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Civil Society, Rights and Welfare: Exploring the Implementation of the Convention on the Rights of Persons with Disabilities in the Commonwealth of Independent States

PAUL CHANEY

Abstract

In response to international concerns about ongoing rights violations, this study presents a comparative analysis of state and civil society organisations' discourse on the early phase implementation of the United Nations Convention on the Rights of Persons with Disabilities (PWD) in the Commonwealth of Independent States. The findings show that PWD continue to experience rights-denial and barriers to shaping policy and accessing social welfare. There is a 'disconnect' between state and civil spheres that hampers effective implementation and explains the endurance of the medical model of disability across the post-Soviet space.

THIS ARTICLE PRESENTS A COMPARATIVE ANALYSIS OF STATE and civil society organisations' (CSOs) discourse on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (PWD) in the Commonwealth of Independent States (CIS) in the period 2008–2018. This is an appropriate locus of enquiry because many of the 15.4 million PWD¹ in the CIS continue to be subject to discrimination and ongoing rights violations (UNDP 2013; WHO 2015; HRW 2015). For example, as the United Nations has noted, 'unfortunately, in practice persons with disabilities face barriers, discrimination and exclusion in society... especially in developing countries

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¹From an international perspective, the preferred term varies across and between territories. This article uses the term 'persons with disabilities' because it is embraced by the disability movement and it is consistent with the social model of disability (for a discussion see Shakespeare & Watson 2002). Alternatives include 'disabled people'. The term 'persons with disabilities' is defined by the United Nations as 'all persons with disabilities including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others' ('What is Disability and Who are Persons with Disabilities?', United Nations Secretariat for the Convention on the Rights of Persons with Disabilities (Enable), 2007, available at: http://www.un.org/esa/socdev/enable/faqs.htm, accessed 6 December 2019).

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TABLE 1
CIS COUNTRIES AND THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

	CRPD signed	CRPD ratified	Number of disabled people*	CSO Sustainability Index score [†]
Armenia	30 March 2007	22 September 2010	186,384	3.8
Azerbaijan	9 January 2008	28 January 2009	520,793	5.8
Belarus	28 September 2015	29 November 2016	516,000	5.6
Kazakhstan	11 December 2008	21 April 2015	627,000	4.1
Kyrgyzstan	21 September 2011	16 May 2019	155,893	4.1
Moldova	30 March 2007	21 September 2010	171,000	3.9
Russian Federation	24 September 2008	25 September 2012	12,500,000	4.7
Tajikistan	22 March 2018	Due 2021	146,000	4.8
Uzbekistan	27 February 2009	-	740,000	_

Sources: *World Health Organization data, available at: https://www.itu.int/en/ITU-D/Regional-Presence/CIS/Documents/Events/Regional%20Initiatives/RI2%20ICT%20access%20for%20dispabled/Implementation%20of%20RI%20CIS2.pdf, accessed 23 December 2020; 'Disability in Armenia', Global Disability Rights Now!, 2020, available at: http://www.globaldisabilityrightsnow.org/infographics/disability-armenia, accessed 23 December 2020; The State Statistical Committee of the Republic of Azerbaijan, 2020, available at: http://stat.gov.az/, accessed 23 December 2020; European Commission Directorate General for Employment, Social Affairs and Equal Opportunities (2010). Notes: †The CSO Sustainability Index measures the strength and overall viability of civil society sectors. In a given country, the index evaluates the overall level of development of the CSO sector as a whole. Seven different dimensions of the CSO sector are analysed to create the index: legal environment, organisational capacity, financial viability, advocacy, service provision, infrastructure and public image. The index's methodology relies on CSO practitioners and researchers, who in each country form an expert panel to assess and rate these dimensions of CSO sustainability. The panel agrees on a score for each dimension, which can range from 1 (most developed) to 7 (most challenged). All of the scores are then averaged to produce an overall sustainability score for the country. Internationally, these scores are clustered into three general stages: Sustainability Enhanced (1–3), Sustainability Evolving (3.1–5) and Sustainability Impeded (5.1–7) (USAID 2017, p. 262).

such as the CIS, persons with disabilities most often do not enjoy their fundamental freedoms and human rights ensured by international treaties, including the Convention on the Rights of Disabled Persons (CRPD)' (UNDESA 2015, p. 34). In response, 'a paradigm shift in how persons with disabilities are perceived and a multi-faceted reform programme are both needed to ensure the full protection and promotion of the rights of persons with disabilities, and the realization of their potential to contribute to society' (UNHRC 2016, p. 8). Notwithstanding the scale and urgency of the problem, it is an issue that has hitherto escaped scholarly attention.

The following analysis is also timely in a number of other regards, not least because over the past decade, the majority of CIS countries have finally ratified the CRPD, the principal international PWD rights instrument (see Table 1). Crucially, and in a manner that resonates with the social model of disability (Shakespeare & Watson 2002), Article 33 of the Convention ('National implementation and monitoring') requires a participatory approach to implementation; one that is not solely driven by state bureaucracies but also involves civil society organisations. Together these factors constitute the underlying rationale for the current study. The following offers a systemic view of the vital, early phase of CRPD

implementation, a key period in which CIS countries began to address their Convention obligations. In the language of historical institutionalism, it was a 'critical juncture' (Capoccia & Kelemen 2007): a point at which member states could break the 'path dependency' of discriminatory and oppressive institutional and policy approaches inherited from the Soviet years and implement new rights-based practices. Thus, by analysing state—civil society dynamics, the following provides insight into the ability of the constituent territorial policy systems of the CIS to adapt, address PWDs' concerns and secure progress against CRPD objectives. At this point in time, it will further our understanding of how the participatory approach is being realised and identify any shortcomings in rights practice requiring remedial action.

A further justification is that 'the disability rights movement—which includes hundreds of NGOs ... is one of the most dynamic, yet understudied post-Soviet social movements' (Phillips 2009a, p. 277). It is also a topic deserving of attention because, throughout the Soviet era, 'the Medical Model of Disability comprise[d] the dominant response to disability matters' (Zagirtdinova 2005, p. 216). As Reiser (2006, p. 135) explains, this outdated conception 'sees the disabled person as the problem ... the focus is usually on the impairment... with the medical and associated professions' discourse of cures, normalization and science'. In contrast, the CRPD is predicated on the social model, which explains disability as a function of 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to social barriers' (Reiser 2006, p. 135). While the social model is not without its critics (Owens 2015), it does constitute a valuable conceptualisation, not least because it continues to inform the United Nations' human rights approach² and is endorsed by disabled people's movements around the globe (Tsai et al. 2010; Fontes 2014; You & Hwang 2018). The difference between the medical and social models has major implications for the nature of contemporary welfare provision and whether social policy in the post-Soviet space promotes medical model dependency or social model empowerment and independent living (Babajanian 2008; Becker & Merkuryeva 2012).

The data for the present study are drawn from hundreds of civil society organisation reports submitted to the UN Universal Periodic Review (UPR) covering Armenia, Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Moldova, the Russian Federation, Tajikistan and Uzbekistan. Introduced in 2006, this five-yearly evaluation process associated with UN rights treaties is conducted under the auspices of the Human Rights Council (HRC). All of the CIS countries studied here have passed through the second cycle review process, undertaken in 2013–2016 and covering developments over the preceding half-decade. As it is a rolling process, three states have also recently undergone a third cycle review, undertaken in 2018. In the following discussion, initial attention is given to regional comparative analysis across all nine states in relation to second cycle data. This is followed by three case studies (Azerbaijan, the Russian

² The Convention's preamble states that disability is an evolving concept. Nevertheless, it does reflect a social model of disability as it clarifies that disability results from the interaction between persons with impairments and external barriers that hinders their participation in society' (OHCHR 2014, p. 17).

³Forty-two states are reviewed each year during three Working Group sessions dedicated to 14 states each. These three sessions are usually held in January/February, May/June and October/November.

Federation, Uzbekistan) where third cycle data are available. These case studies outline the issues, progress and challenges since the second cycle review and give an indication of the 'direction of travel' for PWD rights in the CIS.

In summary, the current research aims are, first, to compare the priority (or 'issue salience'—the level of attention attached to individual policy topics and issues, see below) that civil society organisations and governments across the CIS attach to different policy areas affecting persons with disabilities in the second cycle UPR; second, to compare both sides' use of language (or 'framing') in their CRPD implementation discourse; and third, for the three case studies, to examine the key issues and challenges in relation to CRPD implementation evident in the third cycle UPR (circa 2018). Accordingly, the remainder of the article is structured thus: an outline of the research context is followed by the study methodology and discussion of the research findings; first, as noted, with a comparative analysis of state and civil society discourse at the regional, pan-CIS level, followed by the three case studies. The study's implications and avenues for future research are outlined in the conclusion.

Research context: rights, welfare and persons with disabilities in the Commonwealth of Independent States

The situation facing persons with disabilities in the Commonwealth of Independent States is shaped by the legacy of the Soviet Union. Hitherto there was limited knowledge about the Soviet response to disability. As McCagg and Siegelbaum explain, 'even within the USSR, the dimension of the disabled population and the extent and effectiveness of its treatment [wa]s little publicised, and for decades virtually nothing on the subject reached the foreigner's eye' (McCagg & Siegelbaum 1989, p. 8). The passing of time has begun to reveal details of a sometimes dark history. As Mladenov's powerful account describes, 'the treatment of disabled people in the state socialist countries... was characterized by segregation and stigmatization... the Soviet model [was one] of managing disability by way of coercion and confinement' (Mladenov 2017, p. 104). A UN report concurs:

Under the socialist system, persons with disabilities were subject to discrimination and social isolation, as well as multiple institutional, attitudinal and structural barriers. The stereotyping of and prejudice against PWDs were widespread so that their families experienced social stigma Government policies were based on the Medical Model of Disability. (UNDP 2013, p. 5)

A key element in the foregoing was the 'repressive ... tradition of *defectology* ... that was strong during the whole Soviet period'. It ensured that 'children with developmental disabilities were often locked up in closely regimented institutions' (Kalinnikova & Trygged 2014, p. 243; emphasis added). Emphasis was on the 'improvement' of such children using pedagogical methods. But, as Kalinnikova and Trygged proceed to argue, 'since these were children with developmental disabilities, they were hard to "correct". From a political perspective this science was therefore a failure' (Kalinnikova & Trygged 2014, p. 243). Here it should be noted that, during the Soviet era, attitudes and policy approaches to PWD were not static. Throughout the history of the USSR, one can find influential media representations of people with disabilities working successfully in the

planned economy (Phillips 2009b). These images undoubtedly shaped public attitudes. From a wider international perspective, to suggest that the medical model was solely a Soviet policy response is to distort matters. For a large part of the twentieth century, the ideology of modernisation spanned both West and East. It embraced the twin cults of rationalism and 'scientific management' and, all too often, coercion and confinement existed as modes of 'treatment' of people with disabilities. In turn, the widespread prevalence of medical model responses to disability led to marginalisation and social exclusion for many disabled people throughout the industrialised world, including the USSR. During the Soviet years, the result was that disability was often 'treated primarily as a social welfare issue.... This reflected the widely held belief that people with disabilities needed care and assistance, being unable and incapable of living their own lives' (McCabe 2011, p. 11).

As the following reveals, aspects of this legacy endure in the territories of the former USSR. In many cases there have been 'only limited changes in practical terms for citizens with disabilities due to a lack of implementation methods on the part of the state, lack of an emphasis on disability rights on the part of most NGOs and few consequences for those who transgress stated policies' (Holland 2008, p. 544). As Rasell and Iarskaia-Smirnova explain, the timing of the post-Soviet transition has not been kind: 'in a cruel irony of fate, persons with a disability in Eastern Europe gained greater recognition and freedom over their lives at a time when political and economic instability undermined the potential of state welfare systems to reduce disabling barriers' (Rasell & Iarskaia-Smirnova 2013, p. 6). In part, this has been due to the emergence of a mixed economy of welfare. In this respect, today's 'Russian social welfare system closely follows its Soviet predecessor. Government is responsible for provision of a pay-as-you-go "Solidarity" component, which includes all disability pension payments' (Becker & Merkuryeva 2012, p. 79). However, this has been complemented by the appearance of private disability and health insurance.

Because of the transition to capitalism and marketisation, which was accompanied by the destruction of the large-scale sheltered employment system, as well as wider geopolitical influences, the life conditions for many people with disabilities deteriorated. As Rasell and Iarskaia-Smirnova cogently note, 'although certain scholars ... view the state socialist past as a major source of problems facing persons with a disability [today], a more nuanced view ... also highlights the negative dynamics of neoliberal transition and political authoritarianism in terms of impeding equal rights' (Rasell & Iarskaia-Smirnova 2013, p. 16). It is a point also emphasised by Mladenov, who notes that:

Neoliberal restructuring has resulted in: retrenchment of disability support through decentralization, austerity, and workfare; stigmatization of 'dependency' through the discourse of 'welfare dependency'; responsibilization of disabled people; and depoliticization of disability organizations by restricting their activities to service provision and incorporating them in structures of tokenistic participation. (Mladenov 2017, p. 104)

It is partly as a result of this history that many CIS countries have questionable human rights records. For example, as Human Rights Watch concludes: 'Kazakhstan heavily restricts freedom of assembly, speech, and religion... it recently adopted changes to the criminal

code that contains articles restricting fundamental freedoms' (HRW 2015, p. 3). In a similar vein, Human Rights Watch also notes that Tajikistan's 'human rights record has deteriorated dramatically in the last two years' (HRW 2015, p. 29). In the case of Uzbekistan, a contemporary assessment concludes that the country's

human rights record remains atrocious. The government severely limits freedom of expression, assembly, association, and religion, and continues to wage an unrelenting crackdown on human rights work ... and civic activity. Those who attempt to assert rights, or act in ways deemed contrary to state interests, face arbitrary detention, [and] lack of due process. (HRW 2015, p. 17)

Given these failings, it is significant that, over the past decade, all CIS governments have signed the UN Convention on the Rights of Persons with Disabilities (CRPD) (see Table 1), which sets out a comprehensive rights framework. Notably, it requires governments to ensure a participatory approach to CRPD implementation. In addition, some CIS members have taken their own, albeit faltering, steps to advance PWD rights by passing new laws, as well as reforming archaic and repressive aspects of existing domestic legislation. Examples include the reform of the Moldovan legislative framework (*inter alia*, giving persons with disabilities under guardianship the right to vote for the first time, as well as the right to appeal against the establishment of guardianship);⁴ provisions in the Constitution of the Republic of Azerbaijan⁵ (for example, Article 25, 'the State guarantees equality of rights and liberties of everyone'); and, individual enactments, such as Azerbaijan's Disability Prevention and Disabled Persons (Rehabilitation and Social Protection) Act (1992)⁶ that prohibits 'discrimination against persons with disabilities'.

It is important to note that, in addition to offering new empirical analysis of developments in the CIS, with its focus on CSO and government actions to uphold the CRPD, the present study also engages with a number of strands of social theory. For example, complementarity theory (Klijn & Skelcher 2008) emphasises how politicians seek to deal with complexity by using CSO networks in order to increase external involvement in policy implementation. This not only strengthens input legitimacy but also potential policy efficacy through the pursuit of shared goals. In definitional terms, it should be noted that 'civil society' refers to associational activities involving non-governmental organisations, charities, pressure groups, social movements, community groups and campaigning organisations (Keane 1988). In turn, the participatory approach to public policy-making required by the CRPD is also integral to the deliberative democracy paradigm. As Cohen explains, 'not simply a

⁴Lege pentru modificarea și completarea unor acte legislative 36, 08.05.15 (Law 36 of 8 May 2015 on amending and completing a number of legislative acts), available at: http://justice.gov.md/public/files/transparenta_in_procesul_decizional/coordonare/2015/iulie/Proiect_24.07.2015L.pdf, accessed 22 December 2020.

⁵Azərbaycan Respublikasının Konstitusiyası (Constitution of the Republic of Azerbaijan), Adopted 12 November 1995 (amended 24 August 2002 and 18 March 2009), available at: https://static2.president.az/media/W1siZiIsIjIwMTgvMDMvMDkvNXdmMDZvdmx2Y19Lb25zdGl0dXNpeWFfQVpFLnBkZiJdXQ? sha=d654e4f6cd152b25, accessed 22 December 2020.

⁶Azərbaycan Respublikasının "Əlilliyi olan şəxslərin hüquqları haqqında" 1992-ci il tarixli Qanununun 2-ci maddəsi (Law of the Republic of Azerbaijan on Prevention of Adult and Child Disability, Rehabilitation and Social Protection of Adults and Children with Disabilities), No. 284, 25 August 1992, available at: https://cis-legislation.com/document.fwx?rgn=2873, accessed 22 December 2020.

form of politics, democracy, on the deliberative view, is a framework of social and institutional conditions that facilitates free discussion among equal citizens—by providing favourable conditions for participation, association, and expression' (Cohen 1997, p. 70). In addition, Habermas' theory of communicative action validates the current focus on the deliberative input of CSOs in order to secure PWD rights:

An autonomous basis in civil society, a basis independent of public administration and market-mediated private commerce, is assumed as a precondition for the praxis of civic self-determination. This basis preserves political communication from being swallowed up by the government apparatus or assimilated to market structures. (Habermas 1994, pp. 7–8)

In summary, the history of the post-Soviet states, the policy framework associated with the CRPD and diverse strands of theory all underline the need to examine not only the actions of political elites and state bureaucracies but also the views of civil society organisations.

Methods

The following analysis of policy discourse draws upon the concept of 'frame alignment' (Snow *et al.* 1986). Taken from the social movements literature, this conception emphasises how the chances of successful collaborative policy implementation increase when the frames of key policy actors—such as government and civil society organisations—are aligned (dubbed 'frame resonance'). Frame alignment has two parts—the degree of attention given to individual topics ('issue salience') and the meanings given to these references ('framing').

In methodological terms, the current approach offers a discourse-based technique for studying rights implementation. In furtherance of this, the UN Universal Periodic Review is a singular, rich dataset that advances understanding of the role of civil society as a political space for resistance to oppression and the realisation of PWD rights. Proponents of the UPR argue that it provides the opportunity for each state to outline the actions they have undertaken—and will undertake in the future—in order to promote human rights. It also makes provision for civil society input and allows CSOs to submit written reports to the HRC. The policy guidance is unambiguous: 'The UPR should ensure the participation of all relevant stakeholders, including non-governmental organizations' (OHCHR 2011, p. 7).

The present use of critical discourse analysis is underpinned by diverse strands of social theory, including the interpretive school of policy analysis (Yanow 1999) and social constructivism (Kukla 2000). Both place emphasis on values, beliefs and interpretations germane to a given policy issue (Eden & Ackermann 2004). The epistemological grounding of the present research is standpoint theory, in particular, the notion of 'situated knowledge' (Stoetzler & Yuval-Davis 2002). This states that first-hand accounts, in this case, from organisations representing PWD affected by oppression and discrimination, are a valuable complement to records of jurisprudence and institutional proceedings.

The present method was operationalised by examining issue salience and framing in governments' UPR submissions, as well as a stratified random sample of 166 second-cycle reports by civil society organisations across the CIS, and, for the three case studies, 71 CSO submissions to the third cycle review (circa 2018). In the case of governments'

submissions to the UPR, in each country the ruling administration is allowed to submit one summary report of its actions over the preceding five years. Thus, this study analyses all nine second-cycle government UPR submissions from across the UPR as well as government submissions from the three case studies.

In terms of research practice, first, the corpus of UPR reports was entered into UAM Corpus Tool 3.0 software. Key search terms (inter alia, 'disabled', 'disability', 'blind', 'deaf') were used to identify all sections of the second and third cycle UPR reports relevant to the CRPD. The highlighted text extracts were then coded to reflect 'issue salience' (see Table 3), in other words, the level of attention to policy areas and issues, as well as 'framing' (see Table 2 and the discussion below). A deductive process (Fereday & Muir Cochrane 2006) was used to generate the coding frames for issue salience and framing. The coding involved a detailed reading of the corpus in order to identify key recurrent issues and frames. Subsequently, all text relating to persons with a disability in the corpus was then tagged using the coding frame. During this process a technique from electoral studies was used to control for long, non-discrete sentences that contained multiple policy ideas.⁷ These were subdivided into 'quasi-sentences', defined as 'an argument which is the verbal expression of one political idea or issue' (Volkens 2001, p. 96). The software then allowed the frequency of individual codes in the corpus to be calculated. This revealed the level of attention to (and therefore an indicator of CSOs' prioritisation of) policy topics (law, work/employment, education, public services/welfare, health, social care, poverty/income and transport); as well as frames (inter alia, participation, protection, tackling discrimination, rights, exclusion, justice, support, access and representation). Based on the classic work of Goffman (1974, p. 27), framing is a 'schemata of interpretation'. It analyses the language used by policy actors and informs us about the intrinsic meanings in the text, as well as actors' critical thinking in relation to policy ideas and rights observance. Effectively, it humanises the quantification of attention to policy issues in the corpus by revealing the emotions and meanings associated with the discourse.

In the case of issue salience, the underlying premise for analysing the frequency of references to key issues comes from the literature on political agenda setting (Cobb & Ross 1997). This asserts that the more attention (and thus, higher prioritisation) is given to a topic, the greater the likelihood is that it will translate into action to address issues and shortcomings. In order to uphold rigour in the coding process, the investigator's UAM tags (or codes) were re-checked by a research assistant. In the case of issue salience (N=944) divergent views were held in six cases (<1% of total) which were resolved by discussion between investigator and assistant. In like fashion, four incidences of disagreement arose in the coding associated with framing (N=1,299,<1% of total).

Following established research design principles, region-wide, comparative analysis is first presented in order to gain an aggregate view of state-civil society discourse on CRPD implementation across the CIS. It is followed by three case studies—Azerbaijan,

⁷A worked example: the sentence 'legislative failings have meant that state schooling is still structured around the segregation and institutionalisation of children with disabilities' would be recorded as two quasi-sentences, one under 'law/legislation', the other under 'education'.

⁸See Basedau and Köllner (2007).

TABLE 2 COMPARATIVE FRAMING IN STATE AND CIVIL SOCIETY ORGANISATIONS' UPR DISCOURSE (N=1,299)

	State %	CSO %	State Rank	CSO Rank
Rights	16.6	24.8	2	1
Access/overcome barriers	3	14.9	8	2
Exclusion	9.1	13	5	3
Protection	24.3	10.2	1	4
Anti-discrimination/exploitation	1.1	9.5	11	5
Financial support (non-means-tested and non-contributory) for overcoming barriers to participation	2.1	5.9	10	6
Participation in public decision-making	2.5	4.9	9	7
Needs	16.6	4.2	3	8
'In-kind' support (social model)	2.3	4	7	9
Representation	1.1	3.2	12	10
Independence	0.6	2.5	13	11
Justice	0.3	2.1	14	12
Basic needs income substitution (means-tested and contribution-related)	11.7	0.8	4	13
'In-kind' support (medical model)	8.7	0	6	14

TABLE 3 Comparative Attention to Policy Areas/Issues in State and Civil Society Discourse in the Second Cycle UPR (N=944)

	CSOs %	State %	CSOs Rank	State Rank
Law	26	11	1	5
Work/employment	23	28	2	1
Education	13	11	3	6
Public services/welfare	10	19	4	2
Monitoring, data*	9	3	5	7
Health	9	12	6	4
Social care	7	14	7	3
Poverty/income	2	1	8	8
Transport	2	1	9	9

Note: *Monitoring/data refers to the generic policy issue of the need for: adequate data to underpin effective policy-making and/or appropriate monitoring of policy implementation.

the Russian Federation and Uzbekistan, thus far the only countries to have been subject to third cycle UPR reviews—thus allowing for an initial indication of the extent of progress in CRPD implementation in the CIS over successive UPR cycles.

Study findings: regional analysis

The principal finding that emerges from the following region-wide analysis is the disjuncture between governments' and CSOs' use of language (or policy 'framing') on CRPD implementation (see Table 2). As noted, this matters because it tells us that the key themes and ideas associated with governments' implementation of the CRPD differ from those of civil society organisations representing persons with disabilities in the CIS. The

identification of a disconnect at this point in time is particularly important as the present marks a critical juncture at the beginning of CRPD implementation in the region. For CSOs the lead frame was 'rights', accounting for almost a quarter of quasi-sentences (24.8%, compared to 16.6% in the state discourse). It was followed by 'access/ overcoming barriers' (14.9%) compared to 3% in the state discourse. The CSO discourse gave greater emphasis to a further range of frames that also align with the social model of disability, including: 'anti-discrimination' (CRPD Article 2), 'participation in public decision-making' (Article 1), 'independence' (Article 3), 'financial support for overcoming barriers to participation' (Article 19), 'in-kind' support (social model) and 'representation' (Article 29) (see Table 2). These make up the majority of the CSO discourse (89%), compared to under a half (38.7%) of the state discourse.

In contrast, the state discourse gave greater attention to the 'medical model' frames of 'basic needs income substitution' (means-tested and contribution-related) (11.7%), 'in-kind' support (also medical model) (8.7%), as well as 'protection' and 'needs' (24.3% and 16.6%). 'Medical model' frames 'see the disabled person as the problem ... the focus is usually on the impairment ... with the medical and associated professions' discourse of cures, normalization and science' (Reiser 2006, p. 135).

Textual analysis reveals qualitative differences in the discourse across frames. For example, a significant portion of state language simply enumerates legislative developments associated with the CRPD. Thus the Government of Uzbekistan (2013, p. 3) notes that 'in the period 2009–2012, the legal basis for the enjoyment of social, economic and cultural rights was reinforced significantly. The parliament adopted the ... Charity Act, the Guarantees of Children's Rights Act, a new version of the Social Protection of Persons with Disabilities Act, the Suppression of Trafficking in Persons Act'. In contrast, civil society discourse is critical in nature, pointing to weak enforcement and barriers to accessing justice: 'Most of the rights of persons with disabilities have a declarative nature and are not applied in the Republic of Moldova. There is no mechanism to monitor the exercise of the rights'.

It is also significant to note that, compared to the state discourse, CSOs place double the emphasis on PWDs' participation in public life and decision-making. The following is typical of CSO discourse: 'The law is based on the individual (medical) conception ... it does not address the barriers imposed in society which create obstacles for the full participation and inclusion of persons with disabilities' (UDPO 2012, p. 3). Across the region, civil society discourse underlines the challenge of fostering CSO participation owing to long-established and ingrained social norms and governing traditions, a finding that resonates with Zagirtdinova's account:

There is a more pervasive problem because non-disabled and persons with a disability alike are unused to participating in critical social and political activity in our country. In some senses we are waiting for our foreign friends to help us organize a disability movement. But we know it is

^{9&#}x27;NGO Submission to Third Cycle UPR', Center for Legal Assistance for Persons with Disabilities Moldova, United Nations, New York, 2011, p. 2, available at: https://lib.ohchr.org/HRBodies/UPR/Documents/session12/MD/CLAPD-CenterLegalAssistancePersonsDisabilities-eng.pdf, accessed 19 January 2021.

our own responsibility to do this for ourselves. The current situation of persons with a disability in Uzbekistan is however disheartening and there is a long way to go before people will feel empowered to bring about change. (Zagirtdinova 2005, p. 215)

The analysis also reveals key contrasts in state and civil society framing of financial support. The disability movement regards direct payments for personal assistance as a central tenet of disability rights (personal assistance is included in Article 19 of the CRPD). Thus, compared to the government UPR submissions, civil society discourse places far greater emphasis on 'social model' framing of financial support, in other words, financial transfers that are non-means-tested and non-contributory in nature and designed to overcome barriers to participation, as in direct payments for personal assistance.

A similar division is evident in the framing of 'in-kind' support. The state discourse places greater emphasis on 'medical model' support that tends to segregate and institutionalise disabled people (7.7%), whereas such framing is absent in the CSO discourse. The state discourse is typified by the following claims: 'day-care centres were created, and they are now in operation ... for children with special needs and people with disabilities' (Government of Tajikistan 2011, p. 7); government reforms are 'making it possible for persons with disabilities to receive sanatorium treatment' (Government of the Republic of Kyrgyzstan 2014, p. 15). In contrast, civil society discourse underlines the need for 'social model' financial support that enables equal participation in communities, such as through the provision of assistive technology, or accessible and affordable housing. Thus, for example, the Union of Disabled People's Organisations (UDPO) asked, 'What steps are being taken to ensure that people with disabilities are able to access and afford assistive technologies and devices? ... Although it is mentioned in legislation, there are problems with the provision of hearing disabled people with assistive hearing devices and other technology' (UDPO 2012, p. 11).

The 'anti-discrimination' frame also reveals qualitative differences in government and civil society discourse. The former is often descriptive in nature, listing enactments and institutional matters (for example, 'the constitutional norms guarantee equality and the inadmissibility of discrimination on the grounds of ... disability' (Government of the Republic of Kyrgyzstan 2014, p. 14)), while the latter is critical of the discrimination facing many PWD, as typified by the observation that 'there is no prohibition of discrimination or antidiscrimination legislation regarding persons with disabilities in the Republic of Belarus ... analysis of appeals by PWD to the Office for the Rights of Persons with Disabilities shows numerous cases of direct, indirect, multiple discrimination, denial of reasonable accommodation, victimization and harassment'. However, in terms of timing, it must be noted that, in the wake of this submission there have been some positive anti-discrimination developments in Belarus. For example, in

^{10.} NGO Joint Submission to Third Cycle UPR', prepared by 'GayBelarus' and the Office for the Rights of Persons with Disabilities (disright.org), United Nations, New York, 2014, p. 5, available at: https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=2ahUKEwjs1rmByuLt AhWTShUIHcpuCBMQFjACegQIBRAC&url=https%3A%2F%2Fuprdoc.ohchr.org%2Fuprweb%2Fdown loadfile.aspx%3Ffilename%3D1676%26file%3DEnglishTranslation&usg=AOvVaw0KOKQHM819IGCTR Wgw6R4, accessed 20 January 2021.

2015 new draft laws such as a Bill on Social Security¹¹ have led NGOs to conclude, 'we view in a positive light the inclusion in the Interagency Plan of the provisions on the state cooperation with the civil society organizations for the promotion and protection of human rights'.¹²

Key state–CSO contrasts are also evident in the 'representation' frame (Article 29, 'Participation in political and public life'). Civil society organisations repeatedly underline the importance of 'descriptive representation' (Phillips 1995); in other words, persons with a disability being present as members of decision-making forums, rather than their interests being advanced by others. For example, UDPO asserted:

The level of [government] co-operation with disabled people's organizations [DPOs] is low ... the level of consultation with DPOs regarding projects in the Ministry of Labour and Social Protection towards rehabilitation, social protection and integration into society of persons with disabilities and children with disabilities is insufficient. Organizations of persons with disabilities are not represented in Social Council and in Board of Ministry. (UDPO 2012, p. 8)

In a similar vein, the Center for Legal Assistance for Persons with Disabilities Moldova stated that, 'based on the CRPD, it is necessary to create a national committee involving representatives from civil society, concerned with the problems of people with disabilities, [and] monitoring compliance with the rigors of adjusting the social infrastructure to the needs of persons with disabilities'.¹³

In contrast, the state discourse offers a more sanguine view, emphasising the limited instances of state engagement with civil society. Tellingly, such engagement is restricted to a relatively small number of CSOs favoured by the authorities. For example, 'during the preparation of the UPR report, consultations with NGOs were held... these were attended by senior members of the federal Notary Chamber and Bar Association and representatives of non-commercial organizations such as the All-Russia Society of Persons with a Disability' (Government of the Russian Federation 2013, p. 21).

It is also notable that the state UPR discourse gives limited attention to intersectionality, in other words, the intersection of two or more axes of inequality or discrimination, such as gender and disability, or disability and ethnicity (Crenshaw 2000). This is a violation of Article 5 'Equality and non-discrimination'. Intersectionality is a perspective that acknowledges individuals' multiple, simultaneous identities; its denial risks essentialising PWD as a homogenous grouping. Thus, for example, UDPO questioned:

¹¹Summarised in UNHRC (2015, p. 8, paras 28 and 29).

¹²See, 'Joint Position of Belarusian Human Rights Organizations on Adoption of Interagency Plan of Implementation of Recommendations for Belarus From UN Mechanisms', Belarusian Helsinki Committee, 21 November 2016, available at: https://belhelcom.org/en/news/joint-position-belarusian-human-rights-organizations-adoption-interagency-plan-implementation, accessed 23 December 2019.

^{13&#}x27;NGO Submission to Third Cycle UPR', Center for Legal Assistance for Persons with Disabilities Moldova, United Nations, New York, 2011, p. 3, available at: https://lib.ohchr.org/HRBodies/UPR/Documents/session12/MD/CLAPD-CenterLegalAssistancePersonsDisabilities-eng.pdf, accessed 22 December 2020.

What measures are being taken to ensure that the denial of reasonable accommodation is recognised in the law and draft laws as a form of disability-based discrimination? As well as the incorporation into law of protection against multiple and intersectional discrimination, discrimination by association, and discrimination against persons perceived to have a disability, including effective remedies such as concrete dissuasive sanctions for perpetrators and redress and compensation for victims ...? (UDPO 2012, p. 2)

The analysis also shows that there is a state–civil society 'disconnect' when 'issue salience' is considered (see Table 3). Once again, there is a divide between the medical and the social model. For the new CRPD signatory states, addressing this disconnect constitutes a key challenge.

For civil society organisations, the lead policy areas were law (26%), work/employment (23%), education (13%), public services/welfare (10%) and monitoring/data (9%). In contrast, in the state discourse they were work/employment (28%), public services/welfare (19%), social care (14%) and health (12%). The civil society discourse placed a particular accent on the shortcomings associated with existing legal codes across the CIS, as well as a failure to secure inclusive schooling. For example, in Moldova, 'the law on education lacks any provision on the inclusive education, as well it does not include [in] its "anti-discrimination" provision any mention of the [individual's] physical or mental health status'; '14 'The "defectology" approach generally means physical, social and educational exclusion, as a child's potential is seen as fixed and solely in terms of limitations. Consequently, children with disabilities are considered to be a poor investment in terms of time and money'. 15

On public services, civil society discourse repeatedly criticises the endurance of the medical model approach. For example, 'the majority of people with a mental disability are unemployed and there are no programs to provide coaching and support for them to work in mainstream employment'. Key failings in labour market policies noted in the CSO discourse include weak law enforcement and a lack of monitoring and data with regard to employment of PWD. The former criticism is typified by the observation that while there was a quota for the employment of people with disabilities, it was not filled (UDPO 2012, p. 4). Another CSO, The Coalition of Azerbaijani NGOs, complained that:

Physically disabled people are considered as 'inappropriate for work' for employers.... Not providing such people with employment causes their disintegration from society [sic], marginalization and expose[s] them to discrimination. Despite the existence of legislation it

¹⁴ NGO Submission to Third Cycle UPR', Moldovan NGOs for Child Rights Protection, United Nations, New York, 2012, p. 5, available at: https://www.upr-info.org/sites/default/files/document/moldova_republic_of/session_12_-october_2011/js1-jointsubmission1-eng.pdf, accessed 23 December 2020.

¹⁵NGO Submission to Third Cycle UPR', International Catholic Child Bureau, BICE (Kazakhstan), United Nations, New York, 2014, p. 7, available at: https://bice.org/app/uploads/2014/06/BICE-KENES_UPR Kazakhstan S20 Nov 2014 EN.pdf, accessed 23 December 2020.

¹⁶NGO Submission to Third Cycle UPR', NGO Coalition, 'Perspektiva' Regional NGO of Persons with Disabilities, United Nations, New York, 2013, p. 11, available at: https://www.upr-info.org/sites/default/files/document/russian_federation/session_16_-_april_2013/js6_upr_rus_s16_2013_jointsubmission6_e.pdf, accessed 23 December 2020.

wasn't possible during long years [sic] to hire physically disabled people in accordance with the rules stipulated by the law. ¹⁷

On data-gathering, the CSO discourse is critical of ongoing Article 31 ('Statistics and data collection') violations. For example, 'there is no unified information or database. Disaggregated data on disability is not systematically collected in all sectors including discrimination ... employment, access to justice, political participation, etc. ... DPOs should be involved in and consulted upon the establishment of a unified database' (UDPO 2012, p. 3). A further issue is the disjuncture between political rhetoric and government actions. For example,

state authorities often make statements regarding the necessity to improve employment for PWDs. However, limited measures, if any, are being taken to implement programs to support and promote inclusive employment \dots . The majority of people with a mental disability are unemployed and there are no programs to provide coaching and support for them to work in mainstream employment. (IHRB 2013, p. 5)

The medical–social model divide is evident in the discourse on social care. The civil society submissions repeatedly highlight the endurance of the outdated medical model of the Soviet years. For example, one complained that 'children are placed into institutions of residential care based on the conclusion of [the] psychological–medical–educational commission ... [There is an] urgent need to develop and adopt standards for the provision of social services alternative to residential institutions for children with disabilities'. The CSO accounts also provide evidence of Article 14 ('Liberty and security of person') violations, in other words, the unwarranted institutionalisation of PWD. For example, The Association for the Support of Children with Convulsive Syndrome complained, 'when it comes to the award of the degree of disability diagnosis, this procedure requires the hospitalization of the child with autism ... the child is placed in the room for the most serious mentally ill children, are being tortured by tying bed [sic; that is, being physically restrained, tied to their beds] or worse'. [19]

Emerging evidence from the third-cycle UPR

Attention now turns to three case studies—or territorial policy narratives—covering Azerbaijan, the Russian Federation and Uzbekistan. These studies are based upon discourse analysis of CSO and UN reports and have been selected because, thus far, these

¹⁷'NGO Submission to the Second Cycle UPR', The Coalition of Azerbaijani NGOs, United Nations, New York, 8 October 2012, p. 2, available at: https://lib.ohchr.org/HRBodies/UPR/Documents/Session16/AZ/JS9 UPR AZE S16 2013 JointSubmission9 E.pdf, accessed 22 December 2020.

¹⁸ 'NGO Submission to Third Cycle UPR', Association of NGOs to Protect the Rights and Promote the Interests of Children (Kyrgyzstan), United Nations, New York, 2014, p. 7.

¹⁹'NGO Submission to the Second Cycle UPR', The Association for the Support of Children with Convulsive Syndrome, United Nations, New York, 2012, p. 4, available at: https://www.upr-info.org/sites/default/files/document/moldova_republic_of/session_12_-october_2011/asccs-associationsupportchildren convulsivesyndrome-eng.pdf, accessed 22 December 2020.

are the only countries to have been subject to third cycle UPR reviews, undertaken in 2018. Accordingly, they provide emerging evidence and inform understanding as to whether second cycle CRPD violations had been addressed.

Azerbaijan

Reference to CSO second cycle UPR discourse reveals widespread concern with Article 27 ('Work and employment') breaches and the need to tackle workplace discrimination faced by PWD. For example, from Azerbaijani NGOs for the Universal Periodic Review of Human Rights Situation in Azerbaijan Republic:

[On the subject of] Economic rights of people with disabilities ... the physically disabled people are considered as 'inappropriate for work' for [sic] [by] employers. Hiring these people and creating conditions of privileged labour for them [that is, quotas] are not included in the plans of any employer Not providing such people with employment causes their disintegration [sic], in other words exclusion from society, marginalization and expose[s] them to discrimination. 20

Analysis of third cycle submissions reveals a striking lack of progress on the issue. For example, one strand of CSO discourse highlights discrimination preventing PWD from entering the legal profession. This has prompted the UN to highlight that 'Azerbaijan has not yet established the requirement that employers should make reasonable accommodation for persons with disabilities ... there is no legislation explicitly protecting persons with disabilities from discrimination in training' (UNHRC 2018b, p. 4).

A further key aspect of the CSO discourse concerns Article 3 violations ('full and effective participation and inclusion in society'), as demonstrated by the complaints of the Election Monitoring and Democracy Studies Centre, Human Rights Club, Legal Education Society and Human Rights House Foundation:

Despite many statements by government to ensure equal participation of all groups of population [sic], including ... people with disabilities, minorities in political and public life, Azerbaijan needs to redouble its efforts to eliminate the role stereotypes and prejudices not only through awareness-raising campaigns but also through adoption of proper mechanisms such as temporary quota schemes and rules in certain sectors.²¹

Echoing the civil society discourse, a 2014 UN report pointed to ongoing rights violations arising from shortcomings in the domestic legal code and public policy framework. The UN concluded that, 'the State party's legislation and policies still refer to the Medical

²⁰'NGO Submission to Second Cycle UPR', Azerbaijani NGOs for the Universal Periodic Review of Human Rights Situation in Azerbaijan Republic, United Nations, New York, 2012, p. 5.

²¹'NGO Submission to Third Cycle UPR', Election Monitoring and Democracy Studies Centre, Human Rights Club, Legal Education Society and Human Rights House Foundation, United Nations, New York, 2018, p. 6.

Model of disability' (UN CRPD 2014, p. 3). Allied to this, labelling theory reveals how language reinforces discrimination and oppression faced by PWD (Fitch 2002). This issue is particularly salient in Azerbaijan where, as noted by the UN, 'there is a need for legislative harmonization and the revision of the nomenclature which the State party uses to refer to persons with disabilities, in order to prevent derogatory language' (UN CRPD 2014, p. 3). CSO third cycle discourse echoes this and calls for more work to be done in relation to Article 8 ('Awareness-raising') in order to tackle discrimination, defined as 'persistent negative stereotypes and prejudices against persons with disabilities, which negatively affect their ability to enjoy rights on an equal basis with others' (UN CRPD 2014, p. 3). Specific initiatives called for include training for government officials, health, legal, educational and social work professionals, the judiciary, police, elections officers, and media practitioners.

A further trope in the discourse centred on Article 31 ('Statistics and data collection') violations. As the UN put it, there is a 'lack of data on the number of children born with disabilities who are affected by the State party's high rate of infant mortality, particularly at how this state of affairs is affecting the birth registration of boys and girls with disabilities' (UN CRPD 2014, p. 7).

The Russian Federation

Following second cycle UPR UN recommendations made in 2013 on tackling Article 5 ('Equality and non-discrimination') violations against PWD, Russia noted that it would 'take further measures to strengthen the mechanisms for the protection of social rights, in particular rights of ... persons with disabilities' (UN 2013, Recommendation 140.199). However, the present analysis of third cycle submissions reveals little progress. A key trope in the CSO discourse centres on shortcomings in the domestic legal code. Thus, for example, attention centres on the widespread denial of reasonable accommodation to PWD, a CRPD violation that is not explicitly recognised as an act of prohibited discrimination in Russian law. The UN Committee on the Rights of Persons with Disabilities has also condemned this issue:

While noting the 2014 Federal Law 419 on the rights of persons with disabilities, the Committee is concerned about insufficient efforts to harmonize legislation on persons with disabilities with the Convention and the lack of mechanisms for the implementation of the existing legislation. (UN CRPD 2018, p. 2, para. 9)

In their third cycle discourse, CSOs also complain of Article 13 ('Access to justice') violations, as captured in the following: 'The State party has not formulated policies to empower persons with disabilities to be part of the justice system as direct or indirect participants, such as lawyers, court officers and law enforcement officials' (UN CRPD 2018, p. 4).

On other matters, Article 24 ('Education') asserts that, 'States Parties shall ensure an inclusive education system at all levels'. According to the Russian Federation's submission to the UPR, 'general education, vocational training and professional instruction are delivered to persons with disabilities on the basis of inclusiveness, in

accordance with appropriate educational curricula and individual programmes for the habilitation²² or rehabilitation of persons with disabilities' (Government of the Russian Federation 2017, p. 8, para. 4). However, CSO third cycle civil society discourse reveals ongoing Article 24 violations, including the serious obstacles faced by disabled people in accessing education. In pre-school and compulsory-phase education, the conditions for inclusion of disabled children and those with specific health-related requirements are not met. There are cases of institutions' refusal to enrol disabled people at university and post-university level, even at medical universities. Thus, the common practice of excluding persons with a disability endures to the present day.²³

Existing research (Boberiene & Yazykova 2014) underlines the Russian authorities' continued use of outdated medical model practices, notably with the widespread institutionalisation of PWD. It is an issue repeatedly highlighted in the discourse. For example, Human Rights Watch complained:

Hundreds of thousands of adults and children with disabilities currently live in closed institutions. Many parents are misinformed about their children's disability, and state officials often recommend sending children with disabilities to institutions from a very young age. Reports of serious physical and emotional abuse against children and adults with disabilities in state institutions persist ... many children face physical and psychological violence and neglect and are denied adequate healthcare, education, and play. (HRW 2018, p. 4)

Allied to this, third cycle discourse details the problem of sexual exploitation of children (SEC) in the Russian Federation. One CSO submission reveals how, 'the vulnerability to fall victim to SEC varies, with some discernible groups being most at risk, particularly ... children living in institutions (60,162 children by the end of 2015)'; the submission highlighted that children with learning disabilities were particularly at risk.²⁴

Over recent years, Russian civil society has become increasingly constrained owing to political management by the state (Flikke 2016). This is symbolised by the 2012 enactment of Law No. 121-FZ, popularly dubbed the 'Foreign Agent Law', ²⁵ designed to restrict the activity of non-governmental organisations in receipt of foreign funding who

²²Article 24 of the Convention on the Rights of Persons with a Disability refers to 'Habilitation and Rehabilitation'—where habilitation refers to a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational and speechlanguage therapy, various treatments related to pain management, and audiology and other services that are offered in both hospital and outpatient locations.

²³See, for example, 'NGO Submission to Third Cycle UPR', Anti-Discrimination Center 'Memorial' and Russian LGBT Network, United Nations, New York, 2017, p. 6, para. 25, available at: https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiv2rvW3uLtAhUeaRUIHWTKB4UQFj ABegQIAxAC&url=https%3A%2F%2Fuprdoc.ohchr.org%2Fuprweb%2Fdownloadfile.aspx%3Ffilename% 3D5203%26file%3DEnglishTranslation&usg=AOvVaw2dljLqO4-KcF6JDaGOEJPQ, accessed 23 December 2020.

²⁴·NGO Submission to Third Cycle UPR', Russian Alliance against CSEC and ECPAT International, United Nations, New York, 2017, p. 2, para. 5, available at: https://www.ecpat.org/wp-content/uploads/2018/07/Universal-Periodical-Review-on-Sexual-Exploitation-of-Children-Russia.pdf, accessed 22 December 2020.

²⁵·Lukin pozhalovalsya v Konstitutsionnyi sud na zakon ob NKO', *BBC Russian Service*, 7 February 2013, available at: http://refugee.ru/news/my-ne-agenty-odinnadtsat-nko-napravili-zhalobu-v-evropejskij-sud-popravam-cheloveka-na-zakon-ob-inostrannyh-agentah/, accessed 7 August 2019.

allegedly engage in (legally undefined) 'political activities'. The law requires them to register with the government as 'foreign agents' and is widely seen as a pretext for state harassment and oppression. As Crotty (2009, p. 102) observes, 'in the future, groups will have to contend with Putin's NGO law and its restrictions and ramifications, in combination with the growing number of Marionette Organisations²⁶ dominating Russia's civil space', leading to what has been called a "nationalisation" of Russian civil society'. Against this backdrop, as part of the third cycle assessment, the UN has underlined its 'concern [about] insufficiently transparent and comprehensive framework for ensuring full and effective consultation with representative organizations of persons with disabilities in adoption, implementation and monitoring of legislation and policies pertaining to the rights of persons with disabilities' (UN CRPD 2018, p. 2, para. 11).

The latter viewpoint is echoed in the CSO discourse, here, in a report by Human Rights Watch:

Among the consequences of the 'foreign agent' designation is a significant loss of capacity and effectiveness: government institutions and public officials refuse to cooperate with 'foreign agents', municipalities terminate discounted rent agreements, and the promotion of reports and events is increasingly difficult. Consequences also include hindered access to people with disabilities in institutions who can be accessed only with cooperation from public officials; significant time wasted in court proceedings; intrusive inspections and audits which paralyze NGOs' work; more time-consuming, cumbersome reporting; and hefty fines for alleged failure to comply with the law's requirements, such as marking 'foreign agent' on all publications and event announcements. (HRW 2018, p. 3)

This raises the question of how state repression affects CSO discourse on human rights. Here Otterlei's research suggests that it may be the cause of greater civil society criticism of government failure to uphold international rights obligations such as the CRPD:

NGOs that front issues that for various reasons do not resonate well with the general Russian public [such as human rights] may paradoxically enough benefit when responding to restrictions that target the organizational structure of NGOs. As they have less of a good reputation to maintain to begin with, they can afford to care less about being delegitimized [that is, by the Russian state]—it is less costly for them as they already have a low level of trust in the public ... they therefore allow themselves to experiment more with alternative ways of structuring, such as working without a legal entity [sic] and finding creative ways to keep accessing foreign funding. (Otterlei 2018, p. 86)

It is also the case that state repression of civil society does not directly affect CSO input to the UPR as it is an international process, beyond the Kremlin's control. However, for some CSOs the foreign agent law has curtailed international funding sources. The wider impact has been to reduce the pool of Russia-based CSOs able and willing to submit reports to

²⁶Defined as CSOs 'closely linked to the operations of the state ... usually endowed with office space and other resources either directly or indirectly by the state. Membership ... was usually drawn from the ranking official's circle of associates. ... The primary aim ... was to support the state in its activities, but they were also recognised as official NGOs and represented civil society organisations in this capacity' (Crotty 2009, pp. 91–2).

the UPR. It also raises the prospect of future government reprisals against CSOs that have given critical assessments of state practices to the UN *via* the UPR.

The foregoing concerns also link to ongoing breaches in Article 3 ('Full and effective participation and inclusion in society ...'). Thus, on participation in political and public life, the UN concluded that 'the State Party does not have a comprehensive and binding legislation guaranteeing the exercise of electoral rights of persons with disabilities'. The report goes on to emphasise that more needed to be done to address the denial of 'participation in cultural life, recreation, leisure and sport' (UN CRPD 2018, p. 4, para. 30). As Nosenko-Stein's account underlines, such factors mean that, 'avoidance is a typical reaction to disabled people in post-Soviet Russia. As we can see, these attitudes impact the self-perception and self-representation of disabled people and impede their successful integration' (Nosenko-Stein 2017, p. 168).

Uzbekistan

Writing back in 2005, Zagirtdinova asked, 'when will the social model of disability arrive?' (Zagirtdinova 2005). The third cycle CSO discourse reveals limited progress in this regard and underlines the endurance of CRPD violations. Key tropes in the third cycle discourse include shortcomings in the legal rights of disabled people and their ability to secure redress in the courts. This has prompted the UN to assert that the Uzbek government must 'finalize the elaboration of and adopt a bill on the rights of persons with disabilities that takes into account the provisions of the Convention on the Rights of Persons with Disabilities' (UNHRC 2019, p. 26). With regard to Article 13 ('Access to justice') and Article 6 ('Women with disabilities') rights, major challenges remain. As the International Commission of Jurists (ICJ 2018, p. 2) explained: 'Access to justice, which includes a fair trial and equality before the law, is of particular importance for people living with a disability, who often face inter-sectional and multiple barriers to access justice'. This is because inclusive societies in which all individuals have equal access to justice, require identifying and overcoming systemic and practical barriers that hamper equal access to justice, including in enjoyment of economic, social and cultural rights.

As in the case of the Russian Federation, the persistence of the medical model of disability and authorities' institutionalised approach to disabled children is a key issue in the CSO discourse. As of 2013, Uzbekistan had 12 state-run children's homes. As the United Nations observed, 'the vast majority of the approximately 40,000 children living in [these] institutions are children with disabilities, which strongly indicates that there are inadequate support measures for children with disabilities to live with their families... social and other family support services in general also remain inadequate' (UN CRC 2013, p. 9).

Widespread failings in social welfare provision for PWD are also detailed in the third cycle review discourse. A key issue is widespread social prejudice and stigma against children with disabilities. This is compounded by a lack of disaggregated data, which

²⁷ NGO Submission to Third Cycle UPR', International Commission of Jurists, United Nations, New York, 2018, p. 2, available at: https://www.icj.org/icj-submission-on-universal-periodic-review-of-uzbekistan/, accessed 22 December 2020.

hampers the development of adequate policies to promote equal participation in society. A further issue is the absence of a legal definition of 'inclusive' education and barriers facing children with disabilities.

Article 27 ('Work and employment') breaches are a further key strand in the CSO discourse, typified by the following observation: 'The employment rate among persons with disabilities is very low, despite the measures taken to stimulate their employment, and physical barriers may obstruct their access to social services, the labour market and education'. The report goes on to emphasise that measures must be taken 'to ensure that persons with disabilities enjoy unhindered access to all social services, including schools and employment' (UN CESCR 2014, p. 8).

A further core issue is Uzbekistan's failure to ratify the CRPD. In 2014 this prompted the UN to call for this to be rectified 'as a matter of priority' (UN CESCR 2014, p. 4). In 2019 the UN again repeated this demand (UNHRC 2019, Recommendation 101.2). The third cycle recommendations also call for an end to Article 37 ('Cooperation between States Parties and the UN Human Rights Committee') violations. Inter alia, this asserts that, 'civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the [UPR] monitoring process'. However, the reality is that the Uzbek government has failed to fully engage other parties in fulfilling its CRPD obligations, leading the UN to assert that government must 'continue dialogue with civil society in order to improve the human rights situation, including that of ... persons with disabilities' (UNHRC 2019, Recommendation 101.28). For its part, in 2018 the Uzbek government claimed that it had 'stepped up its efforts to prepare for the ratification of the United Nations Convention on the Rights of Persons with Disabilities' and that preparation had begun on a draft law 'on the rights of persons with disabilities, taking into consideration all provisions of the Convention, and a programme was adopted in 2017 outlining integrated measures for the further improvement of the support system for persons with disabilities and a strengthening of their rights and freedoms' (Government of Uzbekistan 2018, p. 2, para. 4).

As in Azerbaijan and the Russian Federation, a further trope in the CSO third cycle submissions relates to Article 33 ('National implementation and monitoring') violations, and the intimidation of human rights defenders and government restrictions on civil society.²⁸ It is typified by the following observation, 'one of the most alarming human rights issues in Uzbekistan is the continued persecution of human rights activists. The Uzbek government frequently subjects human rights activists to harassment, intimidation, and violence'.²⁹ In its UPR submission, the government refuted such allegations. Instead, it spoke of its favourable treatment of disabled people's CSOs. For example, on the subject of freedom of association it asserted that significant steps have been taken to liberalise the legislation on NGOs. Artificial barriers hampering their work have been

²⁸For example, 'Uzbekistan: Tentacles of mass surveillance spread across borders', Amnesty International, 31 March 2017, available at: https://www.amnesty.org/en/latest/news/2017/03/uzbekistantentacles-of-mass-surveillance-spread-across-borders/, accessed 7 September 2019.

²⁹ NGO Submission to the Third Cycle UPR', Freedom Now, United Nations, New York, 2017, p. 2, para. 6, available at: https://lib.ohchr.org/HRBodies/UPR/Documents/Session16/UZ/FREEDOMNOW_UPR_UZB S16 2013 FreedomNow E.pdf, accessed 22 December 2020.

removed, thus promoting interaction between state and civil society in addressing important problems such as the registration of NGOs of persons with disabilities, who are taxed at 50% of the normal rate (Government of Uzbekistan 2018, p. 14, para. 66).

Overall, the latest UPR cycle raises core concerns about Uzbekistan's lack of progress since 2013, when the UN called on the government to 'adopt a social model approach that is in accordance with Article 23 of the CRPD and other international standards' and to 'address attitudinal and environmental barriers that hinder the full and effective participation of PWD' (UN CRC 2013, p. 15). In the face of ongoing CRPD violations, the UN's third cycle report again called on the Uzbek government to 'continue to improve the support system for persons with disabilities and to strengthen their rights and freedoms' (UN 2019, p. 29, Recommendation 101.199).

While across the CIS, the overwhelming majority of civil society discourse was critical of state failings, it should be noted that the UPR corpus did contain some exceptions, when CSOs highlighted areas of progress. Notable examples include the updating of the domestic legal code in Azerbaijan. Thus, according to the UDPO, 'during the reporting period significant improvements have been tracked towards solution of problems of PWD. Such improvements are mainly related to the legislation' (UDPO 2012, p. 19). Specifically, this refers to the 1992 Law on 'Prevention of Disabilities and Impaired Health of Children and Rehabilitation and Social Protection of the Persons with Disabilities and Persons with Health Problems', which was revised to make it compliant with the CRPD. As part of the reforms, the State Ombudsman Office assumed responsibility for making all national legislation compliant and promoting cooperation with civil society (UDPO 2012, p. 19). Following the second cycle UPR, the CSO discourse also commended a more strategic approach taken to public policy for PWD in Kazakhstan, where the government established the '2012-2018 plan of action to promote the rights and quality of life of persons with disabilities' (Council of Europe 2018). In Moldova, the CSO discourse underlined how the ratification of the CRPD 'has come to improve national policies for people with disabilities by opening many opportunities to benefit from international cooperation and funding in this area' and 'by mobilizing all relevant actors in society'.30

Conclusion

Governments' (often belated) ratification of the CRPD means that the present marks a critical juncture for PWD rights in the Commonwealth of Independent States.³¹ It also prompts the question as to whether CRPD ratification constitutes real progress or is little more than an exercise in symbolic politics on the part of state elites. As the foregoing

³⁰NGO Submission to Third Cycle UPR', Center for Legal Assistance for Persons with Disabilities Moldova, United Nations, New York, 2011, p. 17, available at: https://lib.ohchr.org/HRBodies/UPR/Documents/session12/MD/CLAPD-CenterLegalAssistancePersonsDisabilities-eng.pdf, accessed 22 December 2020.

³¹As noted, at the time of writing in September 2019, Uzbekistan had yet to ratify the CRPD (see, United Nations Treaty Body Database, United Nations Office of the High Commissioner for Human Rights, available at: https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=189&Lang=EN, accessed 23 December 2020).

analysis underlines, civil society holds the key to this question. Civil society's pivotal role is not only because a participatory approach is required by the CRPD (Article 33), but also because, as social theory predicts, without full civil society participation, including a critical role in holding governments to account, there cannot be effective implementation of PWD rights. Not only does knowledge exchange with civil society help politicians formulate complex policy, it also strengthens 'input legitimacy'—in other words, it fosters policy founded in democratic engagement and exchange of ideas and evidence, rather than the top-down imposition of policy by governing elites in which citizens have little say. In turn, the likelihood of effective rights outcomes is enhanced through the pursuit of shared goals.

Accordingly, this study makes an original contribution by presenting new data on territorial rights implementation across the CIS. It is true that, because many member countries have only recently ratified the Convention, it is too soon to expect rapid progress. However, the ongoing rights violations revealed in the foregoing analysis constitute real challenges owing to their systemic nature. Crucially, they relate to the public policy-making process itself. Notwithstanding governments' espousal of NGOs' participation in policy-making, current CRPD implementation often falls short of full and effective engagement with civil society. As long as this remains unaddressed, it is likely that persons with disabilities will continue to experience barriers to shaping policy and accessing welfare as political elites cling to top-down governing styles and outdated medical conceptions of disability. In short, the present study identifies a 'disconnect' between state and civil spheres that is hampering effective CRPD implementation based on partnership working and knowledge exchange.

The present study also reveals how CRPD violations play out at a regional and, in the case of the three case studies, a country level. In the former case, states' greater emphasis on frames such as 'help', 'protection' and 'needs', as well as policy areas such as health and social care, point to the endurance of the medical model of disability across the CIS. In contrast, in its critical pressure for reform, civil society discourse places greater accent on frames that resonate with the social model, including 'rights', 'independence', 'participation', 'representation' and 'overcoming barriers'. These frames comprise the majority of the civil society discourse, compared to a minority of the state discourse. While the social model is not without its critics (Owens 2015), it does constitute a valuable conceptualisation, not least because it continues to inform the UN's human rights approach³² and is endorsed by disabled people's movements around the globe (Tsai et al. 2010; Fontes 2014; You & Hwang 2018).

All of this underlines the need for further transformation of governance practices across the CIS. *Inter alia*, this means a strengthening of the capacity of CSOs representing PWDs and the end to legal restrictions and government repression of civil society. It also signals the need for stronger international monitoring and enforcement of CRPD rights, accompanied by an improvement in equalities data-gathering. To

³² The Convention's preamble states that disability is an evolving concept. Nevertheless, it does reflect a social model of disability as it clarifies that disability results from the interaction between persons with impairments and external barriers that hinders their participation in society' (OHCHR 2014, p. 17).

reiterate, away from the political rhetoric of state submissions to the UPR, an essential factor determining the rate of future progress is the extent to which CIS governments embrace engagement with civil society. As Tudoroiu cogently observes, 'the difficult situation of the non-governmental organizations is paralleled by low levels of civic engagement, trust, and tolerance. ... Genuine democratization cannot take place as long as the structural factors that have prevented it for two decades remain unchanged' (Tudoroiu 2011, pp. 251–52).

As a benchmark study, the current analysis highlights a number of avenues for future research. These include discourse analysis of civil society's role in PWD rights implementation in other regions, thereby providing comparators to developments in the CIS. Another area of future work is to develop qualitative political actor accounts of the way that civil society mobilisation is shaped by contextual factors, such as regime type, the nature of the economy, the role of capitalism in the realisation and/or frustration of PWD rights, and the role of social attitudes, intersectionality, norms and issues of cultural diversity. Whether such future research reveals the success or failure of policies designed to implement CRPD obligations will, to a large degree, depend upon the extent to which governments address the issues of civil society engagement, frame dissonance and legitimation identified here. In this regard, the enduring problems in relation to contemporary CRPD implementation in the CIS do not augur well.

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