leisure facilities and medical support. Another strong indicator that the home has a paternalistic ethic and purports to provide comprehensive 'care' is that residents live in the complex without family members and are therefore made to be reliant on the institution (cf. Oliver 1990). The unfortunate irony thus emerges of disempowering institutional care being provided in architectural conditions that should greatly facilitate independent living. By providing all-encompassing social care rather than basic conditions for mobility, state housing support exhibits paternalistic tinges in which a 'benevolent' state organisation both determines and provides for its disabled residents' needs (Tronto 1993: 170). Needs for social interaction and participation in wider society thus seem to be disregarded, maintaining the assumptions from Soviet times that disabled people are passive dependants on care and thus fundamentally different from the non-disabled population. While some residents, especially those who work at *Desnitsa*, manage to challenge such assumptions by working and moving around Samara, they must come to terms with a residential system that makes them live with other disabled people in an isolated compound and even delivers food to them.

Olga, one of the housing complex residents and a salaried activist with the *Desnitsa* organisation, told me that when moving to the housing village she had initially feared that:

> ‘Everything would be like a residential institution here, that we should quietly sit and do as we are told. I don’t want it to be like that ... Russian law puts such homes in a difficult position, all the regulations infringe the rights of disabled people … there’s a real danger that everything will be done to isolate us, shut us out.’

Although Olga was right that some aspects of life in the complex do not provide conditions for full independence, she and the five other disabled people I met who live in the complex were generally content and cherished the community feeling that had emerged among residents. Certain features of life were nonetheless vexing, for example receiving food from staff and how the security team closes the complex’s gates at 11pm, thereby preventing any entry or exit until the morning. Indeed, I heard tales of guests being forced to sleep in the complex because they stayed beyond the curfew and indeed I was invited to stay over myself. Overall, residence in an architecturally impressive complex was imbibed with the notion of institutional care for ‘unable’ people, which grated somewhat with the independence and mobility for which some residents strived. Indeed, the risks that the complex will isolate disabled people, albeit in an accessible environment, suggests that wider social participation is not acknowledged by state planners as important or a matter for welfare policy.

b) Kazan’s housing complex ‘Ascent’

A housing complex for wheelchair users, intriguingly named ‘Ascent’ (*Voskhozhdenie*), opened in Kazan in 2007 following many years of construction and some controversy over the reassignment of its function similar to that affecting the village in Samara.[45] Indeed, during its construction the purpose of the whole complex was changed from housing to rehabilitation, with the current reality falling somewhere between the two.

Voskhozhdenie is a four-storey redbrick complex on the southern edge of the city with only countryside and a few dachas beyond it. The flats surround a courtyard that serves as a car park for the rehabilitation centre for physically disabled adults situated on the same site. The residential part of the building has eight stairwells each located up a gentle ramp. Handwritten signs on the outside doors jokingly remind visitors to be patient when buzzing a flat because wheelchair users move ‘slowly though surely.’ Once inside the building, generously proportioned lifts travel to floors with wide corridors and several flats. Flats in the complex range in size depending on family size, but in all cases are sufficiently large to allow wheelchair users to move around easily. Indeed, it sometimes seemed that the apartments were somewhat empty because residents’ furniture did not fill all the available space. The flats are furnished in line with the finances of individual residents and also the varying support provided to people moving into the centre by social services departments in their local districts. Thus, Vladimir, a middle-aged man who was paralysed from the waist down due to an injury at work told me how ‘the state provided almost everything in the flat for several families, including us, right down to a washing machine. We got settees and

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[45] During my trawls through the Gazeta Vybor archives, I learnt that the idea of a housing project was first put forward by the same group of parents of disabled children who campaigned for a day school to open in Kazan. Construction started in 1995, but by the time it opened the official purpose of the complex had been changed to one of rehabilitation rather than accommodation (Gazeta Vybor, 21 May 2007, p.2)

televisions, even beds.' However, not all residents enjoyed such largesse from their local social services office and received just a bare apartment, which partly explains the very sparse furnishings I saw in some flats within the complex.

In contrast to the housing complex in Samara, wheelchair users were allowed to move into the flats in Kazan with their families. In some cases this is a spouse and children, in other cases a parent or other relative. Residents do not have to relinquish their previous housing and pay a nominal rent plus full utilities for their premises. Although I did not compare exact figures, this probably means that residents of the Kazan complex spend less than those in Samara on their accommodation. This reflects a somewhat different ethos in the Kazan centre, where a greater focus on independence and privacy means that almost all tasks of everyday living are to be carried out by residents in their accommodation. The facilities and support of the neighbouring rehabilitation centre can be used, but this is not imposed and generally refers to medical, social and psychological intervention rather than food or other basic needs.

In a decision made very close to the opening of the complex, city authorities in Kazan designated the complex as a rehabilitation centre rather than housing service. This means that residents are officially undergoing courses of treatment focused on improving their health. As such, their housing contracts are short-term, for a year at most. Tenancies have so far always been extended, although I heard fears from residents about the permanence of their accommodation, especially during interviews conducted close to the date when contracts needed to be renewed. Indeed, in January 2008 all residents were in fact living in the centre on expired leases. One or two people complained to me that they were not allowed to privatise or officially register themselves in their new flat and as such had no tenancy rights, reflecting the fact that the accommodation is not officially designated as housing. This also means non-disabled relatives must move out of their apartment if the disabled member of the family leaves for one reason or another. Such policies prevent residents from regarding the premises as their home and thereby making emotional and material investments.

As in Samara, the Kazan housing complex is fully accessible to wheelchair users, but there are problems with moving around in the wider area around the buildings. After significant lobbying, residents persuaded the owner of a small shop located several hundred metres from the centre to build a ramp up to its door and ensure there was enough space inside for their wheelchairs to manoeuvre. Whilst it is difficult for people in wheelchairs to reach this shop in winter given huge snowbanks and icy roads, it is a popular port of call in summer and probably lucrative for the shop owner. However, other amenities such as a chemist, supermarket or post office are situated further away from the housing block along paths that are not easily traversable in a wheelchair. As in Samara, the combination of a high concentration of disabled people, geographically isolated location and poor facilities impedes the mobility and social inclusion of residents, pointing to narrow understandings of their needs in policy. Residents of these complexes may have been able to leave their homes, but obstacles to mobility within public spaces often meant that they could not travel to places they may have wished to go.

Given that little was being done to improve the accessibility of public spaces, residents of the Samara and Kazan centres as well as other disabled people in the cities had a common fear that the accommodation would create isolated ‘ghettoes of invalids.’ Ksenia was particularly scathing of the ‘reservation for disabled people’ and in fact rejected a place there despite being trapped in her family’s apartment for much of the year due to its fifth-floor location in a building without a lift. Yet, the fact that none of my research participants in Kazan received offers of state housing other than the housing complex suggests that the local authorities view the issue of housing for disabled people as mainly a question of architectural design rather than broader location and interaction within the community. This ignores the crucial point that ‘the ideal of the home as sanctuary is undermined in circumstances where the home environment becomes the product of withdrawal from wider social networks’ (Imrie 2004: 753).

The two housing complexes suggest several contradictions within disability provision in Russia. At an official level, there seem to be qualms about seeing wheelchair users as independent actors. In Kazan, living in accessible accommodation has been tied to the notion of rehabilitation, while in Samara important aspects of independent living have been assumed by the management of the housing village. As such, legacies of paternalism and medicalisation from the Soviet period are entwined with efforts to provide accessible housing and private spaces. The very development of these residential complexes within cities represents an important departure from Soviet approaches of institutionalising disabled people in remote rural locations. Yet, architecture is an insufficient basis for including people in society and in some ways the separate complexes maintain social isolation. They were built on a large scale, just one for each city of a million people, and therefore run the risk of creating isolated oases of accessibility. Most people living in the complexes were therefore content though not ecstatic with their housing, regretting that mobility and inclusion have not been major foci in such policy developments.

Public spaces: buildings and streets

It says a lot about disabled people's mobility in Kazan that only once, towards the end of my fieldwork, did I by chance see a wheelchair user in a public space of the city. The man in question was rolling in a central park with an acquaintance. Otherwise, I only saw disabled people in cinemas, shopping centres or on the streets when there was a special event or I had arranged to meet someone. The striking absence of disabled people in public areas suggests that they are not given opportunities to be part of public space (cf. Imrie 2001). Although my research participants experienced diverse forms of disability, the inaccessible environment was one issue that affected all of them. As Olga told me: 'every one of us [disabled people] finds it difficult to travel where we have to go, to shops, to other places … nothing is accessible for people here in Russia … even if you go somewhere by taxi or a car with a lift, it's impossible to go inside a building. There are curbs, steps and narrow doors!'

Planning laws in Russia require that all new buildings are accessible to wheelchair users. This should ostensibly mean that the built environment is becoming increasingly accessible and that disabled people's potential mobility is growing. However, such requirements are very much a fiction since regulations governing construction are regularly flaunted. My research participants told me of many cases of new chemists or grocery shops fulfilling the letter of the law by building ramps, but in such unhelpful ways that they cannot be used, highlighting the ‘shadow citizenship’ that arises when ‘law as discursively represented and law as lived are fundamentally at odds’ (Chouinard 2001: 187, cited in Cresswell 2006: 752). Masha, the young outgoing student who worked as a university administrator, exclaimed to me in frustration that:

> ‘Architecture should definitely be improved, at the moment it’s in a bad state … ramps and lifts need to be built and modernised. Of course new buildings are only approved if they have ramps, but the question is what type of ramp! They do not make them in line with legal standards. Next to our house there’s a building with an awful ramp: it’s very steep and has marble tiles, you can’t imagine how treacherous it is! I decided to go there one day, my mum, dad and brother took me, but they also found it slippery in shoes. The owners clearly just ticked a box when they built this ramp, the kind of ramp was not important. It’s like that in many shops and chemists: you won’t make it up them even with help and definitely not on your own.’

The problem of owners and builders simply ticking boxes to suggest compliance with accessibility laws is indeed widespread, reaffirming Chapter One’s argument that it is necessary to go beyond formal documentation about citizenship to look at lived realities. Another common failing is the absence of handrails on ramps, without which a wheelchair user cannot move up or down unaided. According to a disability activist I met in the city of Ekaterinburg, these failures to ensure accessibility stem from prejudice on the part of architects, perceived costs, poor state regulation and a lack of technical expertise.[46] The latter two issues in particular suggest a severe failure on the part of state organisations to ensure that buildings and spaces are open to all. Indeed, in none of the fifteen years of *Gazeta Vybor* archives that I examined did I come across

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[46] My research participant, Elena Leont’eva, campaigns mainly on accessibility issues and has written a technical manual for architects on accessible buildings. One of her biggest achievements was attaining a place on the city planning board through which she can ensure that new applications consider the needs of disabled people at least formally. Her website, http://www.svbdv.ru/, has further information on her work and publications (accessed 30 June 2011).

references to builders and owners being fined or reprimanded for infringing legal requirements about accessibility. Thus, the needs and rights of disabled people do not in practice create obligations on state or other citizens to strive for equal access.

The poor recognition of accessibility as an important issue in disability policy is sharply reflected in the fact that the first wheelchair-friendly building in Kazan was the branch of McDonalds that opened on the main pedestrian street in August 1999. A local disability organisation even held a party there to celebrate the opportunity to meet in comfortable surroundings and try out the city's first toilet built to accommodate wheelchair users (*Gazeta Vybor*, August 1999, p.5). In some ways it is telling that this symbolically important development was a private-sector initiative and one supported by an international company because state services have made uneven progress in facilitating accessibility. Indeed, the Kazan edition of Russia's main tabloid, *Komsomol'skaya Pravda*, published a newspaper article in 2007 highlighting the problems faced by wheelchair users when trying to use supposedly accessible public services such as buses, polyclinics, post offices and chemists.[47] It found that public transport was practically impossible to use and reported many examples of steep ramps and poorly designed automatic doors. An ableist 'architectural apartheid' (Imrie 2001: 232) is thus still in existence in Kazan in which individuals are seen as responsible for failing to be mobile.

As discussed in Chapter One, the concept of mobility embeds movement in networks of social relations. The ways that my research participants moved around did not just

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[47] 'Legko li zhit' invalidu v Kazani?,' *Komsomol'skaya Pravda*, 12 December 2007, available at http://www.kp.ru/daily/24017/87829/ (accessed 30 June 2011)

depend on architecture, but also on their social ties, particularly friends or family members who could help them to leave their flats and navigate stairs, ramps and other obstacles. Yet it is not just personal acquaintances that are important facilitators of mobility and access to space, but also other members of society, whose influence may be positive or negative. Nadya, one of the *Desnitsa* activists in Samara, a young and very fashionable wheelchair user, told me how she was refused access to a nightclub by bouncers telling her 'this place isn't for you.' Her friends summoned the club's manager, who concurred with the security team, blithely citing health and safety guidelines even though Nadya was accompanied by several people who could have assisted in an emergency.[48] As well as spoiling the evening, these prejudiced attitudes were insurmountable given that they were held by people in positions of power (cf. Tronto 1993). My research participants in Kazan had better experiences of getting into nightclubs, although there were also problems once inside. Maksim, a computing student with cerebral palsy, told me how the lift in a multi-storey club he visited one night had been switched off after he ascended to the third floor, ostensibly to prevent other people from 'getting up to no good' in it. However, his friends could not locate the staff member with the key when Maksim needed to reach the toilet on a lower floor. In the end, a friend had to carry him down the stairs while a second brought his wheelchair. Despairing of this case, Maksim noted that 'it's impossible to go somewhere on your own' since staff in the service sector often react negatively to disabled customers. This highlights that 'technical devices, in and of themselves, might facilitate little or nothing if the broader societal value systems and relations, which serve

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[48] Disturbingly, one of Russia's main airlines, S7, regularly denies disabled people entry to its planes through a purported concern with safety regulations. Further details can be found in an online article by Radio Free Europe, http://www.rferl.org/content/Disabled_Activist_Challenges_Airline_In_Rights_Dispute/1508812.html [accessed 30 June 2011]

to stigmatise, marginalise and discriminate against disabled people, or continue to see them as less worthy, are not overturned' (Imrie 2001: 235). The attitudes and practices of key actors and agents – themselves linked to broader ideas of disability in society – are therefore crucial to facilitating or restricting mobility.

Maksim was one of several research participants who went to great lengths to gain access to public spaces and be mobile, enjoying trips to clubs, cinemas and cafes with his non-disabled friends. Indeed, his salary as a data processor gave him a disposable income that he could use for leisure activities. Moreover, he had recently received an electric wheelchair from the state Social Insurance Fund when I met him, which made it much easier to move around outside since he found it difficult to control manual wheelchairs on the street. He proudly told me how he could reach Kazan's largest shopping centre in it: 'I have even travelled to Megamall along the road. Of course it's dangerous and scary to travel on the roads, not on the pavements since they aren't traversable. It's dangerous, but there's no choice. If you refuse to go anywhere, then you'll be stuck within four walls.' For him, the benefits of being mobile, namely freedom and choice, outweighed the associated discomfort and risks. He was able to draw on a network of good friends to assist him in negotiating obstacles in the built environment and demonstrated significant agency in ensuring his mobility and place in society.

After my first meeting and formal interview with Maksim, we agreed to go to a café near to his house a few weeks later. The experience was designed to be social rather than research-oriented, although I learnt much about mobility issues through it. It was the grim month of November, just before the fierce Russian winter starts in earnest. Running a few minutes late, I met him sitting alone in a manual wheelchair on the street outside the door to his apartment stairwell, which his mother had helped him reach. Without someone to manoeuvre and push his manual wheelchair, he was unable to negotiate the steps around his housing block and therefore somewhat stranded until I arrived. Maksim greeted me warmly and then asked me to push him to the shopping centre where we wanted to have dinner. Having often made this trip, he directed me along pavements and over curbs with an encyclopaedic knowledge of the obstacles en route. Eventually we reached a busy dual carriageway. Rather than travel on the pavement, he suggested that we should walk along the hard shoulder facing oncoming traffic. This was certainly not for the fainthearted given the speed of cars rushing past us. The start of sleet accentuated the unpleasantness by falling into our faces and making it harder to push the wheelchair along the tarmac. Things improved dramatically once we reached the warm shopping centre, which like many recently built malls in Russia was equipped with convenient lifts and ramps allowing Maksim to take control of his wheelchair. Having had to bend slightly to grip the handles of the wheelchair, my shoulders were cramped after the trip while my upper arm muscles were sore from pushing an adult around. The return journey was even more exhausting, but gave me huge admiration for friends and parents who regularly make such efforts to facilitate the mobility of relatives who use wheelchairs. The trip revealed how disabled people’s experiences of being in public space reflect a complex interaction of self-image, bodily characteristics, social interactions with others and the socio-physical structuring of places (Butler and Bowlby 1997: 421). Mobility is thus not completely structured by external factors, but also requires the ‘self-motivation to take on the hassles and hurdles involved in negotiating their way around the built environment' (Imrie 2000: 1650) and the support of other people. As demonstrated by the cases of Ludmila and Ksenia discussed above, this readiness to challenge the disablist status quo and assert one's presence in society can be very difficult to sustain in the face of significant social and physical obstacles to mobility.

My story of going to a café with Maksim indicates that disabled people must spend significant time and effort working out elaborate routes with the fewest possible barriers. For example, Olga and her disabled siblings searched long and hard for an accessible branch of *Sberbank* (the main savings bank in Russia and one which pays out pensions) in Samara: "we spent a lot of time looking for a branch that we could pop into and in the end found one where there was a ramp, although this had obviously been done recently, because people with disabilities were only starting to go there.' Olga also told me how 'You can only reach *Desnitsa*'s offices by bus. Of course there are some daring people who go on the streets, but only in summer, in winter they don't even try. But they know their streets like the back of their hand and remember where you can cross and where there are curbs.' Accessibility is therefore a rarity rather than a rule for people using wheelchairs in Russia and certainly not something that can be assumed, thus making it important that trips are planned rather than spur-of-the-moment. Yet this planning risks turning mobility into an activity that is 'programmatic and purposive, almost instrumental or something which is reduced to a specific, definable journey' (Imrie 2004: 1647) and thereby detracts from the freedom and choice tied up in many types of potential mobility (Freudendahl-Pedersen 2009).

Like Maksim, Olga also had experiences of travelling in her wheelchair along busy main roads because they are generally free of obstacles: ‘overall it is best to travel in the middle of roads, where there are no steps or other barriers. The only thing is that there should be lights so that drivers can see us, because many drive without looking. It’s deadly dangerous.’ The nature of the built environment, especially the lack of low level curbs on pavements, thus forces wheelchair users who want to be mobile to hazard travelling on roads even though Russia has a very high rate of road accidents. Achieving mobility and freedom in a highly inaccessible environment can thus mean accepting a high level of risk (cf. Burns, Paterson and Watson 2009). This risk largely arises when disabled people try to use public space in ways that challenge official conceptions of their mobility and is thus indicative of personal agency in the face of strong discursive and physical barriers (cf. Richardson and Jensen 2008). Such mobility-related risk raises interesting questions for ‘spatial justice’ and citizenship since wheelchair users like Maksim and Olga feel compelled by the inaccessibility of the built environment to accept a high level of danger in order to be mobile (Cresswell 2006: 741).

Accessibility is acutely a policy issue in terms of raising the well-being of disabled Russians because inaccessible buildings reduce the effectiveness of any state programmes and support for this group of people. Whilst inclusion goes much further than ‘the ability of pre-defined groups to reach pre-defined destinations’ to encompass a complex range of activities (Cass, Shove and Urry 2005: 553), differential access and mobility are important because they reveal and perpetuate power inequalities (Richardson and Jensen 2008: 219). For example, a job fair for disabled people in

Kazan held in December 2007 as part of the ‘Day of Disabled People’ celebrations took place in a hall on the first floor of a cultural centre with no lift, thereby preventing wheelchair users from taking part. Similarly, a round table for disabled youth organised by a local disability organisation in Kazan faced problems because the public library hosting it had very narrow entrance doors through which wheelchairs could not pass. As a result, people with spinal paralysis had to be carried into the building in the arms of volunteers, which was hardly dignified or comfortable. In the last chapter, I mentioned that Kazan’s day school for disabled children has no lift and therefore cannot accept pupils once they become too heavy for other children to carry up and down their narrow staircases. Chapter Four similarly gave the example of the lift in one of Tatarstan’s main health resorts for disabled people only operating during working hours, effectively trapping disabled patients in their rooms on higher floors during evenings and weekends. All these obstacles to access and mobility indicate how ‘the physical construction of urban space often (re)produces distinctive spatialities of demarcation and exclusion’ (Imrie 2001: 232). Beyond undermining the potential usefulness of state services, inaccessibility thus also promotes inequality among citizens by reducing the social inclusion of disabled people.

Without wishing to idealise the mobility levels of physically disabled people in Western Europe, not least in light of Rob Imrie’s masterful critiques (2000; 2001), Olga’s experiences in Finland are telling of how much remains to be done in Russia. She spent almost a year there as a volunteer in a home for children with mental disabilities. While several of my research participants had travelled abroad on study trips related to their work in Western-funded disability organisations, Olga was the only person I met who had spent a long period in a foreign country. She felt that:

> ‘This [Samara housing] village can be compared with Finland since there are similar conditions and almost everything is accessible, but only within the fence. Outside it’s a completely different matter. In Finland, when you go beyond the fence you can go wherever you want, there are pavements, but they have ramps almost everywhere. You don’t have to think, what if I go along this pavement and there’s a curb and I can’t go further? You can go everywhere and find a place with appropriate facilities. But here you go and discover that there’s a step so you need to find another place … Over there [in Finland] you can travel along the pavement like a normal person, there are crossings everywhere. In this sense, it is better there, everywhere is accessible, but here only within the fences of the village.’

In this interview extract, Olga focuses on the positive experience of largely unrestricted mobility. The possibility of assuming that pavements and roads are traversable in a wheelchair greatly reduces the frustrations of being constrained in where one can go and needing to carefully plan routes. Mobility can instead be flexible, spontaneous and enjoyed by an individual wheelchair user without the help of other people. Being able to go where one wants without prior planning or even a concrete destination provides a sense of freedom that rarely arises in Russia. Related to this, mobility generates feelings of being ‘like a normal person’ by using public facilities and interacting with wider society. In contrasting mobility in Samara and Helsinki, Olga focuses on how she feels rather than what she can do when being mobile, thus prioritising the subjective experiences of everyday mobility and citizenship (e.g. Cresswell 2010; Watson et al 2004). Indeed, mobility was rarely problem-free in Russia, which placed logistical and emotional pressures on all my research participants regardless of how mobile they were in practice.

Transport and moving around spaces

Having already considered the role of place and people in shaping the mobility of disabled people, the transport infrastructure is a final dimension in understanding spatial and social exclusion (Uteng 2009). As a collection of systems that makes mobility possible, transportation is an important element in the production of mobility-related identities and inequalities (Richardson and Jensen 2008). In this section I discuss how the use of private cars and public transport shaped the mobility and social participation of my research participants. I thus engage with questions of the positive freedoms that may be generated by mobility (Urry 2007: 206). While each means of transport clearly provides ‘different experiences, performances and affordances’ to users (Sheller and Urry 2006: 216), they are all potentially problematic for disabled people.

As mentioned in Chapter Three, state funding to provide disabled people with specially adapted automobiles was cancelled in 2005. No substantive reason for this cut was given by politicians, leading many experts and disabled people to feel that it was pure cost-cutting. Until five years ago, disabled adults whose *MSEK* diagnosis did not prohibit them from driving were eligible to receive hand-controlled cars produced in Russia. While these cars were small, cheaply built and uncomfortable, their significance for individual research participants is hard to overestimate and arguably greater than studies of ‘automobility’ in general populations assume (Urry 2007; Freudendahl-Pedersen 2009). Having a car overcomes many of the barriers and obstacles associated with using wheelchairs on pavements or riding on public transport. Sergei, a middle-aged military veteran who used a wheelchair, explained that ‘it’s great that I have a car, it lets me do things that I simply couldn't before.' These activities could include travelling to work, shops, friends and even taking part in rallies of disabled drivers for which a special club has been founded in the Kazan housing complex. Most of the disabled activists working in the *Desnitsa* organisation in Samara had cars, which greatly helped them to realise the 'independent living' philosophy they promoted. They were almost affectionate in their attitudes towards their cars. As one person told me as she gave me a lift to an awareness-raising event, 'yes, they're noisy, slow and temperamental, but you get there in the end and that's a real achievement for us disabled people.' Indeed, not owning a car was a large concern for some research participants. Olga explained that 'it's a big stress if I need a car and I constantly worry that I will need someone to help me. It is such a headache when we travel somewhere, how to find a car, how to get there, how to get inside the building. It's always a long story, but that's normal for us.' Given that receiving a car was an official entitlement for disabled people until 2005 (albeit one fraught by shortages), its cancellation represents a sharp blow to the already weak elements of inclusion and mobility in Russian disability policy. It is very hard to see how disabled Russians will be able to acquire cars in the future given the discrepancy between disability pension levels and the cost of a car, especially given the corollary effects of this policy change, for example the closure of driving classes for disabled people and workshops that adjusted cars to hand control. The abolition of automobile provision thus dispels ideas that disability policy in Russia is growing more inclusive over time.

The unavailability of state-funded automobile transport for disabled people makes the accessibility of public transport a very salient question. Kazan's public transport network was overhauled in 2007 when many routes were changed and the city's entire fleet of minibuses and old buses replaced with new vehicles built in Belarus, China and Russia. The new buses were all painted red and therefore present a strong visual image in the city. This new transport infrastructure is an interesting case for the study of mobility and citizenship due to the 'socio-technical geometries of power' it may generate through which mobile subjects 'are framed within the narratives of imagined mobile futures as well as being materially assembled in physical infrastructures' (Richardson and Jensen 2008: 222). The buses were officially proclaimed as disabled friendly since they have a low step and wide automatic doors in their centre. The vehicles certainly represent a change from the cramped minivans and Soviet buses that had very high entrances and several steep steps to reach the seating area. However, the new buses are very rarely used by wheelchair users. For one, they are often overcrowded and there is little room available for wheelchairs, prams or other bulky items. Secondly, the 'low step' nonetheless represents a significant barrier, being roughly forty centimetres above the road. Crucially, not all of Kazan's new buses are equipped with ramps to help overcome this barrier and these ramps are generally a theoretical possibility than usable tool even when they exist. Certainly, in my year of daily bus rides around the city, I never saw a ramp being used in a bus, even for pushchairs or small trolleys. As such, initial excitement among some of my research participants about the possibilities of riding around Kazan, for example to the city centre to see the impressive Kremlin, soon subsided as it became clear that such travel would not be straightforward.

Only one of the wheelchair users I met during my research regularly travelled on buses in Kazan. Masha is a very lively and energetic student who travelled every day by bus from her flat on the edge of Kazan to her job as administrator in the private university TISBI, which is located in the city centre. Although she had negotiated work hours of 10am-4pm with her employer to help her avoid the busiest times on the buses, she still endured protracted journeys. Each morning her father would escort Masha to the bus stop near their flat, from which she and her mum would travel about forty five minutes to work. They generally preferred to take the slow, not express, bus to work because it stopped closer to her family's flat. Her mum would generally go back home, but had to return to the city centre in the afternoon to help Masha make her own journey home. Travelling the same route every day, many drivers and bus conductors knew Masha and made sure that the bus was properly aligned with the pavement for her to board in her wheelchair. She cheerily spoke of her adventures and experiences on the bus, although her ability to laugh at the bags, bottoms and other objects frequently thrust in her face belied a depressing and gruelling reality. She had various tactics to try to minimise the stress of travelling on the bus. For example, when travelling home in the afternoon she would board at a bus stop located further away from her work because the buses on that route started there and thus had fewer passengers. However, this bus stop was at the bottom of a steep and potholed hill on which it was difficult to control a wheelchair, requiring her mum to take special care when helping her travel down it. Her strategies for being mobile therefore required much energy, creativity and some degree of risk, as was also the case with Maksim and Olga's experiences of travelling in their wheelchairs along main roads discussed above. Masha's efforts also reflect how disabled people's awareness of their corporeality is ‘arguably heightened at the point of seeking to move around by public transport’ that is ill-designed for diverse users (Imrie 2000: 1647).

When I first met Masha, I was very intrigued to meet a young wheelchair user with an office job who used public transport. It seemed that she had overcome the barriers to mobility and inclusion facing disabled people by working, going out regularly and having a strong network of friends. However, her optimistic and enthusiastic character perhaps understated the burden of the transport problems she and her family faced. Indeed, after about a year, she unexpectedly told me that she had resigned from her post. Although I knew she was unhappy with her administrative work, she told me that the main factor was that her mum was exhausted from all the travelling, which obviously occupied a lot of her time and significant reserves of mental and physical energy. Indeed, Kazan’s buses are noisy, uncomfortable, overcrowded, overheated in summer and winter and often prone to jolts as drivers brake suddenly in the city’s rapid traffic flow. Masha’s decision to stop working would not have been taken lightly given that her mum is very energetic and determined that Masha should not be disadvantaged by her spinal impairment. The case affirms how the transport system in Kazan is not conducive to disabled people’s inclusion in society, be it regular employment or simply moving around. The inaccessibility of the public transport infrastructure, especially if disabled people wish to travel alone, thus sets up significant barriers to their mobility and life activities (cf. Uteng 2009).

The cancellation of specially adapted cars and the inaccessibility of public buses left many of my research participants with transport difficulties if they needed to travel somewhere. Taxis, whether official or black market ones, are regarded as expensive, especially journeys to facilities like the rehabilitation centre or main hospital in Kazan, which are located far away from central and residential areas of the city. The city has no system of ‘social taxis’ or special transport to bring disabled people to their destinations for free or at subsidised prices. Yet, the case of the *Desnitsa* organisation in Samara shows that dedicated transport can be invaluable to disabled individuals and even their organisations. Olga told me that this disabled people’s organisation was only able to organise larger projects and include more people in its activities after it received a minibus specially equipped with a lift for wheelchair users. The bus was used on a daily basis to bring staff to the office, run events in other locations and to ferry members to a local university at which many of them were studying on a part-time and part-distance basis. Indeed, the organisation effectively closed when their volunteer driver was unavailable through illness, holiday or private business. The minibus was a lifeline for their non-governmental organisation since not all members could rely on private cars. However, it was not a complete substitute for being able to freely use transport to travel whenever and wherever one wants since a constellation of organisational, financial, physical and temporal factors had to align before the minibus could splutter into action (cf. Cass, Shove and Urry 2005).

Disabled people in Kazan are thus largely alienated from a transport infrastructure that essentially prioritises the movement of ‘productive bodies’ (cf. Imrie 2000: 1644). The failure of the new bus system to be inaccessible and the cancellation of personal automobiles has abrogated the responsibility of state structures for everyday mobility and devolved it to individuals whose financial and social resources make the use of transport very difficult. When combined with the highly inaccessible built environment and frequently hostile attitudes to mobility, disabled people's citizenship can be characterised as rather immobile. Although some of my research participants sought to challenge these messages and tendencies, such agency demanded high levels of energy, motivation and planning that still significantly differentiates the experience of mobility from non-disabled people. It is thus accurate that 'subjects involved in or excluded from everyday mobility practices may appropriate new infrastructures or modes of mobility in unpredictable ways' (Richardson and Jensen: 222), but they may equally be largely excluded from such infrastructures (Uteng 2009).

Seasonal dimensions of mobility

A frequent issue I heard in relation to mobility was that winter precludes almost all opportunities for disabled people to travel outside due to the obstacles posed by snow and ice. Although the effects of weather are not explicitly theorised in the mobilities literature, they reflect the broader point that 'mobilities are given meaning in particular contexts' (Cresswell 2006: 735). This contingent factor was often mentioned by research participants and certainly gave a seasonal dimension to their mobility. Even in the rare cases when pavements in Kazan are cleared of snow and ice, they are neither salted nor gritted to create the friction that is much needed by pedestrians and wheelchair users alike. This inaction on the part of authorities means that summer is the season of relative freedom and mobility for disabled people.

In the section above on moving around public spaces, Olga mentioned that her fearless colleagues who drive their wheelchairs along roads to reach the *Desnitsa* office do so only in summer. Yet during her yearlong volunteer placement in Finland, she learnt that it was practically possible to move around cities in a wheelchair despite winter conditions, an activity that is off-limits to disabled people in Russia. Masha faced difficulties getting to her university workplace in winter. I met her in mid-autumn and she told me that 'winter is coming up and Mum and I are already scared because they don't clear the snow from all of the streets. The main ones are cleared, but not the back streets. They are covered with snow so you cannot travel on them or get through.' Similarly, in the last chapter we heard that during the four years when Masha attended her local school on a daily basis, she was nonetheless home educated in the winter period since it was difficult to reach the school due to ice and snow.

The upshot of the poor provision to remove winter-related barriers to accessibility is that this season means confinement to apartments for long periods, often months. Even if Ksenia's friends or family members carried her down from her fifth floor flat, she had difficulties travelling through the snow with either a walking frame or wheelchair. Her mother despaired that Ksenia's resulting isolation in her apartment meant that she 'does not know what winter is since she hasn't been out in it once.' Damir faced the same problem of being unable to leave his apartment in Kazan's housing complex in the winter months: 'winter has already begun; I rarely go outside because of this. It's very slippery and I could fall. I could fall and break all my limbs, which would be terrible. I will go out more often in summer.' Although moving around in summer was far from easy for the reasons mentioned in this chapter, winter was very much a period of spatial isolation for most of the wheelchair users to whom I spoke. This reflects the fact that the environment and our moorings in it are ever-changing and in flux (Adey 2006), meaning that immobility and the exclusion are not fixed conditions, but can vary with the time of year along with changing social relations and welfare policies.

Public services in Russia do not seem to recognise that the issue of mobility for disabled people becomes sharper in winter. There is, for example, no special transport in this period or provision of wheelchairs capable of traversing snow. Although snow clearing and road gritting services are admittedly uncommon in Russian residential areas, particularly in regional cities, I heard of no efforts to ensure that disabled inhabitants could access key services like chemists, libraries or grocery stores, for example through mobile units or home delivery services. Disabled people's chances of mobility, inclusion and social activity thus become even more illusory as the weather grows harsher. By ignoring seasonal dimensions of accessibility, it would seem that policies do not respond to the everyday concerns and experiences of disabled people and do not understand that the conditions precipitating disability vary during the year.

Conclusions

This chapter has found limited policy action to reduce the physical and social barriers affecting disabled people's opportunities to take part in society and therefore enjoy an inclusive form of citizenship. Even in my small sample of research participants, three people were confined almost permanently to their flats and hence deprived of firsthand contact with the wider community. Others faced significant problems in entering buildings and moving between places, thereby impeding their use of various services and contact with other members of society. These high levels of immobility suggest that the social model of disability – according to which social and environmental conditions disable people with impairments – does not significantly influence Russian disability policy. Indeed, the lack of modifications to roads and buildings confirms the conclusion made in Chapter Four that state provision seems founded on an association of impairment and disability that orientates policy towards the 'rehabilitation' of individuals' health rather than the adaptation of the environment in which they live. With 'ability to move independently' being a criterion in *MSEK* classifications, mobility is naturalised as the inherent property of particular bodies rather than regarded as socially construction. The upshot is the (re)production of 'distinctive spatialities around the binaries of the "healthy" and "unhealthy" body' (Imrie 2001: 233). In positing that disabled people cannot move due to their bodies, welfare policies in Russia indicate how a 'nexus of mobility, rights and citizenship, while attributing various meanings to mobility, is produced through a logic of othering' (Cresswell 2006: 737-8).

Patchy state activity to facilitate mobility means that participation and interaction with other members of the community cannot be taken for granted in disabled people's everyday lives and citizenship (cf. Uteng 2009). State provision in fact tends to separate disabled people from the population and immobilise them by doing little to reduce overall inaccessibility and creating 'special' institutions for them such as housing complexes or the schools discussed in the previous chapter. Such moves reveal that 'disabled people's corporeality, in the context of their mobility needs, is an object of a punitive culture which draws attention to their impairments while reinforcing the view that they ought to be grateful for what is provided' (Imrie 2000: 1645). Indeed, the recently opened housing village in Samara aims to 'provide for' disabled people rather than help them to undertake everyday activities, although the Kazan housing complex is better in this respect.

Against this backdrop of strong immobilising pressures, it is important to recognise that many of my research participants tried hard to challenge the social isolation that arises from an official conception of people with impairments as immobile due to supposed bodily defects. They for example built ramps in their apartment buildings and drove their wheelchairs along roads meant for cars in order to avoid otherwise impassable obstacles. In so doing they articulated a vision of their mobility and citizenship that differed considerably from official conceptions in terms of who should use space (cf. Richardson and Jensen 2008). They thus tried to expand their 'potential mobility' in order to have greater access to public space and the activities taking place in society.

Yet this agency, like mobility and immobility, needs to be understood as relational. The experiences of mobility and space strengthen the conclusion made in the last chapter that citizenship is rooted in social relations and a 'subtle interplay of micro and macro relations of power' that prioritises certain forms of movement (Paterson and Hughes 1999: 606). The effect of these relations can be positive or negative depending on context. There have thus been examples of how 'unequal mobilities are, then, at least partly a consequence of unequal power relations' (Richardson and Jensen 2008: 219), for example in confrontations with nightclub bouncers. Yet, the support of friends and families indicates that social relations may play an extremely positive role in structuring disabled people’s use of space, be it climbing floors, navigating obstacles on streets, ascending steep ramps or clambering onto public transport. As a result, a lack of ties – for example in Ludmila’s case – is frequently associated with immobility and social exclusion. However, the presence of people willing to help does not guarantee mobility or accessibility, as testified by the many disabled Russians stuck in their flats during winter. Some structural obstacles to inclusion are thus too large for individuals and their social networks to overcome, meaning that the absence of concerted state activity to improve mobility has significant implications for citizens with disabilities in Russia.

Chapter Seven

Citizenship in action: promoting agency and rights

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As explained in Chapter One, studies of everyday citizenship examine how rights, entitlements and obligations are constructed in ordinary life. In the previous three chapters I considered the ways in which state policies affected my research participants' citizenship in three arenas: need interpretation and classification; livelihoods; and, mobility. I often mentioned how disabled people engage with and sometimes challenge the practices of state organisations and personnel, thereby raising the question of their agency as citizens (cf. Lister 2003: 37ff). This final empirical chapter focuses explicitly on this theme by looking at the ways in which the people I met tried to shape their welfare entitlements and social citizenship through their own actions. I am also interested in how they perceived their relationship to the state and status as citizens (cf. Henry 2009). Such discussions of agency and self-identity help to allay concerns within citizenship and disability studies that disabled people are portrayed as fundamentally passive or weak (Oliver 1996; Marks 1999).

I first discuss how my research participants engaged with the frontline bureaucracies of the welfare system, explaining that their agency is constrained by exhausting procedures, the assumed expertise of state employees and the poor provision of information. I go onto explain why the disabled people I met are not powerless in the face of state organisations, even if achieving a victory requires much energy and perseverance. My discussion of agency goes beyond individuals to also look at the roles played by civil society actors, families and close friends. Non-governmental organisations were rarely perceived as offering valuable support, but family ties proved crucial to asserting entitlements and participation in society. In light of all these experiences, I finish the chapter by discussing my research participants' subjective impressions of citizenship, suggesting that their critical comments indicate a refusal to accept the position in society allotted to them by the welfare system even if it is very difficult to overcome.

Obstacles to realising rights and entitlements

According to the accounts of my research participants, processes for claiming social provision and challenging official decisions are complicated by a lack of information and a tendency in the Russian welfare system to privilege 'professional' knowledge in ways that 'can lead to a lack of control, passivity and inefficiency' (Knijn and Kremer 1997: 355). The energy needed to endure queues and paperwork is also a very real factor that can dissuade people from interacting with state organisations. I discuss these issues in this section before looking at the ways in which my research participants tried to insist upon their rights and entitlements.

Despite the fact that disabled people comprise a significant client group for Russian social and pension services, very few attempts have been made to smooth procedures for them. For example, the Pension Fund does not accept postal applications and its staff does not make home visits or organise affairs by telephone.[49] The lack of such procedures is significant because Russian social policy works on a declarative basis

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[49] There seems to be little flexibility about the rule that applications must be made in person, which is explicitly stated on the website of the Tatarstan branch of Federal Pension Fund, http://www.pfrrt.ru/people/edv_1.php, accessed 30 June 2011

(*zayavitel'naya osnova*) where provision is only granted to those who request it and prove their eligibility. The onus is thus put on disabled people to claim their welfare entitlements, with little being done to contact people who have not applied for support.[50] Masha, the student and part-time university administrator, explained to me how this works: 'if you go to them, then they will do something, but if you don't go, then they don't have to do anything at all.' Frequent visits to the relevant authorities are necessary since many social benefits in Russia must be renewed on an annual basis, in particular housing subsidies and the 'social package' of medicines, free local transport and sanatoria stays. Meeting deadlines is crucial since otherwise benefits may be delayed or, in the worst cases, unavailable until the following year.

Drawn-out procedures and long waiting times make visits to departments of social services quite vexing, especially when application deadlines loom, for example for housing subsidies or the social package. On my visit to the social protection office in the *Novo-Savinovskii* district of Kazan, I found a large group of people waiting in the corridor by a closed office. Despite fixed office hours and an earlier conversation with the social worker about when I should come, none of the three staff supposedly on duty were present and there was no information about their whereabouts or possible return. They eventually arrived after what for me was a forty-five minute wait. Coupled with confusion about the appropriate office to visit for various services, the empty and locked room naturally caused some consternation by arousing feelings of not having control, including over time, which is highlighted in the mobilities literature as an important dimension of freedom (Urry 2007: 29). Venera, a disabled pensioner who

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[50] I heard one interesting exception to this rule from the mother of a friend in Kazan whose job at the Pension Fund in the 1990s entailed visiting care homes for disabled adults to check that residents were receiving their pensions, which was frequently not the case.

was very frustrated with social services, told me in an interview that ‘You must stand in line for a very long time to get the free transport ticket. You have to wait without any facilities and stand in the corridor.’ A lack of chairs or public toilets in the buildings I visited may certainly cause high levels of discomfort. Particular difficulties may arise for disabled people if sent to departments or offices on floors above street level due to the lack of lifts. Such queues and uncomfortable conditions do not create a welcoming atmosphere and fail to encourage interaction with social services or an impression of client orientation.[51]

Another constraint on the agency of disabled people is the reverence accorded to ‘professional’ knowledge in the procedures of state welfare organisations. Such esteem places disabled people in unequal relationships to medical staff and social workers, who are the supposed ‘experts’ in welfare matters (Thomas 2007: 60-62). The medical-social commissions (*MSEK*) discussed in Chapter Four are a strong example of this since representatives of disabled people’s organisations are not included on these boards and there is no element of self-assessment, with unfamiliar doctors controlling the collection of information and its subsequent assessment. Such arrangements suggest that the experiences and knowledge of disabled people are not highly valued within the welfare system and that there may be disdain for care receivers (Tronto 1993: 120). This may account for the haughty stance *MSEK* personnel are perceived to take vis-à-vis disabled people. When unhappy with the Group Two disability classification given to Anton, his mother was told by a *MSEK* doctor ‘to be content that he is not terminally

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[51] This is not to criticise individual social workers, who face extreme caseloads, poor working conditions and very low salaries (Iarskaia-Smirnova and Romanov 2002). Rather, it suggests that social services and administration, especially in relation to disabled people, have not become a sufficient policy priority to warrant the resources and organisational changes that would facilitate higher standards of care.

ill, that he isn't an idiot or tuberculosis victim.' Such hostile attitudes make it understandable that I did not come across a single expression of praise for the *MSEK* commissions among the letters of gratitude to particular medical and social staff regularly published by *Gazeta Vybor*.

The lack of client orientation and use of professional status to establish inequality between state officials (both medical and administrative) and disabled people can be seen in the complicated legalese often used in communication from social protection organisations. The question and answer pages of *Gazeta Vybor* in which representatives of various state organisations respond to questions are especially revealing of this phenomenon, as the following example shows (13.06.2007, p.4):

> Q) I am a veteran of the Second World War with a Group Two disability classification and III-degree inability to work. I received a medal as a defender of the heroic city of Leningrad. I have been on the waiting list to receive a car since 2004. Can I receive this car and how long will this take?
>
> A) You have been on the waiting list to receive a free car that will be driven by a third person since 27.09.2004. As of 03.05.2007, your place in the republican register of citizens waiting for the provision of special transport in line with Federal Law "On Veterans" is 434 based on the date of your addition to the list.
>
> The Ministry of Labour, Employment and Social Protection of the Republic of Tatarstan has sent the list of disabled people in the republic eligible to receive special transport to the Federal Agency for Healthcare and Social Development, which currently controls the list of citizens registered as eligible for special transport in the social protection departments of regions of the Russian Federation.
>
> The provision of automobiles to disabled people who had a place on the waiting list in social protection departments before 1 January 2005 will continue in line with the delivery of cars from the Federal Agency of Healthcare and Social Development.
>
> Nataliya Butaeva, Deputy Minister of Labour, Employment and Social Protection

On the one hand, the style of the letter reflects the Russian administrative tradition of citing laws and decrees in official correspondence. Nonetheless, the bureaucratic response fails to specifically address the question of when the car will be delivered. While other responses from state employees are sometimes better in these respects, their language is nonetheless not necessarily accessible to ordinary readers due to their frequent citing of laws and administrative procedures. The use of highly technical language and lack of tailored responses suggests a lack of will to empower clients by providing clear information. It means that the interpretation of rules and control over entitlements lies with state employees rather than their disabled clients (cf. Yaroshenko 2001; Haney 2002), who receive little support in understanding and navigating the procedures underpinning the welfare system. Indeed, one of the main goals of *Gazeta Vybor* is to explain legislative points in simple terms to its readers.

In addition to deference to professionals and the practical difficulties of interacting with the authorities, a lack of useful information represents a third obstacle to the realisation of social rights and entitlements. Although the importance of information is noted in a report from Tatarstan’s Ministry of Social Protection on disability provision in Tatarstan (MTZSZ 2008: 16-18), I came across few efforts within state organisations to circulate helpful details about services and welfare provision. Indeed, the report mentions just two sources: the ministry’s website and a free weekly newspaper, *Moya Gazeta* (‘My Newspaper’). Other possible forms of information provision, for example a telephone hotline or boards and leaflets at rehabilitation centres and polyclinics, were not in evidence during my visits and never mentioned by research participants.

Until 2007 the website[52] of Tatarstan's Ministry of Social Protection was both informative and reasonably easy to navigate, especially in comparison with the confusing portal of the equivalent federal ministry.[53] However, it was then replaced by a far inferior site following a merger with the region's Ministry of Employment[54] onto which little of the information from the former website was transferred, thereby ending access to analytical reports, news and a special portal for disabled people. This deterioration in provision may not have been a serious blow given that governmental portals did not seem to be a major source of information for my research participants who regularly use the Internet. Indeed, not a single person I met told me that they had found information on an official website or that it was even a place they would think about looking. The disbelief I encountered that a government website could be helpful underlines the extent of my research participants' scepticism about state provision and their dislike of the approaches taken by state welfare actors. One disabled resident of Kazan has enterprisingly created a website about disability issues,[55] but its hit count reveals few visitors to this example of online action to disseminate information about social services. Such low use of web resources raises the question of whether information on welfare provision is available in more traditional formats.

Moya Gazeta ('My Newspaper') is the official publication of Tatarstan's Ministry of Social Protection and is available for free at social services and branches of *VOI* (Association of Disabled People) in Kazan. The paper claims to be an 'informational

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[52] The website previously maintained by the Ministry of Social Protection of Tatarstan, www.msrt.ru, has not functioned since late 2009.

[53] Website of the Ministry of Health and Social Development of the Russian Federation, available at www.minzdravsoc.ru, accessed 30 June 3011

[54] Website of the Ministry of Labour, Employment and Social Protection of Tatarstan, available at mtsz.tatar.ru, accessed 30 June 2011

[55] Website of Airat, available at http://aupam.narod.ru/index.html, accessed 30 June 2011

bulletin,' although it has a strong tendency to report on special events and human interest stories rather than offer detailed guidance on social provision. Indeed, none of my research participants read it on a regular basis and one local activist dismissed it as 'useless rubbish from the ministry' during a conversation with me. This official mouthpiece of the regional government is complemented by occasional publications produced at a more local level. For example, the social protection department of the *Privolzhsk* local district in Kazan produced an informative guide to accessible buildings, roads and shops (*Gazeta Vybor*, 16.04.2004, p.4). An audio cassette to help visually impaired people move around the district was also produced with the support of the local branch of Russia's Organisation of the Blind (*VOS*). Unfortunately, neither guide has been updated to reflect the city's quickly changing landscape or extended to the rest of Kazan, meaning that they only benefited a small number of people in the city for a few years.

The lack of measures to explain policies and procedures can have severe implications for disabled people. Letters to *Gazeta Vybor* suggest that many people find it difficult to understand the ramifications of choosing between cash payments and the 'social package' of free healthcare and transport when the monetisation reforms were introduced in 2005. This decision is important because it cannot be reversed until the following year regardless of shifting need and circumstances, for example a change in health. Anton, a disabled law graduate, provided another example of poor information having unhelpful consequences: until his mid-20s, he was unaware that *MSEK* could assign permanent disability status and thus tolerated the re-examination process every year until told by friends to insist on a long-term diagnosis.

I asked a *MSEK* director who agreed to discuss her work with me whether her organisation provided information about the classification procedure or which social services to visit in order to organise pensions, benefits and prosthetics. There were no leaflets to take away or details of how to contact local disability organisations and support groups, but she did refer me to long printouts of the laws and decrees regulating the work of her organisation posted on the walls of the commission's waiting room. However, the tiny font size and reams of dry legal text would hardly be legible to people sitting or, as is often the case, standing in the waiting room. Furthermore, *MSEK* commissions do not alert other government offices about people newly classified as disabled, which could smooth processes of registering for social benefits and services. Such a failure to connect various state organisations working with disabled people reflects the very disjointed nature of the state and clearly has implications for the available welfare provision. Thus it would seem that poor information is an issue from the very first stages of engaging with the disability system, with little effort by state organisations to explain available provision and coordinate procedures for obtaining it. While this affects the potential for disabled people to determine how their rights are instantiated, it would be wrong to see them as powerless vis-à-vis state organisations, as explained in the following sections on different forms of agency.

Challenging the actions and decisions of state institutions

Although disabled people in Russia are clearly not in a strong position to assert their rights and shape their citizenship in line with their own ideas, this does not mean that they accept the status quo. During my fieldwork, I frequently heard of research participants trying to instantiate their entitlements and rights through letters, phone calls and meetings about individual complaints (cf. Turbine 2007). Such actions can be seen as part of a broader Soviet and post-Soviet traditions of complaints and letter-writing (Fitzpatrick 1996; Henry 2009: 59). While only a few research participants took part in organisations that offer mutual support or attempt to change policy and social attitudes to disabled people, many received crucial support from their friends and families.

Venera, a disabled pensioner who uses a wheelchair, energetically complained and intervened on behalf of other disabled pensioners through letters and phone calls, these being ways she could feel active and productive while trapped in her flat. Indeed, the progressive deterioration of her muscular strength meant that she was increasingly immobilised in her second-floor flat and therefore needed an activity to feel useful and maintain her self-identity as a proactive person (cf. Lister 2003 on the subjective feelings of agency). On the day we met, she had just finished writing a letter to help break the vicious circle that prevented her from receiving prescription medicines: her doctor would not issue a prescription for the hormonal drugs she took since they were not available in the local chemist, while the chemist would not stock them until her polyclinic had ordered them. ‘They told me to write straight to the top, but I’m not sure whether they’ll answer. Complaints are usually passed up the system, but it’s exceedingly difficult to track their progress.’ So whilst Venera was aware that she should receive a reply from the responsible government department within a month, she knew from experience that state organisations do not always respond to citizens (cf. Henry 2009: 59). She had a strong sense that entitlements should be met and that it was legitimate and necessary to complain about infractions, for example that she and her neighbours paid for the maintenance of the public areas of their apartment building even though it lacked a front door. She lamented that most people were unwilling to challenge the authorities: 'there's no action, just apathy.' Rather than arising from indifference, reluctance to hold authorities to account may reflect resignation that such moves will be unsuccessful. Indeed, Venera's challenges were only occasionally successful, though the actual process of trying to claim rights was symbolically important to her. Her complaints thus represented 'a choice to engage with the government rather than avoid the public sphere' that had continuity with earlier practices in the Soviet Union and (Henry 2009: 63).

When she had problems receiving a small car (before the abolition of this benefit in 2005), Venera wrote 'to Moscow and received an answer, although it came so slowly that they could have replied to me a hundred times. They sent a standard response that I had not completed the application properly. At the end of the letter, they wrote that in any case I had to appeal through the courts.' Although *Gazeta Vybor* occasionally reports on judicial decisions in which disabled people win particular points or cases (most usually in regions other than Tatarstan), none of my research participants had used the legal system to insist on their rights or seek redress for discrimination. Venera told me that she occasionally consults a lawyer working for the local social protection department.[56] She praised this support, but was one of the few people I met who had sought legal advice. Although she had never gone to court, the frequency with which she mentioned possible cases suggested that she did not exclude this possibility.

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[56] Two disability organisations in Kazan also have lawyers on their staff, pointing to the importance of legal advisors to both help members and resolve issues for the organisation.

Russia’s civil law system would however mean that a victory would only help a single person rather than benefit other people in the same situation by creating a precedent. Ultimately, then, court intervention did not seem a realistic option for affirming formal rights and entitlements, a finding that chimes with other sociological studies of everyday rights in Russia (Turbine 2007; Henry 2009).

The wide range of state welfare organisations interacting with disabled people meant that the chain of responsibility for a particular policy matter was not always clear to my research participants. They therefore turned to many branches of the state apparatus in the hope of obtaining assistance from at least one. Masha, the student and university administrator, noted at least three possible sources of support beyond the local social protection department: ‘We appeal to the mayor and to Shaimiev [President of Tatarstan] and to the Ministry, but it’s rare for them to listen or do anything.’ Indeed, the existence of multiple organisations to which claims can be directed mean that requests may be shunted between state agencies. Raising three disabled children in a dilapidated house without running water or a telephone, Olga’s parents wrote to a number of state organisations hoping that one would provide them with alternative accommodation. Their frequent letters to various authorities were answered with referrals to other departments: ‘We wrote letters for so many years and of course answers arrived: turn to another organisation, we do not deal with these questions … Overall they didn’t give us anything, just pieces of paper.’ Responsibility was fragmented and the family was unable to identify and have a direct dialogue with the state organisation, let alone concrete employee, in charge.

Another factor impeding the instantiation of welfare entitlements and responsiveness of state services to disabled people's concerns is the considerable distance between citizens and certain state organisations. The social reforms in 2005 made many areas of disability provision the responsibility of the federal government, meaning that queries often cannot be solved a local level. When trying to arrange compensation for the car she never received, Venera told me 'I didn't actually need the car, but it became about the principle. It turned out that our Tatarstan lot washed their hands of the matter because Moscow started to deal with such affairs. I wrote to the local authorities, but they said it wasn't their jurisdiction, then I wrote to Moscow who said that I wasn't eligible.' Venera did manage to achieve her modest goal of being reinstated on the waiting list for free cars and despite languishing at the bottom 'felt that I was in first place' That she persevered with a long, slow correspondence makes her achievements an interesting example of agency.

Yet, the multi-level nature of the Russian welfare state was at times useful in helping to realise entitlements and rights. Venera recalled how she wrote to an office of the central government to complain about local developments in Tatarstan: 'we have a representative of the federal government and I wrote to them "please explain why your laws do not work in the Republic of Tatarstan." After this letter everything was solved immediately and they compensated me.' The survival of the independent newspaper *Gazeta Vybor* is similarly predicated on a policy clash between different levels of government: after Tatarstan's Ministry of Social Protection withdrew its funding and tried to force the publication's closure in the late 1990s, the editors successfully applied for a federal grant for non-profit media that saved it from bankruptcy. Such cases suggest that the welfare state's multi-level nature is not always negative since one tier may regulate another or provide another source of resources.

The cases discussed in this section suggest that some people do try to challenge policy decisions, although the chances of overturning them are limited. Indeed, state organisations tend to regard disabled people as passive citizens and discourage them from expressing personal agency through a singular lack of mechanisms, information and clear procedures to promote an interactive two-way relationship. The resulting disempowerment raises the question of whether third sector organisations help to overcome the absence of official support to disabled citizens, which I discuss in the next section.

Forms of organised agency

Although a number of officially registered disability organisations as well as looser self-help groups exist in Kazan, it was striking that very few of my research participants were active members. This was not necessarily related to a lack of information about organisations – which Hemment (2007: 5) suggests was an issue for Russian women's groups – since people were broadly aware that the national disability association *VOI* had offices in Kazan, even if they were less informed about smaller local groups. Rather, there was a general feeling that joining disability organisations was not personally useful, which chimes with other research suggesting that many Russians feel grievances at an individual rather than group level (Henry 2009: 63). Without a feeling of strength in numbers (Kay 2000: 122-3), the motivation for group agency is likely to be weak, especially if there is ambivalence over strongly self-identifying as disabled in a culture that discriminates against people with impairments (Thomas 2007: 77).

I certainly heard very little positive about the *VOI* Association of Disabled People (*Vserossiskoe obshchestvo invalidov*), a national organisation that claims to be the official mouthpiece of disabled people in Russia and represents them in federal and regional government affairs. Irina, an experienced disability activist in Kazan told me somewhat disparagingly that ‘oh yes, *VOI* offers office hours (*priemnye chasy*), but they provide little else,’ hinting at its highly bureaucratic nature. She expressed regret that the organisation had ‘no fresh ideas’ given that it could potentially achieve much given its relatively high level of resources, including local offices in each of Kazan’s seven districts. Indeed, *VOI* chimes well with the characterisation of ‘clientelistic’ NGOs as ‘providing real resources and services to their members but without potential for genuine social initiative or interest articulation’ (Cook and Vinogradova 2006: 38). This perceived lack of dynamism may stem from the fact that the *VOI* leadership, particularly in Tatarstan, is strongly enmeshed in local politics and state administration and therefore takes quite a bureaucratic and unchallenging approach to disability provision. Its chairman of fourteen years sits in the city council as a representative of Vladimir Putin’s ruling party, pointing to the elite reproduction and muted activism related to it that other scholars have identified (Hemment 2007: 141; Henry 2006). Such politicisation and co-option of the regional disability movement by the state apparatus was also visible in the Kazan-based disability organisation *Vera* (‘Faith’), which is in fact a branch of the *United Russia* party, complete with flags, posters and speeches from leading politicians on the walls of its state-funded offices. Although its chairman played his organisation’s political association down as ‘simply political show,’ it had received a reasonable city centre office opposite United Russia’s main premises, attesting to the benefits of being politically on-side. Such dynamics in Tatarstan’s disability movement make it understandable that many of my research participants could not relate to these organisations or find value in their activities. It also explains why the two largest disabled people’s organisations in Russia – both affiliated to the political elite in Tatarstan – were neither particularly active in challenging discrimination nor very open to foreign discourses and models around disability (cf. Cook and Vinogradova 2006).

Indeed, the official *VOI* organisation was relatively marginal for my research participants, none of whom were members, either notionally or actively. Ksenia’s mother had been a member for twelve years, but grew frustrated at their lack of support. She could not perceive any advantage or change for her daughter or other disabled people. She felt that membership of a disability organisation should bring some benefits, not necessarily in material terms, but also in the sense of taking action to achieve improvements. Yet, Ksenia grew up and remains isolated in their fifth-floor flat and the family did not receive any advice from the organisation on resolving this or improving her quality of life. They therefore felt that *VOI* was redundant. Anton, the qualified lawyer, had volunteered as a legal consultant at *VOI* in the hope that it would help him gain experience and find work. However he was disappointed that the organisation did very little to help people find employment and left it after a few months. There was thus no sense of mutual support to solve practical problems, which is a factor that drives many people to join organisations (cf. Kay 2000).

One area in which *VOI* in Tatarstan seemed particularly inactive was filling the informational gap surrounding social provision, which I highlighted above as a key obstacle to disabled people asserting agency during their interactions with state organisations. For a long time, the organisation's website[57] was outdated and now it no longer functions. It produces few pamphlets and publications to offer its members or the general public. Such a situation contrasts with the activities of certain disability organisations in other cities I visited, including the *VOI* branch in the city of Perm which is well-known for its impressive publishing house.[58] The *Desnitsa* organisation in Samara used a grant from the American government agency USAID to tackle the information vacuum in which many of its disabled members find themselves by producing a comprehensive directory about disability, the disability movement and social services in 2007 that is available in book form and on their website[59] (Desnitsa 2007). It also maintains an active network of volunteers responsible for channelling information between the organisation and disabled people living in their neighbourhood.

I did not hear of *VOI* staff in Kazan facilitating such structured lines of communication and information. Instead, the organisation tends to focus on arranging cultural activities and some material support for members. The nature of its events often did not appeal to my research participants. Maksim expressed strong frustration with the lack of programmes for young adults with disabilities, noting that 'in theory we do have

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[57] Website of the Tatarstan Republic Organisation of the All-Russian Association of Disabled People, www.trovoi.kazan.ru [already not functioning on 30 March 2010]

[58] Website of the newspaper and publishing company *Zdravstvui* (Hello), available at http://hello-perm.ru/, accessed on 30 June 2011

[59] Spravochnik 'Udochka dlya …', available on the website of the Desnitsa disability organisation, http://samara-desnica.narod.ru/index.htm, accessed 30 June 2011

disability organisations, but it is a miserable state of affairs ... until I was 18, there were many events organised by organisations, but that was when I was considered a child. When I became an adult, that was it.' He felt bored and out of place at *VOI* events that were generally targeted at and attended by middle-aged and older people with disabilities.

Nataliya, a 35 year old activist in the Samara disability organisation *Desnitsa*, echoed Maksim's sentiments and was critical of what she felt was a preoccupation within *VOI* with parties and cultural events:

> 'I didn't like what *VOI* had to offer… to go there and sit at a table on the International Day of Disabled People or 8th March [International Women's Day] so that people could sing and dance for us. They would give us lunch. I'm now an adult and that sort of thing is boring. I have already grown out of nappies and pinafores ... it's possible to do more than just entertain and feed disabled people once a year, you can change something in their environment.'

Nataliya believed that one-off events put disabled people in a passive position, treating them as recipients rather than agents and citizens. She felt that the activities of disability organisations should focus on social determinants of disability, for example attitudes and accessibility.[60] She also objected to the closed nature of *VOI* events, holding that the tendency to invite only disabled people perpetuated their lack of place and voice in society. After spending quite a few years isolated at home, Nataliya became an activist with the disability organisation *Desnitsa* in the city of Samara, which explicitly bases itself on international models of 'independent living' and a human-

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[60] Nataliya's critique perhaps underrates the positive of such activities in raising the psychological well-being of attendees, many of whom may be confined to their flats in winter. Indeed, some letters from older readers to Gazeta Vybor express thanks for beautiful parties held at social assistance centres. However, the emotional and symbolic value of such events certainly does not overcome problems with accessing public and social arenas, participating in society and having equal opportunities.

rights approach to disability. Her move from sceptical curiosity to a strong passion for the organisation represented one of the few tales I heard of a Russian disability organisation offering personal and social transformation to its members:

> ‘A friend told me about *Desnitsa*, that it had lots of interesting people with whom I could chat. She told me about it and I thought there wouldn’t be anything interesting there for me, just barbeques, perhaps some sporting events, that’s all. I wondered why I needed any of that. But then I started to hear other things about the organisation.’

Nataliya was initially invited to the organisation to look around and went onto become an unpaid volunteer and then a salaried staff member organising public awareness events: ‘I’m grateful to *Desnitsa* that it helped me to find something new inside me … earlier running a workshop would have seemed impossible to me, but now I understand that it’s what I like and need.’ Other employees also told me that their work in the organisation helped them to develop as individuals while promoting the rights of disabled people as a group, thus expressing a strong narrative of self-transformation (Phillips 2008; Zigon 2011). However, *Desnitsa* was the only organisation of its kind I met in the five regional cities I visited.[61] Certainly in Kazan, most of my research participants were disenchanted with their regional and local *VOI* branches and had little faith in organised forms of agency. Indeed, whilst many Russian NGOs are conceptualised as facing a dilemma between simply offering services or acting as advocates of change and reform (Kulmala 2009), neither type of organisation seems to operate for disabled people in Kazan.

Venera, the very active disabled pensioner who enjoyed pressing the authorities to provide the welfare entitlements of her acquaintances, was also saddened by a lack of

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[61] *Desnitsa* does however have partner organisations in several other Russian cities, for example *Perspektiva* in Moscow and *Invatur* in Nizhnii Novgorod.

direct action by disabled people and organisations representing them. She told me that 'we are indignant about social provision, but we are not active and no one notices or listens to us.' She continued that:

> 'I see on the news how trade unions abroad protest and receive support, but we don't even have a trade union! Our comrades (*tovarishchi*) are completely inactive. There were pro-independence rallies in the nineties here in Tatarstan ... of course the press became a little freer, a place where you could write about your grievances. But that was all, sadly there isn't any action. People might be annoyed, but there's no-one to support them, no leader or organisation. Sometimes there are invitations to protests, but even then no-one goes.'

Venera alludes here to what she saw a weak disability movement and a lack of determination at a group level to challenge perceived injustices. Interestingly, my archival research revealed that *VOI* did engage in protest campaigns during the 1990s. For example, it organised a demonstration of disabled people in a central Kazan park in May 1994 to support equal rights and campaign for greater state support (*Gazeta Vybor*, No. 21, May 1994). This fits with other interpretations of the bottom-up energy and dynamism of many organisations in the mid-1990s (Kay 2000; Hemment 2007). However, such profile-raising tactics have long been abandoned, in part due to a clampdown on public action by various levels of government in Russia and a strategy of 'selective corporatism' that brings NGOs into the state arena (Salmenniemi 2010). Disability organisations in Kazan did not take part in the spontaneous nationwide protests that erupted across Russia in January 2005 over social benefit reforms. Indeed, one of the more energetic *VOI* activists in Kazan has publicly expressed regrets that the organisation's national council (led by a pro-government politician) preferred consultation instead of firm opposition to these social reforms, a feeling echoed in focus groups conducted by Laura Henry (Henry 2009: 59). In his words, 'how can we negotiate when the authorities don't listen to us and don't want to listen?' (*Gazeta*

Vybor, 21.09.2007, p.3). Such sentiments suggest there is some desire for more active forms of engagement with the authorities, albeit muted by resignation that such forms of agency are missing and perhaps not possible.

Beyond *VOI*, several small non-state associations in Kazan work with physically disabled people. Some are not strictly bottom-up, including the organisation *Vera* that doubles as a local branch of Vladimir Putin's United Russia party. Organisations overwhelmingly tend to focus on a single type of impairment or disability with the result that there are many small clubs and groups with little overall coordination or cooperation.[62] Given that most of these groups are not institutionalised, they are not affected by struggles for resources that have divided other movements (cf. Kay 2000), but partnership is nonetheless absent as members try to support each other internally rather than promoting a supposedly 'shared' cause. Irina is a disabled person (although not a wheelchair user) and one of the leading activists in the city, running the small independent organisation *Nika* for physically disabled young adults almost singlehandedly out of her own home.[63] Her main activities in this role are organising events, particularly for young adults, and taking up the complaints of disabled people in relation to state provision. She worked at *Gazeta Vybor* for several years during the 1990s and has a legal background that equips her to challenge decisions on behalf of other disabled people. For example, she intervened with the city authorities to ensure

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[62] Gazeta Vybor's annual directory of non-state organisations working with disabled people lists separate associations for diabetics, cancer patients, blind people, deaf people, physically disabled people, Chernobyl victims, people living with multiple sclerosis, haemophiliacs and various groups of military veterans (12 January 2007, pp.2-3). Interestingly, there seems to be no organisation for people with intellectual disabilities or mental health concerns.

[63] This seems to be a relatively common situation since two activists who work on their own in the city of Ekaterinburg have in fact formally registered their activities as an organisation in order to increase their potential clout and recognition when dealing with officialdom. Julie Hemment also mentions the use of domestic settings – and indeed family support – in maintaining women's organisations (Hemment 2007: 144).

that Masha's bus route to work was not cancelled during the comprehensive redesign of Kazan's public transport network in 2007. As Masha told me:

> 'When they changed the route of the bus that goes to TISBI, she and my dad went to the transport authorities. She's a very good lawyer with a fighting spirit. She defended my rights so that they reinstated the old route and made the buses drive right up to the pavement so it's easier for me to get on. We succeeded in doing this.'

Irina believes that a dialogue with authorities is important to achieve change or at least record complaints. This approach makes her stand out from 'Western' models of civil society that start from a standpoint of opposition to the state (cf. Holland 2008). She thus made sure that a round table she organised for young people with disabilities finished with the formulation of a letter of concerns and requests that she then sent to the president of Tatarstan. Her organisation nonetheless receives scant attention and support from the authorities, as demonstrated by the huge efforts it took for her to organise this meeting of young disabled people. The event was repeatedly postponed because of the uncertain commitment of municipal premises and a ministerial minibus. It eventually took place in a local children's library that turned out to be unsuitable for wheelchair users due to its narrow doorways and lack of step-free access. Such problems also plagued her attempts to arrange a confidence-building workshop for young disabled people led by a psychologist from TISBI, meaning that very few could attend such an innovative event.

Although it is not a disability organisation, the regional newspaper *Gazeta Vybor*[64] ('Choice'), where I conducted my archival work, can be seen as an important non-governmental vehicle supporting disabled people's social rights. It is a small and

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[64] Much to my pleasant surprise, *Gazeta Vybor* has recently launched a well-designed website, http://vibor-kazan.ru/ [accessed 30 June 2011]

editorially independent publication based in Kazan that provides information on new legislation and policies along with a mixture of letters, horoscopes, television programmes and health tips. As mentioned in Chapter Two, this weekly paper has a protracted relationship with the regional authorities for its critical stance, having initially started as a ministerial publication before having its local funding cancelled in the late 1990s due to what was perceived as criticism of the government. Quite a few of my research participants were familiar with *Vybor* and some were regular readers, finding it useful in understanding welfare bureaucracy and feeling that they were not alone with their problems. Particularly in light of poor informational provision by state organisations, the paper can be a very important source of advice, especially on new laws and other legal matters. This in part explains why Venera and several other research participants were strong fans and sometimes refer to the paper's articles when interacting with state organisations, as indeed the journalists recommend.

While disability organisations seemed rather weak in the lives of my disabled research participants, I did hear of more informal forms of group agency that occasionally achieved important changes. For example, the residents of Kazan's housing complex for disabled people were able to persuade the owner of a nearby corner shop to build a gentle ramp up to its entrance. Their success in making this facility accessible was important given the lack of grocery shops in the vicinity. In another example of group pressure, the staff of *Desnitsa* studying for a university degree were able to persuade the lecturers to hold lessons in the organisation's office, which was accessible and easy to reach using the organisation's minibus.

With the exception of the *Desnitsa* staff in Samara and perhaps Irina in Kazan, most of the people to whom I spoke did not feel that disability organisations could strengthen their social rights and entitlements to welfare provision. Even Masha, the bold university coordinator who was one of the few people to have an office job, only had a loose affiliation to Irina's organisation, occasionally taking part in their summer excursions to the countryside. I can only speculate about whether Masha or Maksim would have been activists were an organisation like *Desnitsa* to exist in Kazan. Although associations do exist in the city that fulfil the formal definition of disabled people's organisations (run by and for disabled people), they were perceived as inert and ineffective in the face of policy and structural barriers affecting disabled people's citizenship. The resulting lack of engagement with third sector associations is one of the reasons why family and friends are key bulwarks of support for my research participants, as discussed in the next section.

Family and friends

As explained in Chapter Three, living in family and community settings is a relatively new form of citizenship for disabled people in Russia given policies of institutionalisation during the Soviet period. As this section explains, friends and relatives often provide the most important support to disabled people given the perceived weaknesses of disability organisations and failings of state care. They are both conduits for wider social contact and can also assist with daily tasks, highlighting how citizenship is strongly underpinned by social relations and mutual interdependence, as highlighted in theories of care (Tronto 1993; Kittay 1999; Watson et al 2004)

Many of my research participants with a disability since childhood felt that their parents’ actions were crucial in shaping their experiences of disability. Both Masha and Maksim were encouraged to play with other local children when little, giving them broader circles of friends and contacts than research participants who spent most of their time at home. Maksim explained that ‘after I was born, my mum made large efforts … she was not embarrassed that she had a disabled child and constantly took me to the places where kids played so that I had friends from early childhood.’ Masha similarly had a wide range of friends ‘from school, our courtyard, neighbours, my grandparents’ village’ since her parents ensured she mixed with everyone around. Such social ties meant that, when older, the two students had networks of friends who offered regular social contact and could help to facilitate their involvement in society, for example going to cafes or attending events. These links greatly shaped their lifestyle and allowed them to feel that they had choice and independence in their lives even though they both were home-schooled.

One of the key reasons that Masha and Maksim had been able to build strong social networks was that they lived in housing blocks that were largely accessible by local standards.[65] The relatively few obstacles to their mobility meant that their parents could arrange play with other local children. Indeed, parental efforts may sometimes be confounded by the nature of the built environment, as explored in the previous chapter. Ksenia’s parents were unable to prevent her from being socially isolated as a result of living in a fifth-floor flat in a building without a lift. As discussed in Chapter Six, they

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[65] As explained in the last chapter, Masha’s dad did however have to build ramps for her wheelchair in the staircase of their apartment block since the local authorities refused to make these adjustments.

tried for many years to obtain an apartment in a more accessible building, but only received offers of unsuitable housing. This placed her parents in the difficult position of deciding to stay in their own flat even though it meant social isolation for Ksenia. Although her mum tried to support her attendance at their local primary school, this became unfeasible as she grew older and Ksenia was therefore transferred to home education. Living in a highly inaccessible flat gave her very few opportunities to make friends and interact with neighbours as she grew up. I met her when she was in her early twenties and thinking about dating. However, the inaccessible environment in which she lives makes such an activity very difficult for her – despite her mother's encouragement – and dents her hopes of eventually raising a family. While Ksenia was an active user of social networking websites, she was prevented from face-to-face contact due to the social conditions that undermined her potential and actual mobility.

As well as being crucial, albeit not always sufficient, for social contact and inclusion in the wider community, the support of relatives and friends is also important in realising entitlements to welfare provision. For example, after receiving a shipment of electric wheelchairs, the Social Insurance Fund told Maksim and Ksenia to claim them within two days otherwise they would be allocated to other people. With his wide range of contacts, Maksim was easily able to ask a friend with a goods van to deliver the new equipment. However, Ksenia's family found it more problematic to arrange the paperwork and collection of a bulky and heavy wheelchair. They also succeeded, but not without considerable stress and some panic. On a smaller scale, it often falls to relatives or friends to collect medicines, buy groceries and perform many other tasks that physically disabled people may be prevented from doing by inaccessible and uncomfortable settings. Indeed, few of my research participants reported buying their own food, particularly in winter, when it is difficult for wheelchair users to navigate icy and snow-covered paths.

Friends and other disabled people were often the most useful source of advice for the disabled people I met and thus helped to overcome the power imbalance caused by the poor provision of information by state organisations discussed in the previous section. Masha told me that ‘it doesn’t happen that you hear about something from the social protection department or on television. Sometimes when you find out about something important, you wonder why they didn’t tell you.’[66] The informal exchange of information was particularly strong in the housing complexes built for wheelchair users in Kazan and Samara due to the concentration of disabled people, especially those active in legal, social and non-governmental spheres. Otherwise, telephone calls and online chat facilitated communication between disabled people who knew each other from school or rehabilitation centres, but found it difficult to meet due to inaccessible environments and transport. The co-ordinators of university courses for disabled people at TISBI, where Masha worked, were also an important channel of news and information, relaying information between students who were otherwise quite isolated and rarely knew each other personally.

The upshot of the socially embedded nature of citizenship is that disabled research participants without strong social ties were often isolated and found it difficult to use services. Ludmila’s case is a strong example, for she lived on her own with no relatives

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[66] Certainly, state informational campaigns concerning the social reforms in 2005 gave very little detail or explanation, simply asserting that monetisation would improve living standards and social provision. The cancellation and restructuring of major entitlements thus came as a shock to the population.

and very few acquaintances to provide emotional support, social interaction or assistance with practical tasks. She had a very small amount of contact with her neighbours, one of whom provided her with the weekly television programme from *Gazeta Vybor*. However, she lacked someone to help her leave the inaccessible flat in which she lived and consequently had not been outside in eight years. Her main source of social contact was a care worker who visited twice a week to perform basic household chores rather than offer social interaction, which is not a 'need' as defined in the regulations governing homecare provided by Kazan's local government. Yet, Ludmila had no-one to accompany her to a sanatorium, meaning that she could not take advantage of its combination of social interaction, medical treatments and change of scene. The resulting isolation that can result from the absence of close social ties explains the worry that several parents expressed to me over care arrangements for their disabled children after their death or if they became disabled themselves. Ksenia's mother, for example, explicitly mentioned that 'We aren't immortal and will leave her at some point.' She desperately wanted Ksenia to finish her law degree and find work (in spite of being classified as 'unable to work') so that she had the best possible opportunities to be independent. This would avoid the isolation and immobility that often affect disabled people and also prevent the worst-case scenario of being transferred to a residential home.

The importance of family support to disabled people's well-being and experiences of citizenship is very poorly recognised in welfare policies, which consequently provide very little assistance to families with a disabled member or indeed disabled people who are themselves carers. In an eerie echo of feminist concerns in Western contexts

(Tronto 1993; Kittay 1999), it seems to be taken for granted that families (generally women given gendered assumptions about care) are responsible for looking after and supporting their disabled relatives. This 'privatisation' of care is suggested by the miserly 1,500 ruble benefit (approximately £30) paid to full-time carers each month, which does almost nothing to replace even low wage or part-time income.[67] Furthermore, there is no system of respite care or day support: care assistants from local social services only visit people deemed to have no possible family support, ignoring the fact that parents often make great sacrifices for their disabled children.[68] The absence of assistance for carers exacerbated feelings among my disabled research participants that they could be a burden to their parents. Nataliya was explicit that 'there definitely aren't enough helpers and assistants. I understand that it's not good to constantly rely on my parents, but I can't perform some daily activities myself.' Olga had similar sentiments, feeling uncomfortable about frequently asking her parents to drive her around Samara or do other tasks for her. One of the key reasons for Masha resigning from her job was that her mother was exhausted from all the travelling it entailed, as discussed in the previous chapter. In all cases, the problems of state provision affected not just disabled individuals, but also the employment, time, income and energy of their family members. Whilst this interdependence was certainly not begrudged by the relatives I met and associated largely with positive feelings, the time and resources they devoted to providing support goes unrecognised in welfare policy with the result that 'both carers and disabled people have had their lives colonised by naturalistic assumptions' (Watson et al 2004: 338).

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[67] The carers' benefit was only increased to 1,500 rubles during my fieldwork; Masha told me that it had previously been 500 rubles and, a few years earlier, just 75 rubles (enough for five loaves of bread).

[68] Another concern is that the homecare provided by state organisations focuses on bare subsistence and has no broader goals of social inclusion or interaction, pointing to a very functional interpretation of needs (Tronto 1993).

In sum, social ties undergirded the citizenship of the disabled people I met by affecting both their use of welfare services and wider position in society. The actions of families and friends can greatly facilitate mobility, social interaction and livelihoods, thereby shaping the type of citizen that a disabled person can be, for example employed, mobile or socially connected. The agency of my research participants was thus mediated by their social relations, making it appropriate to speak of their ‘relational autonomy’ (cf. Fine and Glendinning 2005: 615). However, state policies neither comprehensively support disabled people with few social connections nor assist the families and carers of disabled people. Such inadequacies inevitably arouse powerful feelings about the priorities and values underlying state provision. The next section brings the discussion of citizenship to a close by considering its subjective and emotional dimensions, namely how my disabled research participants felt poorly understood and valued by the state.

Attitudes towards citizenship

While I did not directly ask my research participants for their opinions on what it means to be a disabled citizen in Russia, they often commented on their relationship to the state during our interviews and informal conversations. Letters published by *Gazeta Vybor* also linked specific complaints about welfare provision to wider points about how disabled people are regarded and treated by the state. Such connections strengthen the theoretical conviction underpinning my thesis that welfare services are an important element of how citizenship is personally experienced. Also interesting is the critical stance displayed towards state provision, implying that people do not passively accept the policy status quo and feel unfairly treated as citizens.

Although my research participants differentiated between various state institutions when talking about the different forms of support they received, their criticisms were often directed at ‘the state’ in general. There was an overall impression that policymakers and officials do not care about them: in the words of one *Gazeta Vybor* article ‘the state does not love disabled people’ (20.04.2007, p.1). The lack of attention and care from the state was bluntly put by Ksenia, who noted that raising a disabled child was regarded as the problem of parents because ‘if you are disabled, you aren’t needed by anyone’ (*ty nikomu ne nuzhen*). This feeling of not being valued as a citizen, especially by official structures, suggests that the formal equality between disabled and non-disabled people in Russia introduced in the post-Soviet constitution is not experienced as a reality. Ksenia dejectedly continued that ‘in our country everything is written down beautifully on paper, but nothing is implemented.’ As a law student, she knew that there was a large mismatch between the positive tones of official discourse and the concrete realities experienced by disabled people.

A recurring theme in discussions with disabled people was that government organisations do not properly comprehend the problems relating to disability. Anton’s mother commented that ‘if only disabled people would come to power, only they understand how difficult it is for a disabled person.’ Often specific complaints about poor services were linked to broader reflections about the state, for example Maksim’s frustration with the inaccessibility of public transport: ‘here the state still hasn’t adapted anything at all, even these new buses.' When asked about his wishes or hopes for the future, Maksim responded that 'I want the disgusting relations towards [disabled] people in our state to change … not such crumbs of monetary help. So that the buses would be accessible and I could enter any building without assistance, so that I could be independent in this life.' Maksim, who strives to enjoy a lifestyle similar to his non-disabled friends, saw the authorities as responsible for the multiple forms of exclusion and immobility faced by disabled people in Russia. He felt that the state's approach to disability was extremely narrow with support focused on material needs rather than societal participation and self-determination. Indeed, his quotes linked mobility to citizenship by twice mentioning the state of Kazan's buses, reflecting how he was frustrated at the efforts it takes him to be mobile and thereby take part in societal life. Maksim was also aggrieved that the welfare system devotes most attention to children and older disabled people and thereby neglects the needs of twenty to fifty year olds, particularly concerning employment and leisure. While his friends did much to help him overcome obstacles that could prevent him from going out, their efforts did not excuse the lack of official action to facilitate mobility, especially by making the built environment accessible, or improve his chances of a stable livelihood.

While Maksim was most upset by the lack of state action to tackle immobility, the frequent shortages of social and medical assistance were another frustration for many research participants. Indeed, research participants often spoke of being 'entitled' (*mne polozheno*) to traditional forms of welfare support such as sanatoria stays or free medicines that had been available as a matter-of-course in the Soviet period (cf. Henry 2009: 57). A disabled woman exasperated by the hassle involved in obtaining services guaranteed by law concluded a letter to *Gazeta Vybor* that ‘the weaker you are, the stronger you must be. The standards of living created for disabled people in our country force them to be strong – otherwise you won’t survive’ (*Gazeta Vybor*, 01.12.2006, p.3). This pessimistic note suggests that some disabled people may feel unsupported and alone, echoing Ksenia’s impression that disabled people are not valued by the authorities. Yet, it also suggests that disabled people can demonstrate agency by looking after themselves with their own resources and social ties. Another disabled reader of *Gazeta Vybor* similarly concluded that ‘disabled people are superfluous people, deprived of any protection’ (*Gazeta Vybor*, 12.10.2007, p.4). Although it is not necessarily accurate that the state provides no assistance to disabled people, these statements are poignant in suggesting that state provision is ineffective and that the state deliberately neglects this group, who must consequently ‘survive’ through their own action. This contributes to a feeling of being regarded at an official level as inferior citizens whose needs are not understood and entitlements not instantiated, even when clearly spelt out in law.

My research participants’ impressions that their needs and citizenship are not taken seriously were fuelled by state activities that provide one-off attention and resources at symbolically important moments instead of striving to change everyday conditions. Reports from local social protection departments in Kazan proudly describe the events organised around the ‘International Day of Disabled People’ each December, involving a series of job fairs, cinema screenings, concerts, parties and the distribution of presents. Such activities are used by the authorities as proof of the attention and care paid towards disabled people (e.g. MTZSZ 2008).[69] However, it can seem that this is the only time that the authorities acknowledge disabled people, which gives welfare entitlements and rights a charitable and benevolent flavour that detracts from citizenship (Oliver 1996; Powell 2002). The grandmother of a disabled child observed that ‘bureaucrats are only interested in disabled children, whose lives are trapped within four walls, once a year – on the International Day of Disabled People (and even then not in all of them). They organise a concert, sometimes give presents, but afterwards there’s silence again all year long’ (*Gazeta Vybor*, 06.10.2006, p.3). Disabled people encouraged to telephone Kazan’s Centre for Social Assistance on this day similarly complained that ‘they are forgotten in everyday life, and only remembered on the International Day of Disabled People’ (*Gazeta Vybor*, 22.12.2006, p.4). Contrary to the expectations of staff at the centre, most of the phonecalls did not relate to legal matters or social services, for which specialists in these matters were on hand to provide advice. Rather, they concerned the social isolation that arises from the general inaccessibility of the built environment and lack of social connections, something that the social workers were less able to solve in the frameworks developed by policymakers for their work. The foci of disability policies thus seem misdirected and poorly matched to the actual concerns of disabled people, in particular such daily problems as immobility or unemployment. This suggests that the authorities have a poor understanding of how disability is experienced and consequently a mistaken interpretation of disabled people’s needs (Tronto 1993: 108).

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[69] The policy preoccupation with formal events and one-off parties is not unique to disabled people, as various events organised by the Russian authorities around International Women’s Day indicate.

My research participants' reflections about their relationship to the state were piqued by annoyance that the country's rising wealth was not being used to help disabled people, be it materially or by improving opportunities for education, employment and accessibility. The Russian economy grew steadily during the 2000s, but the disparities between low living standards and the increasingly confident rhetoric of politicians was very frustrating. In particular, my research participants did not discern any change as a result of Vladimir Putin's much-lauded 'national priority projects' on healthcare and education. These schemes were not perceived as reducing shortages, raising standards or improving accessibility and livelihoods – 'new grand projects replace others, but in reality little changes for us' (letter from a disabled pensioner, *Gazeta Vybor*, 12.10.2007, p.4). Indeed, documentation for these well-funded programmes makes no reference to disabled people, pointing to their invisibility as citizens. To borrow the analytical terms of Nancy Fraser (1997), disabled people benefited from neither symbolic recognition nor socioeconomic redistribution.

The social benefit reforms that came into force in 2005 aroused particularly strong resentment that politicians were trying to reduce spending on services for disabled people despite healthy state budgets.[70] The paradox that welfare support received by individuals was falling while state revenues grew irritated my research participants. As a seventy year-old man exclaimed in a letter to *Gazeta Vybor*, 'saving money on disabled people and veterans is shameful!' (26.05.2006, p.4). Such annoyance over the discrepancy between substantial government budgets and poor resources for disability provision was mirrored at a regional level. An older Tatar reader noted that 'it is clear

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[70] Overall, the reforms may in fact have cost the Russian government more than it previously spent on social benefits due to miscalculations and concessions made in the face of mass protests (Wengle and Rasell 2008: 749)

that … money is needed [for welfare provision]. But, after all, we live in a region that produces millions and billions of tonnes of oil' (*Gazeta Vybor,* 12.10.2007, p.4). Indeed, the obvious fact that Tatarstan's widely advertised public wealth is not being spent on improving conditions and services for disabled people was a source of indignation and sorrow. The proclaimed focus of Tatarstan's government on charity and disability in 2007 did not affect my research participants' everyday life, creating feelings of political unimportance and official neglect. Such public discourses raised the question: 'do we really not have money in this rich republic to help disabled people?' (*Gazeta Vybor,* 31.03.2006, p.4). Speaking of the modest funds required to compensate disabled people for transport benefits lost during monetisation in 2005, one local disability activist – the same who regretted the weak response of *VOI* to monetisation – asked 'surely this is not an impossible amount for an oil republic?' (*Gazeta Vybor*, 21.09.2007, p.3). Such sentiments suggest that disabled people are far from passive in their reactions and ideas about social provision in Russia, in fact challenging dominant political discourses with hard facts based on their own experiences. They feel distant from and unvalued by the state (cf. Henry 2009).

The assessments of the Russian welfare state that I heard from disabled people were often juxtaposed against ideas about life abroad. This was perhaps because of my British background, which prompted questions about social policy in my country. However, it also came from an awareness of practices abroad and occasionally from personal contacts. In general, 'Europeanness' was felt to be positive in relation to disabled people, implying that Russian approaches were negative or inferior. Olga spoke of how convenient she found conditions for wheelchair users in Finland, where she spent a year as a volunteer in a residential home for children with mental disabilities: ‘in Helsinki I saw the state university, where the doors open automatically, you enter and there are no curbs. That means you can enter from the pavement, lifts and toilets are accessible, it’s great. We don’t have that yet.’ Anton’s mother mentioned a friend who went abroad and noted the visibility and mobility of wheelchair users in public spaces: ‘things are in order there, but our Russians can’t even get out onto the streets.’ Several research participants expressed a wish to move abroad, often related to strong frustrations that their opportunities and quality of life are severely limited by living in Russia. Maksim even told me that he had written [unsuccessfully] to the Belgian Embassy in Moscow asking for asylum. The mother of Ksenia (who speaks very good English and has several penpals and acquaintances outside Russia) commented that ‘I don’t think that things are like this abroad; there is more action than talk there. It’s insulting (*obidno*) that we have such a bad state of affairs here.’ Implicit in such views are beliefs that states and their governments have obligations for the conditions in which their disabled citizens live and that Russian disability provision does not compare well to that in other countries. My research participants thus felt disadvantaged both compared to their non-disabled peers within Russia and in relation to disabled people abroad, who were felt to have more opportunities to be active and independent citizens.[71]

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[71] Interestingly, I heard no consideration that disabled people in some countries might be worse off than their Russian counterparts, for example in neighbouring CIS countries like Ukraine and the states of Central Asia.

Conclusions

Both this chapter and my overall thesis have discussed forms of agency at individual, family and group levels, ranging from insistent letters and appeals to cases of direct action, for example building ramps in apartment buildings and supporting children in local schools. Although not always successful, such activities suggest an active form of citizenship in which people attempt to challenge official practices and hold state organisations to account (cf. Henry 2009). My research participants' comments about their relationship to state institutions reinforce the conclusion that they are critically engaged with questions of welfare provision and their position in society.

The experiences discussed in this chapter suggest that dealing with state institutions in Russia is far from easy. Disabled people must frequently interact with local state welfare services in order to claim and renew their entitlements to social provision. The associated 'street-level bureaucracy' is however burdensome since it happens on terms dictated by administrative needs and regulations. Queues, paperwork and a lack of easily accessible information are likely to make disabled service users less successful at navigating the welfare system and asserting their rights and entitlements. It would however be wrong to think that my disabled interviewees passively accepted the welfare provision and citizenship experiences available to them. Rather, they tried individually and through enlisting the assistance of friends and family to assert both their rights vis-à-vis the state and their broader place in society.

There was admittedly little faith in collective action and organised forms of support, which partly chimes with other research on social organisations in Russia (e.g. Hemment 2007). Scepticism about joining disability organisations, especially Tatarstan's branch of the national association *VOI*, stemmed from sentiments that they are unhelpful, uninteresting and do not support participation in society, which is what many research participants want most of all. With a few exceptions, the conceptualisations of agency and citizenship that I heard did not encompass group support or the third sector. It is instead individuals and their families who do most to fashion citizenship from below. Indeed, agency emerged in this chapter as highly embedded in networks of social relations without which it can be exceptionally hard to overcome many barriers to full citizenship (Lister 2003: 106). Parents, relatives and friends not only help with daily activities at home, but more fundamentally influence the social interaction enjoyed by their disabled kin. This may be through supporting them in attending local schools, accompanying them on sanatoria trips or acting to make their apartment block accessible in a wheelchair so that disabled people can enter and leave freely. Conversely, having few acquaintances and friends severely impacts on opportunities for disabled people to participate in society. Citizenship and agency should therefore be understood in the context of interdependence and not as concepts pertaining to single individuals (Twine 1994; Sevenhuijsen 1998). Yet, Russian welfare policies rarely focus on the relationships and surroundings that shape how disabled persons live, neglecting such questions as mobility and the care provided by families.

Indeed, my research participants were adamant that policymakers and state organisations poorly understand disability. Their statements linked inadequate welfare provision to broader questions of the state’s responsibility for its citizens. Instead of such traditional forms of assistance as money and medicines that treat disabled people as passive recipients, people wanted to live free from discrimination and restrictions on their mobility and livelihoods. They felt that their citizenship was unsatisfactory because they are not provided with the same opportunities as non-disabled people or indeed disabled people abroad. Inequality and misunderstanding are certainly common features of the lives of Russians with disabilities, as will be surmised in the next and concluding chapter, which draws together my empirical material in a discussion of the nature of disabled citizenship in contemporary Russia.

Conclusions

Social citizenship, disability and welfare provision in Russia

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This thesis has examined formations of social citizenship in contemporary Russia by studying the everyday lives of a small group of physically disabled people in Kazan and several other cities, focusing in particular on their interaction with local and regional welfare systems. I sought to give a bottom-up perspective on how their rights and entitlements to social provision are negotiated and realised on a daily basis. Theories of care and mobility framed this investigation as tools for understanding how definitions of needs and citizenship are highly contested and socially mediated. As I explained in the Introduction, analysing personal concerns and voices is important to ground academic and political debates about citizenship in praxis and because there is a well-grounded fear that welfare systems can isolate and oppress people with disabilities. In this conclusion, I consider what my research reveals about state-citizen relations and the position of disabled people in Russian society. I also discuss the theoretical implications of these results for studies of social citizenship and explore the transnational dimensions of this highly local study. Finally, I make suggestions for further research on disability provision in the postsocialist region and offer a short epilogue on the most recent developments in Russian disability policy.

Social citizenship and disability provision in Russia: empirical results

The starting point for my empirical discussions was the historical overview of Russian disability policy given in Chapter Three. This rooted current social policies in the

Soviet past, but emphasised that they are not unchanged legacies. Rather, today's welfare system represents a hybrid in which new ideas and reforms have been grafted onto older approaches and practices. As a result, what it means to be a citizen with a disability has changed somewhat in the twenty years since the collapse of the USSR although social care remains largely a mechanism of control rather than empowerment. The right of disabled people to live in communities instead of large residential institutions has been officially recognised, but deinstitutionalisation was not accompanied by policy initiatives to actively encourage social inclusion. Post-Soviet reforms in the disability sphere have rather concerned health services, pensions or classification schema, all very traditional policy fields in which disabled people are regarded as passive recipients. There has thus been a 'privatisation' of care for disabled people towards families, but national legislation on the rights of disabled people in Russia has only patchily asserted the importance of equal opportunities and inclusion in society.

Against this somewhat bleak policy context, Chapter Four looked at how disability is officially conceptualised and classified in Russia by applying a 'politics of need interpretation' approach (cf. Fraser and Gordon 1994). I discussed how the term *invalid* promotes a negative image of disabled people as abnormal, unable and dependent on state care. The welfare system defines people through their impairments and does not explicitly recognise disability as a socially constructed phenomenon, which is how my research participants experienced it. Despite the blanket term *invalid*, there are differences in the quality and quantity of state assistance available to disabled Russians depending on their perceived military or labour contribution to society before their impairment, pointing to a state-created hierarchy among disabled people based on notions of ‘deservingness.’ This places people with childhood impairments in a structurally unequal position compared to veterans and workers disabled through workplace accidents since they receive minimal support to work and thereby fulfil the purported obligations of citizenship. Indeed, the official equation of disability with inability means there is a strong policy emphasis on ‘rehabilitation’ and medical support rather than tackling the disabling culture and environment in the country. Although unhappy that state support focused largely on health services and pensions, my research participants nonetheless felt that they had strong rights to such provision. Chronic shortages of medicines and sanatoria places were therefore regarded as unsatisfactory along with the lack of mechanisms to enforce entitlements and challenge diagnoses made by medical commissions. The people I met were often deterred from obtaining goods and services, especially medicines, due to the difficulties of interacting with state personnel and organisations. The flawed implementation of policies to meet supposedly medical needs therefore has the paradoxical effect of discouraging the use of state welfare provision and thereby weakening state-citizen relations.

The dominance of medical understandings of disability means that inclusion and equal opportunities are poorly facilitated by welfare provision in Russia. There is certainly little attempt on the part of authorities to offer disabled citizens similar experiences of state provision and everyday life as their non-disabled counterparts. Instead, many of the policies and services discussed in this thesis direct disabled people down separate pathways. This was particularly obvious in Chapter Five’s discussion of opportunities for education and employment. Special schools, home education and compulsory unemployment all mean that abstract rights to education and work are instantiated in very different and unequal ways for disabled and non-disabled citizens. My research participants frequently condemned such policies for isolating them from society and preventing them from building livelihoods. The equation of disability with ‘inability to work’ aroused particularly fierce emotions for undermining the independence of people with impairments and positing that they are incapable. In a country where citizenship was long based on labour contribution, official proclamations that disabled people cannot work if they wish to receive state support maintain a focus on bodily difference and negate the role of social barriers. Such thinking leaves disabled people relying on miserly state pensions, although they can occasionally find informal work and sources of income in order to circumvent the role of inactive dependant allotted to them in official thinking.

The citizenship experiences of the disabled people I met were greatly shaped by restrictions on mobility and access to space. Whereas research participants emphasised that they wanted broad rights to independent movement, social participation and the use of space, state services focus more narrowly on individuals’ health and income. Many of them found it difficult to exit their flats and travel around their local neighbourhoods, be it in wheelchairs or on public transport. They therefore had limited opportunities to participate in society through work, education and leisure despite their best efforts, together with families and friends, to attain a modicum of inclusion. Indeed, disabled people are officially assumed to be intrinsically unable, making it unnecessary to adapt the social environment to their needs or provide them with opportunities equal to those of non-disabled citizens. Chapter Six highlighted that the problem of immobility extends far beyond inaccessible architecture and urban landscapes to include hostile attitudes and misconceptions about disability. Discriminatory or paternalistic thinking can undermine opportunities for moving around public spaces and thereby taking part in society even when progress has been made in adapting the built environment. Thus the two new housing complexes for wheelchair users discussed in Chapter Six meet exacting architectural criteria for accessibility, but are run as care and rehabilitation institutions where residents are regulated and monitored. Such practices support my evolving claim that state disability policies in Russia focus largely on people’s impairments rather than the social conditions that disable them.

In view of the exclusionary workings of state services, Chapter Seven looked at how my research participants interpreted and challenged dominant messages in disability policy. It found that exhausting procedures within state organisations and a lack of clear information reduce disabled people’s control when engaging with the welfare system. As a result, entitlements to social provision are often perceived as uncertain and arbitrary. In discussing different types of agency as citizens, I identified significant scepticism among research participants about the potential of civil society organisations to support their priorities and rights. While partly reflecting the low profile of the non-governmental sector in my fieldwork location of Kazan, such sentiments suggest that group or organised forms of agency were not seen as vehicles for promoting rights in everyday life. My research participants instead relied on the support of their family and friends to work, study, move around and engage with society. Relatives may spend time and energy caring for disabled people at home, supporting their school attendance, fighting for social benefits or making housing blocs traversable in a wheelchair.

Without their actions, state provision would be less used and less effective since disabled people find it very difficult to access many services on their own, for example sanatoria, chemists and schools. Practices of citizenship and welfare entitlements are therefore embedded in social contexts.

Overall my thesis explored the premise that state welfare provision can reveal much about formations of citizenship for physically disabled people in contemporary Russia. The empirical chapters showed that social policies do indeed have a large impact on disabled Russians' everyday lives, their interaction with state organisations and their position in society. These results strengthen old and new arguments that social citizenship provides an appropriate analytical framework for understanding state-society dynamics in the post-Soviet region (Manning 1993; Henry 2009; Yalcin-Heckmann 2009). Indeed, my research participants regarded the provision of social assistance and services as obligations of the state even if they were displeased with how their concomitant entitlements were realised. As such, it is legitimate to include welfare systems in the list of topics examined by studies of postsocialist citizenship, thereby expanding a literature that so far has looked mainly at questions of nationality, gender and civil society. I can thus only concur that 'examining citizenship through the lens of social rights offers an intriguing way to explore changing ideas about the appropriate relationship between state institutions and citizens in Russia by illuminating both top-down and bottom-up processes of redefinition' (Henry 2009: 52).

In showing the relevance of the social citizenship concept to Russia, my findings challenge the assumption often found in research on the postsocialist region that the state irrevocably withdrew from social life during the turbulent 1990s. It seems inaccurate to suggest that disabled people experienced a ‘shredding of the safety nets that existed under the Soviet regime, safety nets that depended on the workings of the state’ (Field and Twigg 2000: 3). Disability provision in Russia is a sphere of state activity that remained and in fact changed significantly *after* 1991, especially at a local level, with a new housing complex, adult rehabilitation centre and distance learning university courses all opening in Kazan in the last few years. The problems faced by my research participants are caused less by an absence of state support than by the specific forms of assistance available to them. State organisations and social provision thus do play an important role in the lives of Russian citizens, at least those with disabilities. Indeed, the citizenship experiences of disabled Russians are unevenly moving away from the explicitly exclusionary and medical approaches of the Soviet period precisely because state support for this group is changing. These findings strengthen arguments within postsocialist studies that ‘the nature of the state and its engagement with the processes of producing social security is complex, fragmented and at times contradictory and cannot be explained by a singular paradigm of withdrawal’ (Kay 2008: 9).

Reconsidering citizenship: theoretical reflections

In Chapter One, I argued that the strongly normative flavour of academic and policy debates on citizenship makes it valuable to look at bottom-up interpretations of rights, entitlements and state-citizen relations. My thesis should be read as part of a growing empirical literature that tries to ‘combat the somewhat abstract nature of much theorizing on citizenship' through studies of lived or everyday citizenship (Lister 2007: 55). The conceptual points I make ultimately agitate for a more nuanced understanding of how citizenship and welfare provision relate to each other and are experienced at a personal level.

My results suggest that I was correct in Chapter One to critique universalistic concepts of social citizenship – most famously associated with T. H. Marshall – for failing to recognise that experiences of rights and state provision vary greatly among groups of the population (cf. Somers 2008: 20-22). Here the theorisations of power offered in the care literature proved very useful (Tronto 1993; Kittay 1999). It is too simplistic to claim that welfare states automatically promote social rights since formal status as a citizen clearly does not guarantee complete citizenship in practice. Indeed, disabled people in Russia clearly have a very different type of citizenship and set of opportunities to participate in society than non-disabled members of the population. The existence of inequalities within a society and the state's role in creating them are often ignored in the classical literature on social citizenship, particularly comparative work discussing models of citizenship at a national level (e.g. Roche 2002). This makes it necessary to remove 'the universalist cloak of the abstract, disembodied individual' citizen by acknowledging the existence of diversity and difference within communities and recognising that experiences of citizenship inevitably vary due to this pluralism (Lister 2003: 68ff).

The focus of my thesis on the single case of Russia, and more specifically the city of Kazan, highlights that formations of social citizenship are specific to local contexts rather than generic or universal across communities and countries (cf. Bowlby et al 2010). It is clear that ‘political and cultural histories … shape over time what we might call nation-specific citizenship “complexes” or “regimes,” with unique structures of internal inequality and forms of inclusion and exclusion’ (Saraceno 1997: 27). The particular citizenship relations between the state and disabled people in Russia are indeed rooted in the country’s distinctive history and politics (cf. Alexopoulos 2006: 527). Yet, the tendency to reduce disability to impairment and consequently see disabled people as a negative ‘other’ has much broader resonance (Tronto 1993; Watson et al 2004). Similarly, the ideologically tinged hierarchy created by the state within the group of disabled people highlights that notions of ‘deservingness’ will always shape welfare politics as well as the conditions, histories and values in a particular setting, be it national or more local.

Another crucial theoretical point arising from my research is that the citizen-state relationship entailed by social provision is not always empowering. Welfare systems may in fact regulate and restrict the opportunities of citizens (cf. Oliver 1996). In my empirical chapters, we saw that social provision in Russia often forces my research participants to assume roles and positions anathematic to them, namely as dependants requiring help that is delivered by excluding them from mainstream society. This reveals that the ‘caring’ functions of the state are bound up with more coercive elements and confirms that welfare is ‘a power-inflected site’ (Morgen and Maskovsky 2003: 317; cf. Tronto 1993; Kittay 1999). Indeed, the tensions within welfare systems between providing care and supporting rights may in fact be dialectical and inherent since all forms of support make value judgements about the needs of citizens and how best to meet them. These decisions are often governed by subjective considerations of 'deservingness' and 'contribution' (Fraser and Gordon 1994; Kay 2011a). Sometimes the norms governing welfare provision may gel with people's own ideas, but otherwise unequal power relations mean that state welfare structures can impose politicised ideas about the needs of citizens receiving welfare assistance.

However, it would be wrong to see citizenship as a relationship that is unilaterally determined by state actors. Basing my study on disabled people's experiences and voices has highlighted that the meaning of citizenship is contested from below in discourse and practice. Although welfare systems are structurally saturated with power imbalances, my research participants did not passively accept the assumptions about disability found in state policies. Instead, they challenged the authorities and circumvented parts of the welfare system in the hope of achieving a more inclusive position in society. The examples of personal agency scattered throughout my thesis reinforce arguments that disabled people are not inactive and dependent, but participate in the construction of their life worlds (cf. Oliver 1996). More broadly, they indicate that citizenship should not be regarded as a top-down relationship shaped solely by the state since people rework the ideas and messages contained in policies, as was suggested by the literature on care and mobilities discussed in Chapter One. Citizenship therefore represents a complex interplay between agency and wider forces (Lister 2003: 37ff), albeit one that is arguably unbalanced in the case of disabled people in Russia.

Related to the analytical importance of acknowledging the role of agency, social relations emerged in my thesis as a crucial dimension of lived citizenship and a significant influence on how disabled Russians use welfare services and engage with society. This is an important point because citizenship is often discussed in academic literature as a relationship between single individuals and states, thereby ignoring the wider contexts and networks in which citizens live (cf. Somers 2008; Carey 2009). Other people influence opportunities for inclusion and well-being in negative and positive ways, from hostile kindergarten teachers refusing to admit wheelchair users to sympathetic employers willing to flout labour laws that deem disabled people to be incapable of work. The conception of agency in relation to citizenship should therefore be ‘one that not only locates it in a dialectic relationship with social structures, but that also conceives of it as embedded in social and cultural relations’ (Lister 2003: 38). In my study, the support of family members turned out to be particularly important in promoting inclusive citizenship due to the absence of state programmes and non-governmental organisations to actively integrate disabled people into communities. Citizenship must be therefore recognised as explicitly ‘social’ in that experiences and practices are greatly influenced by other people regardless of formal policies and rights.

The transnational dimensions of area studies

In approaching the topic of citizenship through a micro-level study in a different culture, I invite a key question confronting all area studies specialists: the broader relevance of a locally grounded and contextualised study. Although I started my area studies training in the late 1990s when the discipline of Russian and East European Studies was very much on the defensive (e.g. Bunce 1995), the completion of this PhD in 2011 occurs in a climate of renewed governmental and academic interest in language-based area studies. It is with some pride that scholars welcome the ‘move away from a prioritisation of western experiences in favour of a more open engagement with the dynamics of non-western societies’ (Flynn and Oldfield 2008: 2). This development is useful given that many social issues, including the marginalisation and well-being of disabled people, transcend national borders and East-West divisions (cf. Kay and Kostenko 2008 on crisis among men). In this section I therefore consider the transnational dimensions of my study, focusing on policy transfer into the region and the lessons which can be learned from this research for wider policy and academic debates.

Through its focus on bottom-up experiences of disability provision in one region of the contemporary Russian Federation, my research was well-placed to consider ‘transnational’ influences on Russia’s welfare system. Ethnographically minded policy analysts have long emphasised that concepts do not ‘travel’ or ‘transfer’ across contexts, but are rather ‘translated’ such that ‘their schemes, content, technologies and instruments are continually changing according to sites, meanings and agencies’ (Lendvai and Stubbs 2007: 15). As well as considering the local meanings attached to policies, it can also be useful to consider what is lost in the process of translation or not adopted at all. Indeed, the everyday lives of my research participants and the welfare services available to them often seemed far removed from what I anecdotally knew to be the case in western and northern European contexts.

At the macro-policy level, Chapter Three highlighted that it is difficult to identify direct foreign influences on Russian disability policy. This is partly because the federal legislation governing disability provision is neither comprehensive nor up-to-date. The last and only post-Soviet law focused on disabled people was issued in 1995 and since then policy changes have primarily been made through laws concerned with other issues, especially fiscal federalism and pensions. Policy transfer is also limited due to the marked hesitation on the part of federal governments in Russia since 2000, when Vladimir Putin became President, to associate themselves with foreign models (Cook 2007) and the absence of a powerful outside impetus for policy transfer as exists in many Central-Eastern European countries (e.g. Cashman 2008). Indeed, global discourses surrounding disability are fragmented, for example between the European Union, United Nations and World Health Organisation, such that there is no single concept of disability and disability policy that could be uncontroversially drawn upon by Russian politicians (Priestley 2007). This weak policy transfer means that the strongest foreign influence on disability practices arguably comes from multinational companies such as McDonalds and Ikea who have promoted disabled people's access to space by applying standard construction blueprints that reduce barriers to movement.

Transnational aspects of disability policies at the regional level seem similarly opaque and indirect. The location of my fieldwork in regional Russia, specifically the city of Kazan, is important to understanding the limited and partial policy transfer from abroad identified in my research. Scholars of Russian civil society have long highlighted the concentration of international aid in Moscow and St. Petersburg (e.g. Henderson 2000: 75), which also have greater access to foreign expertise as the richest and most connected cities in Russia. Whilst Kazan is one of Russia's wealthier cities, its political life is very controlled with very few independent civil society organisations, even around welfare issues (Lussier 2008). There are therefore few conduits for accessing foreign expertise and influencing social policy at the regional level. Indeed, Tatarstan lacks the political and external impetuses to support social programmes and civil society that exist elsewhere in Russia, most notably in Karelia and the north-east due to Nordic influence (Kulmala 2009). The small organisations devoted to various disabilities in Kazan have therefore not been able to link into national and international networks of funding, support and ideas, meaning that the city lacks a disabled people's organisation like *Desnitsa* (Samara) or *Perspektiva* (Moscow) that would raise this group's voice and public profile.

Despite the limited foreign influences on disability policy in Russia and Tatarstan, the focus of my study on the lived experience of welfare provision makes it relevant to ask how disability policies and practices abroad were framed by my research participants. Chapter Seven discussed how 'the West' represented a positive 'other' for many of my research participants against which they contrasted the frustrating conditions in which disabled people in Russia live. On the ground, many professionals were aware of such foreign concepts as inclusive education (*inklyuzivnoe obrazovanie)* and accessibility (*dostupnost'* or *bezbar'ernaya sreda*) and Kate Thomson's work has highlighted the multiple obstacles to their instantiation (Thomson 2002a). During my fieldwork I encountered some professionals who would refer to 'Western' practices to try to justify their own activities as well as certain disability activists who saw the West as providing useful models of collective action. The reference to foreign practices to claim legitimacy is an interesting discursive tool that obscures the messy and partial translation of foreign practices into the region. As discussed in Chapter Six, Samara's village of accessible houses may have been built to European blueprints, but its constitution as a *pansionat* or care home reflects an extremely narrow interpretation of disabled people's needs. Broader concepts from abroad, for example about the social inclusion and independence of disabled people, are not present in Russian policy discourses around welfare provision, suggesting that the take-up of 'soft' ideas and norms – as opposed to specific policies or procedures – has been limited. Indeed, some professionals I met – including the director of *MSEK* in Tatarstan and the chairperson of the regional *VOI* branch – did not refer to foreign practices at all during my interviews with them, suggesting that ideas from abroad are not diffusing into higher levels of state bureaucracy.

Ultimately my study suggests that the international influences on ideas and practices around disability have been weak both in Kazan and at a federal level. Professionals, journalists and disabled research participants frequently asked me for information on welfare services and disabled people's lives in the United Kingdom, pointing to the poor awareness and low availability of information about practices in other countries. Yet, it would be deeply problematic to presume that Russia's role should be limited to absorbing approaches and models from elsewhere. Indeed, my local and very specific study of a region in this country has broader implications for both policy and conceptual debates about citizenship and disability.

Many of my empirical findings about the pressures on disabled people's lives – the unsympathetic disability classifications, discriminatory attitudes, social isolation and low levels of material resources – resonate with similar studies in other countries (e.g.

Ingstad and Whyte 2007). This highlights the wider phenomenon that politicised discourses of ‘need’ and ‘deservingness’ underpin how states and societies react to socially constructed difference, for example disability. The lesson that welfare systems may generate discrimination and marginalisation through their own practices is relevant to a wide range of contexts and demonstrates that welfare provision is not a technical and value-neutral process (cf. Clarke 2004). Indeed, current welfare cuts in the United Kingdom and other western European countries traditionally seen as epitomes of disability provision are sharply revealing the politicised nature and moral undertones around the definition and prioritisation of needs.

The ‘genealogical’ focus of my thesis on how needs are politically constructed has interesting policy implications since it exposes the assumptions and messages underlying welfare provision (cf. Fraser and Gordon 1994). Revealing that most disability policies in Russia are founded on the equation of impairment with defect and weakness could help to drive policy change rooted in a more accurate understanding of disability as a complex interplay of the social and physiological (Thomas 2007). Indeed, it is not clear whether Russian policymakers consciously believe that disabled people are ‘unable’ or whether this idea has been inherited from the Soviet period and maintained in the policy circles and culture of contemporary Russia. More broadly, any social policy would benefit from the analysis of its normative underpinnings and connotations. Such a move could help to ground social policies across the world more firmly in ideas of equality, rights and respect for diversity.

Another implication of my research that goes beyond Russia concerns the crucial role of social ties, especially family and friends, in supporting the inclusive citizenship of disabled people. This finding challenges some of the strongly individualistic formulations found in the Western disability movement and citizenship literature (cf. Hughes et al 2005; Lister 2003). It is clearly misleading to focus solely on individuals since this removes them from their broader social relations and life worlds, thereby ignoring the fundamental fact that humans are interdependent beings (cf. Tronto 1993; Watson et al 2004). Although significant improvements could be made to the state services provided to both disabled people and those caring for them in Russia and elsewhere (Kittay 2011), the importance of relations to citizenship and well-being must nonetheless be recognised. This sociality and its obligations of caring may be intensive and not completely voluntary, but social bonds are a crucial resource for inclusion. It is true that social networks and mutual support are especially important in Russia due to the strains of daily life and limited welfare provision (Salmi 2006), but this does not detract from their universal relevance. Academic scholarship thus needs to acknowledge that citizenship is explicitly relational, whilst social policies would be more effective at developing inclusive citizenship if they focussed on informal *relations* of care rather than *individual* ‘care givers’ and ‘care receivers’ (cf. Tronto 1993; Watson et al 2004; Hughes et al 2005).

In offering a study of citizenship from below, I did not ground my analysis in an explicitly political agenda of human rights. While ethical or normative formulations of ideal-type citizenship are undoubtedly helpful frameworks, they are often far removed from daily experiences and local instantiations. Indeed, my research reveals that the usefulness of rights is an empirically open question since the content and realisation of certain entitlements and rights may in fact be unhelpful and oppressive. Studies of citizenship therefore need to explore what citizenship means in everyday reality rather than focus simply on legislative and policy formulations (cf. Turbine 2007). Whilst translating academic concepts into policy is generally a fraught exercise in simplification, this framework of everyday citizenship could be useful in seeking to humanise welfare policy. In particular, understanding citizenship as a relational, emotional and embodied concept rather than a simple status on paper could help to ground policy discourses in the experiences and perspectives of users of social services and their families and friends. Both the care and mobilities literature emphasise that personal identity and access to social networks are crucial elements of social inclusion. Such a notion of 'lived' citizenship moves beyond legalistic framings and would help policymakers to think about how social care makes people feel and shapes social relationships (Bowlby et al 2010: ch. 7). A focus on everyday life thus demands a holistic and far wider consideration of well-being than narrow debates about physical access or material resources tend to offer.

My final reflection on the transnational dimensions of my study concerns the overall conceptual frame of social citizenship. Although Russian political discourse rarely connects questions of disability and social provision to citizenship, the notion that welfare systems structure citizens' links to the state and wider society has proved to be accurate and worthy of detailed study. This suggests that studies of citizenship in regions or countries with some form of state welfare should engage more closely with questions of social provision. Even in developing countries where anthropologists tend to view welfare through the lens of ‘social security’ (Benda-Beckmann and Benda-Beckmann 2000), the state is nonetheless implicated in the production of well-being and social inclusion such that there could be interesting engagement with the notion of citizenship. Indeed, I note with interest that the most recent issue of *Citizenship Studies* (Vol. 15, Issue 3-4, 2011) devotes significant space to questions of social citizenship based on ethnographic research in postcolonial, postsocialist and post-Cold War settings.

Suggestions for future research

My study of state provision for disabled adults living in their own homes has tried to extend the small literature on disability in Russia that focuses largely on children, residential institutions and non-governmental organisations. More broadly, it contributes a non-Western perspective to citizenship studies that highlights the importance of local context and expands the geographical scope of the discipline. While all forms of state welfare provision in the postsocialist region raise questions about social citizenship, I confine myself here to suggestions for future research specifically related to the interplay between disability, state support and social rights.

This study deliberately focused on disabled adults who do not live in residential institutions since official acceptance that they should reside in communities is relatively new (post-1991). Yet, the experiences of those in institutional care should not be neglected and certainly raise sharp questions about the instantiation of political and social rights. The methodology underpinning my research meant that I did not speak to people living in institutions, reflecting the depressing fact that residents very rarely move from these homes into the community. Gaining access to such care homes may be difficult, particularly as a foreign researcher, but is likely to offer extremely valuable material for analysing the links between citizenship and disability provision in Russia.

My study had an urban focus and looked at disability policies in a relatively wealthy and socially progressive Russian region with the aim of seeing what innovation in the Russian welfare sphere might mean for social citizenship. The lives of disabled people in small towns and villages have so far not been considered in English or Russian language research, but would offer an interesting contribution to emerging literature on forms of social support in rural areas of the postsocialist region (cf. White 2004; Kay 2008; Thelen, Cartwright and Sikor 2008). Several of my research participants had lived in semi-rural areas and their talk of latrines, outside wells and dirt roads painted a very different picture to the urban landscapes and lifestyles of Kazan. The citizenship of rural inhabitants with disabilities is likely to be mediated by different social, cultural and environmental factors to those in cities and studying them would enhance our understanding of how local context shapes rights.

Although I have deliberately focused on service users’ experiences in my thesis, this could be neatly complemented by research looking at how staff in Russian welfare institutions conceptualise and construct disability in their daily practices. In light of questions about legacies from the Soviet period, one interesting professional group to study would be the ‘defectologists’ working in schools and children’s rehabilitation centres. Such research would help to extend an existing body of work that interrogates the assumptions and values influencing the provision of care within single institutions in eastern Europe, for example frontline social services, soup kitchens or hospitals (cf. Yaroshenko 2001; Haney 2002; Caldwell 2004; Read 2007). Studying how staff understand their work and interact with disabled people would shed greater light on how the ‘welfare state’ functions and influences constructions of social citizenship.

I strongly hope that future research will recognise cross-cutting social differences within Russia’s disabled population. The transitions of young disabled people to adulthood would be an important topic since social expectations, inaccessibility and legal barriers prevent many common experiences of teenage life. It would also be refreshing to see work on relationships and sexuality among disabled people in Russia in order to challenge common policy and academic preconceptions that this group is asexual. During my fieldwork in Kazan I heard from several research participants about their aspirations and problems in meeting people and having intimate relationships. I did not include such material in my thesis due to its focus on state welfare services, but the issues raised would shed light on questions of disabled personhood and identity in a non-Western cultural context (cf. Sinecka 2008). Such work could extend the lens of citizenship into the domestic or private sphere by showing how state organisations and other citizens determine the sexual rights and freedoms of disabled people (cf. Das and Addlakha 2001).

There also needs to be more work on different forms of disability. I myself am guilty of perpetuating a research focus on physical disabilities as the worlds of Russian citizens with autism, Down’s syndrome, dementia and other cognitive impairments go unreported. Allison Carey's magnificent study of the 'citizenship on the margins' of Americans with intellectual disabilities highlights that their social rights are affected by a different set of discourses and practices to wheelchair users (Carey 2009). Studying mental health or mental disability in Russia would be valuable in light of what is generally seen as extremely oppressive psychiatry in the Soviet period and even less professional and public understanding of these conditions than is the case with physical disability.

Epilogue: the path to equal opportunities?

Although I have spent more than four years studying experiences of disability in Russia, I am still struck by the same questions that arose when I first saw a disabled person in Moscow at the start of my fieldwork: how do social policies affect him, what support does he receive from the state, how does he live? I have tried to offer tentative answers in this thesis by discussing how state services in Russia shape the social rights of disabled citizens. It proved very easy to find flaws in Russian disability provision from a service user perspective. However, it is important to recognise that the uneven developments of the last twenty years have taken place in extremely challenging political and socioeconomic times. Furthermore, issues of power, inaccessibility and unequal citizenship are certainly pertinent in other countries and contexts. While much needs to be done to align Russian disability policies with bottom-up concerns, basic principles like living in community settings and the right to education have been established. This is perhaps why a recent United Nations report on disability policy in

Russia was optimistically titled ‘On the Path to Equal Opportunities’ even though it was highly critical of many practices (UNDP 2009).

The practices and values currently underlying Russian disability provision have important implications for future policies. The Russian government signed the UN Convention on the Rights of Persons with Disabilities in September 2008, thereby committing itself to an explicit human rights approach and the inclusion of disabled people in all possible fields and institutions of society. However, any reforms introduced when Russia ratifies the Convention will be applied over established institutions that segregate disabled people and offer them a very limited range of opportunities. New laws will only strengthen disabled people’s rights and make their citizenship more inclusive if accompanied by measures to overhaul attitudes and procedures both within the state welfare system and more broadly in society. Any legislative changes will otherwise be interpreted and implemented in line with previous approaches in which rights are incomplete and inaccessible.

The experiences of welfare services and everyday life in Russia discussed in my thesis make it hard to disagree with the conclusion that ‘the state does not love disabled people’ (*Gazeta Vybor*, 20.04.2007, p.1). Official support does little to promote full or inclusive forms of citizenship compared to the great efforts that disabled people and their families make to achieve a semblance of well-being, equality and social participation. This thesis is therefore testimony to the role of personal struggle in trying to overcome the many social factors – including state policies – that negatively affect the lives and rights of disabled people in Russia.

List of research participants

Although all names have been changed to protect identities, research participants are listed in alphabetical order with brief biographical details. All references to study imply education through distance-learning courses as explained in Chapter Five. A number of the experts that I interviewed were physically disabled, but have not been included in the list below if they spoke to me mainly about their professional activities rather than personal experiences.

1. Aleksei, late thirties, undertakes piece work for a stationery supplier
2. Anton, 26 years old, law graduate
3. Artem, 44 years old, military veteran and telesales operator
4. Damir, 24 years old, law student
5. Ira, 52 years old, lawyer, historian and disability activist
6. Ksenia, 22 years old, law student
7. Lena, 24 years old, trained seamstress and home economics teacher
8. Ludmila, late forties, former technician
9. Maksim, 22 years old, computer specialist and I.T. student
10. Masha, 22 years old, management student
11. Nataliya, 35 years old, disability activist
12. Natasha, early thirties, disability activist and social work student
13. Nikolai, 37 years old, former soldier
14. Olga, mid-thirties, disability activist and social work student
15. Renat, 23 years old, physics student
16. Rustam, 34 years old, electrician

17. Sasha, 43 years old, legal advisor in rehabilitation centre for disabled adults, Kazan
18. Sergei, 45 years old, charity volunteer, former soldier
19. Sem, 29 years old, university degree in Tatar and Russian languages
20. Svetlana, 41 years old, disability activist
21. Tatyana, late thirties, telephone dispatcher
22. Venera, early 50s, former technical engineer
23. Vladimir, late thirties, former factory technician
24. Volodya, 34, public administration student

List of social services centres and non-governmental organisations

1. ‘Sozidanie i Pomoshch’ Community Organisation, Kazan
2. ‘Vera’ Community Organisation of Disabled People, Kazan
3. Samara Community Organisation of Disabled People and Wheelchair Users ‘Desnitsa,’ Samara
4. Republican Office, VOI Association of Disabled People, Kazan
5. Head Office, VOI Association of Disabled People in Tyumen Region, Tyumen
6. Republican Centre for Social-Psychological Assistance, Kazan
7. Izgelek Vocational Rehabilitation Centre, Naberezhnye Chelny
8. Adult Rehabilitation Centre ‘Ascent,’ Kazan
9. Children’s Rehabilitation Centre, Kazan
10. Derbyshki Residential Home for Mentally Disabled Children, Kazan
11. ‘Gaile’ Centre for Families and Children, Kazan
12. Department of Social Protection, Novo-Sadinovskii district
13. Gazeta Vybor newspaper, Kazan
14. Day School for Disabled Children, Tyumen

List of expert interviews

This list has been removed from the online version of the thesis in order to protect the identity of research participants.

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