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eprints@whiterose.ac.uk https://eprints.whiterose.ac.uk/ Disabling legal barriers Oliver Lewis¹

Abstract

In dictatorships as well as democracies, throughout history and today too, the world is awash with laws that promulgate rather than penalise prejudice. This article is a reflection on fifteen years of human rights litigation and advocacy focused on improving the lives of people with mental health issues and intellectual disabilities in Central and Eastern Europe. The article provides two examples of case-work – Shtukaturov and Stanev – which have had n wider impact than just the lives of the individual applicants and illustrates how creative lawyering can contribute to advancing social justice. The article offers a personal reflection about what it means to work alongside activists striving to give voice to people whom the law has rendered invalid. Like many other marginalised people, children and adults with labels of mental health issues or disabilities face abuse in every-day life, partly as a result of discrimination embedded in law. Normalisation of discrimination nudges the public to welcome segregation and ill-treatment rather than accept difference and celebrate diversity.

Introduction

In July 1942 in Nagpur, a group of people held a meeting called the "All-India Depressed Classes Conference" to create an India-wide lobbying group on Dalit rights. In a speech to the conference, the jurist Bhimrao Ramji Ambedkar urged delegates to,

"[...] educate, agitate and organize; have faith in yourself. With justice on our side, I do not see how we can lose our battle. The battle to me is a matter of joy. The battle is in the fullest sense spiritual. There is nothing material or social in it. For ours is a battle, not for wealth or for power. It is a battle for freedom. It is a battle for the reclamation of human personality".²

Ambedkar cajoled the delegates to take action to reverse the injustices faced by Dalits, the "untouchables", who faced – and still face – widespread discrimination in all areas of life. A Dalit himself, he went on to chair the drafting group of the first Constitution of India in 1950, the same year as the European Convention on Human Rights was adopted.

The struggle for social justice is filled with anguish – of the victims of human rights violations as well as those that seek to defend their rights – a theme to which this article returns. Alongside anguish, the article is about two other things as well. Activism: how lawyers in particular, but others too, can use their knowledge and power to engage in the struggle for universal human rights. And argument: how ideas are advanced and battles won through critical conversations, robust disagreement, deployment of norms, evidence and emotion.

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² D. Keer, Dr. Ambedkar, Life and Mission (Bombay, Popular Prakashan, 3rd ed., 1971), p. 351.

"Barely out of bed"

Modern human rights activism started in the 1970s and I was born in the middle of that decade, fifteen days before the European Commission of Human Rights accepted the case of Winterwerp v the Netherlands, which was to become the first mental health case at Strasbourg. The barrister Oliver Throrold at Doughty Street Chambers took Ashingdane³ in the 1980s and Johnson⁴ in the 1990s against the UK, and few cases emanated from other countries. Sir Nicolas Bratza – the former UK judge at the European Court of Human Rights – noted ten years ago that, "the jurisprudence of the Court in the succeeding twenty years [since Winterwerp] is notable for the almost complete dearth of judicial decisions in this vitally important area." He explained this as, "a reflection not of adequate safeguarding by member States of the Convention rights of those with mental disabilities but rather of the acute practical and legal difficulties faced by an especially vulnerable group of persons in asserting those rights and in bringing claims before both the domestic courts and the European Court."⁵

Activists in the United States were more litigious, but even cases by the prestigious Bazelon Center for Mental Health Law in Washington DC, while making considerable advances to domestic law, neither drew from nor contributed to the development of international human rights law. It has only been since the turn of this century that mental health, disability and international human rights law have come together in any serious way, and the vast majority of the regional cases have been in Europe.⁶

Against this backdrop it seems odd that the human rights project is under assault by scholars who characterise it as an endgame, or in its twilight.⁷ At a health and human rights conference Professor Paul Hunt (the former UN Special Rapporteur on the Right to Health), retorted to these critiques: "Twilight? Dawn has just broken and we're barely out of bed." ⁸

We are indeed in the opening movement of this subject's intellectual and operational symphony, yet there have already been significant advances. The adoption in 2006 of the UN Convention on the Rights of Persons with Disabilities (the "CRPD") is clearly one. People with disabilities and their representative organisations called for the treaty and took an active role in drafting and negotiating it. The focus of this paper, however, is the boutique body of case-law that exists in large measure thanks to a programme of sustained innovation by human rights litigators, many of whom I have worked with over the last fifteen years. This article derives from an inaugural lecture dedicated to these lawyers with humility and huge gratitude.⁹

³ Ashingdane v UK (1985) 7 E.H.R.R. 528.

⁴ Johnson v UK (1999) 27 E.H.R.R. 296.

⁵ Foreword by Sir Nicholas Bratza, in P. Bartlett P, O. Lewis and O. Thorold, Mental Disability and the European Convention on Human Rights (Martinus Nijhoff Publishing, The Netherlands, 2007).

⁶ An exception of note is the African Commission on Human and Peoples' Rights case of Purohit and Moore v. The Gambia, Communication No. 241/2001, Sixteenth Activity report 2002-2003, Annex VII.

⁷ See S. Hopgood, Endtimes of Human Rights, (Cornell, Cornell University Press, 2013); and E. Posner, Twilight of Human Rights Law (Oxford, OUP, 2013).

⁸ Yeoh Tiong Lay Centre for Politics, Philosophy & Law inaugural "Law and Justice Forum: Human Rights and Development", Friday 28 October 2016.

⁹ Steven Allen, Gauthier de Beco, Dmitri Bartenev, Paul Bowen QC, Steve Broach, Barbara Bukovska, Jude Bunting, Ann Campbell, Zuzana Candigliota, Robert Cholensky, Bruce Chooma, Monika Chromeckova, Luke Clements, Zuzana Durajova, Sarka Duskova, Viktor Ewerling, Jan Fiala, Caoilfhionn Gallagher, Aneta Genova, Oana Girlescu, Yonko Grozev, Aleksandra Ivankovic, Sanja Jablanovic, David Kabanda, Felicity Kalunga, Allana Kembabaz, Zuzanna Kovalova, Victoria Lee, Fred Manyindo, Yuri Marchenko, Maros Matiasko,

Framing social issues as rights claims

The NGO Mental Disability Advocacy Centre (MDAC) was founded by George Soros's Open Society Foundations (then Institute) to disrupt a system of disability segregation. Its first headquarters opened in Estonia in the spring of 2001 while I was pupil barrister in London. By some fluke I became the organisation's first legal director and moved to Tallinn. Soon afterwards I visited my first social care institution, in the town of Valkla, half an hour's drive east of the capital. We were greeted by the director, a psychology student who was a former Estonian Air flight attendant, brought in following a scandal with the previous director. Her predecessor had presided over an institution that the European Committee for the Prevention of Torture (CPT) found was, "pervaded by a pernicious culture of violence, where discipline and control were entrusted to staff having no specialised training, who in turn delegated many of the more challenging tasks (e.g. working with agitated or disturbed patients) to other patients".¹⁰

Valkla was a taster of how victims of human rights violations were used as political pawns. The CPT had sent its report on Valkla and other places of detention to the Estonian government in 1997 but the government authorised publication only in late 2002, just over a year before Estonia acceded to the European Union, cleverly denying the public the opportunity to leverage change out of the system in those precious pre-accession years.

By the time of my visit, there may have been less violence but there was no shortage of neglect and abuse. Valkla's buildings, reeking of urine and detergent, housed 300 people who slept in bedrooms with up to ten others, beds tightly packed together. Residents wore multiple layers of old clothes as it was cold inside and sub-zero outside. The clothes were shared, as were the bars of soap and toothbrushes. Residents were allowed to wash once a week in a communal room. To enter the dining room residents had to pass a nurse and swallow a pill before getting food, making survival contingent on compliance with medication: a Foucauldian field trip. Slop was served, as residents had no teeth. A locked seclusion room contained a highly sedated person. A group of around twenty men with intellectual disabilities were locked together in a room with green walls and wooden benches and nothing else. A resident told us in fluent English how he had been placed in the institution several years ago because of a family dispute. I remember him saying that he appreciated he had somewhere to live but did not want to live there.

The institution was clearly horrible but what was less clear was how any of it related to international human rights law. In early 2002 MDAC and I relocated to Budapest and I spent that year visiting each of the eight eastern European countries which acceded to the EU in 2004 as well as Bulgaria and Romania which acceded in 2007.¹¹ In each country, I spent two days conducting site visits to social care institutions, hospitals, children's homes and prisons,

Barbara Méhes, Sophy Miles, Rowena Moffatt, Eddy Musimami, Lycette Nelson, Jesse Nicholls, Chipo Nkhata, Patricia Odong, Louise Price, Annabel Raw, Ion Schidu, Andrea Spitalszky, Doina Straisteanu, Patrick Vandenalotte, Wamundila Waliuya, David Zahumensky, James Zeere.

¹⁰ European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, "Report to the Estonian Government on the visit to Estonia from 15 to 21 December 1999", Strasbourg, 30 October 2002, CPT/Inf (2002) 28.

¹¹ O. Lewis, "Mental Disability Law in Central and Eastern Europe: Paper, Practice, Promise", (2002) 8 Journal of Mental Health Law 293, re-printed in J. Peay (ed) Seminal Issues in Mental Health Law (Ashgate Publishing, London, 2005).

and spoke to as many civil society and governmental people as I could. Oliver Thorold and I wrote a short training pack on the ECHR and mental disability which was translated to the relevant languages and guided two-day training seminars we delivered for lawyers and activists. In many of the countries ours were first public events that brought a rights-based perspective to mental health and disability.

Through the lens of the European Convention on Human Rights (ECHR), the rights to life, liberty, ill-treatment, privacy, fair trial, property, assembly and expression, and of course intimate rights like sexual and reproductive health and marriage were all engaged. Beyond the ECHR, violations of the economic and social rights of housing, health (including but not only mental health), social welfare and education were on clear display. In addition to the ECHR there were a couple of little-known UN documents: a 1971 text on mental retardation and a 1991 on mental illness,¹² and a more promising Council of Europe recommendation on incapable adults from 1999.¹³ But the titles spoke for themselves, and despite some strong rights rhetoric, these texts were focused on removing rights rather than repatriating them.

Standing back from the sea of individual rights, what we could see, and what we still see today across Europe, are the three interlocking systems of mental health, social care and guardianship. This last topic of guardianship is now called "legal capacity" in the international legal discourse, a system in which important decisions like where to live and what sort of healthcare interventions to have are made by someone else. This was an area of law altogether hidden from the purview of human rights. Guardianship was the slip-road into segregation, so we went after it as a strategic priority.

From Alsatian dog to the Alsace - Shtukaturov v Russia

Pavel Shtukaturov was a 24-year old man with a diagnosis of schizophrenia who lived with his mother in St. Petersburg, Russia. At home one day, he found a piece of paper, a court order, dated the previous year placing him under the guardianship of his mother. It was the first he had heard about it. He searched for help on the internet and found Dmitri Bartenev, a lawyer in St Petersburg who works with MDAC. Dmitri met with Pavel and agreed to represent him to restore his legal capacity. They signed a power of attorney.

A couple of weeks later Pavel called Dmitri. He had been taken into Psychiatric Hospital No. 6 in St. Petersburg, and had used the phone of another patient's relative to make a snatched phone call asking Dmitri to get him out. I happened to be in St. Petersburg and late one afternoon went with Dmitri during one of his multiple unsuccessful attempts to meet Pavel. It was cold and dark and the hospital's mortuary was signposted on the ground floor where the security guard's Alsatian dog roamed free. We went up to the second floor where Pavel was detained, and at the door was opened by the charge nurse. She told us that no visitors were allowed. "I'm not a visitor, I'm his lawyer", Dmitri said. "He can't have a lawyer because he's under guardianship. Speak to his mother" the nurse replied. The law was that a guardian could authorise so-called "voluntary" detention and treatment, bypassing the legal process

¹² "Declaration on the Rights of Mentally Retarded Persons" General Assembly resolution 2856 (XXVI) of 20 December 1971, 46/119; "The protection of persons with mental illness and the improvement of mental health care" 17 December 1991, A/RES/46/119.

¹³ Committee of Ministers, "Recommendation to Member States on principles concerning the legal protection of incapable adults" Rec No. R(1999)4, 23 February 1999.

that provided checks and balances like a court review. It was a legal fiction and would have made a cracking Kafka storyline.

But however absurd it looked from the outside, we knew that Pavel was being forcibly medicated behind the door. The authorities had effectively blocked access between lawyer and client, so we asked the European Court of Human Rights to grant interim relief, which it did, faxing an order to the now infuriated Russian authorities, ordering them to let Dmitri speak to Pavel in private. The hospital failed to comply, and Dmitri was kept out. The St Petersburg bar council threatened to disbar Dmitri for so binging disrepute to the integrity of mother Russia's mental health system. We ploughed on, winning the case in Strasbourg some months later.¹⁴

This was the Court's first significant guardianship case. It ruled that system amounted to a "very serious" interference with Pavel's right to private life under art.8 of the ECHR, admonishing the law that allowed person A to authorise the detention and forced psychiatric treatment of person B against B's will. We litigated this point at the Russian Constitutional Court which went on to quash three areas of law, including the permissibility of a guardian to authorise detention.¹⁵ This was the first higher court legal capacity judgment in the former Soviet Union. Through a combination of international and domestic strategic litigation the law was reformed.

Soon afterwards, a notification from the St Petersburg Bar Council landed on Dmitri's desk. With some trepidation, he opened it to find a note explaining that the leadership of the Bar Council was so proud of their star member that they had bestowed upon him a special award in recognition of his outstanding achievements in advocating for the rights of people with mental disabilities.¹⁶

Shtukaturov wrested power from the fading nobility of Soviet psychiatry and was a reimagining of a just mental health system. The case did so without a vibrant movement of activists behind the litigation, and that has been a problem for MDAC. While travelling around the region in those early days, some civil society activists held the view that, "we don't do disability rights, we do human rights". There were few NGOs of people with mental health issues and none of people with intellectual disabilities: they were instead represented by their parents, who like all parents were well-meaning but paternalistic. Civil society was precarious and fragile. People under guardianship were prohibited in law from establishing or joining NGOs, so were barred from organising a challenge to their oppression. The plight of human rights defenders is now worse: in Russia, internationally-collaborating NGOs are labelled foreign agents and shut down.¹⁷ Many NGOs in Europe that receive funding from the State to run services do not advocate for change; fear of losing funding means they selfcensor.

Reimagining the victim – Stanev v Bulgaria

¹⁴ Shtukaturov v Russia (2012) 54 E.H.R.R. 27.

¹⁵ Mental Disability Advocacy Centre, "Press Release: Russia: Constitutional Court forges the Way out of discrimination for people with mental disabilities", 3 March 2009.

¹⁶ Annual conference of the St. Petersburg Bar, 27 March 2009.

¹⁷ The day before this lecture was delivered, Amnesty International's Moscow office was raided and sealed off by the authorities. See Amnesty International, "Russia: Amnesty International's Moscow Office sealed", https://www.amnesty.org/en/latest/news/2016/11/russia-amnesty-internationals-moscow-office-sealed/.

The Shtukaturov case is an example of strategic litigation (or impact or test-case litigation), a method that seeks not only a win for the individual client, but also to change the position of others: the court obviously, and often the government and civil society groups as well. At a minimum, strategic litigation has a documentation role as judicial findings are seen as balanced, unbiased and carry more weight than reports of NGOs or national human rights institutions.¹⁸

At MDAC we have always tried to locate disability rights within mainstream civil and political rights like the right to fair trial and freedom from ill-treatment, deploying concepts such as arbitrariness, proportionality and discrimination. These claims help challenge the view held by many policy-makers and lawyers that disability is at best a social issue, or that it belongs in the CRPD basket, and other specialist treaties concerning civil and political rights, economic and social rights or the conventions on torture or women or children should ignore people with disabilities.

The beauty of human rights litigation, to which I will return below, is that it creates an asymmetric battle which has a deviant feel. The otherwise passive and helpless "victim" role transforms into one of strength and defiance. The applicant who dares to put the State in the dock becomes emblematic of others' plight, adopting a universal role of the meek against the powerful. I have seen how this empowering effect benefits the litigant in profound ways even when they receive no material benefit.

Strategic litigation has a trickle out effect too, by creating an invitation from the government to the policy table where none existed, thereby sparking wider law, policy and system reform. Litigation not only protects and defends the space in which social movements operate, but can inspire nascent movements to organise. An example is MDAC's case of Stanev v Bulgaria. (A point about gender, as these two case examples both concern men. Genderbased violence is rife, and our litigators everywhere have found it more difficult to sign women up as litigants. MDAC is implementing a strategy funded by the UN Voluntary Fund for Victims of Torture to address this, an example being the November 2016 conviction and imprisonment for 13 years of a psychiatrist in Moldova who raped several of his female patients over the course of more than a decade.¹⁹)

Advocating for inclusion

Rusi Stanev was in his 40s and lived at home in Bulgaria. He had a mental health diagnosis, as one in four people worldwide do, but was coping fine. In 2002 on 10 December,²⁰ an ambulance came to his home and Rusi was put inside. He was driven 400km away to an institution called the Pastra care home for adults with mental disorders: no one told him why or how long he would stay. Like Pavel, Rusi had been placed under guardianship behind his back. His guardian had arranged a transfer to this institution where he found terrible conditions. Freezing winters resulted in a ten percent mortality rate. He had to share a

¹⁸ O. Lewis, "Advancing legal capacity jurisprudence", [2011] (6) E.H.R.L.R. 700.

¹⁹ O. Lewis, "Institutionalised and raped: Moldova turns shocking case into bold example of justice for vulnerable victims", The Conversation, 31 October 2016, <u>https://theconversation.com/institutionalised-and-raped-moldova-turns-shocking-case-into-bold-example-of-justice-for-vulnerable-victims-67744</u>.

²⁰ With some irony, on World Human Rights Day. Stanev v Bulgaria (2012) 55 E.H.R.R. 22at [14]-[15].

bedroom with several other men and saw people die. He escaped but was brought back. He wrote letters to various authorities but to no avail.²¹

But he survived. The Bulgarian Helsinki Committee, an NGO, carried out human rights monitoring in that institution, and their monitors met Rusi who asked them to help him. We worked with that NGO and appealed unsuccessfully through the domestic courts, judges throwing the case out because as a person under guardianship he lacked standing to bring the case without the guardian's permission. We applied to the European Court of Human Rights in 2006 and in 2010 there was an oral hearing before the seven-judge Chamber. We flew Rusi over to Strasbourg, and it was clear that the Chamber sensed the importance of this case as it challenged the set-up of social care systems in most European countries. It came as little surprise when the Chamber relinquished the case to the seventeen-judge Grand Chamber for determination. The Grand Chamber also held an oral hearing, which Rusi also attended.

Six years after the application was lodged the Grand Chamber delivered its judgment in 2012.²² It found a violation of art.3 of the ECHR (the right to be free from torture and other forms of ill-treatment) for the degrading conditions of the institution, the first successful invocation of this provision in any disability case. It also found a violation of the right to liberty under art.5, the first such violation in a social care case.

We had argued that Rusi's right to a fair trial under art.6 of the ECHR and his right to respect for private life under art.8 were violated as a result of the guardianship. The Court agreed with the former but found no separate issue arose under the latter. Perhaps at sixty-one pages they had run out of judicial steam. The Court's handling of this part of the claim stood in sharp contrast to its existing body of case law, including Shtukaturov.²³

In her dissent on this issue, Bulgarian Judge Kalaydjieva regretted that the Court failed to investigate this point. She correctly identified legal capacity as "the primary issue" in the case. She noted how the government offered no justification for ignoring Mr Stanev's preferences, and that "instead of due assistance from his officially appointed guardian, the pursuit of his best interests was made completely dependent on the good will or neglect shown by the guardian." She observed how the Bulgarian law, "failed to meet contemporary standards for ensuring the necessary respect for the wishes and preferences he was capable of expressing," code for art.12 of the CRPD that sets out how everyone with disabilities should have legal capacity on an equal basis with others, and how the State is required to make assistance available to those who need it in exercising their legal capacity. It is said that "dissents speak to a future age",²⁴ so litigators need to be persistent and bring multiple cases to the Court: it will eventually concede this point and find violations on the substance of guardianship and institutionalisation, not just on procedure.

The Bulgarian social care system incarcerates 7,000 people with disabilities, most of whom are under guardianship, and this case should have an impact on all of them.²⁵ The judgment

²¹ Amnesty International, Bulgaria: Far from the eyes of society: Systematic discrimination against people with mental disabilities (2002), available at <u>http://www.amnesty.org/en/library/info/EUR15/005/2002</u>. "Report to the Bulgarian Government on the visit to Bulgaria carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 16 to 22 December 2003," CPT/Inf (2004) 23, 24 June 2004, para. 22.

²² Stanev v Bulgaria, (2012) 55 E.H.R.R. 22.

²³ See O. Lewis, 'Stanev v. Bulgaria: On the Pathway to Freedom', (2012) Human Rights Brief, Winter ed, 2-7.

²⁴ Attributed to Ruth Bader Ginsburg, Associate Justice of the US Supreme Court.

²⁵ Mental Disability Advocacy Centre, "My Home, My Choice in Bulgaria", (Budapest, MDAC, 2014).

tells the Bulgarian government to "ensure the effective possibility" of people under guardianship accessing courts. Given the many countries that have a similar system, the general measures ordered by the Strasbourg Court are of great significance, so we used this as a hook to mount pressure on the government.

The human rights historian Samuel Moyn has suggested that, "[a]gendas for the world are argued in terms of morality",²⁶ and we have also found non-normative arguments persuasive alongside those grounded in international human rights law. In MDAC's theory of change, courts are only part of the answer. After a judgment in Strasbourg, the file is transferred across the road to the Agora Building which houses the Committee of Ministers secretariat. In 2015 the Bulgarian government submitted an Action Plan to the Committee of Ministers, explaining how an amendment already passed gave people in institutions fair trial rights (which was incorrect), and that a draft law would plug the other gaps the Court had identified. In February 2016, working with domestic NGOs, we met with government officials and judges in Sofia to support the draft law which at that time faced opposition from the Ministry of Social Affairs.

A month later we briefed diplomats at the Committee of Ministers in Strasbourg and urged them to pressure the Bulgarian government to pass the draft law. We also met with secretariat officials and in April followed it up with a "Rule 9 submission". In June 2016, the Committee of Ministers published its report, drawing from our submission.²⁷ It encouraged the government to, among other things, take steps to give people under guardianship direct access to courts. In July 2016, Nils Muižnieks, the Council of Europe's Commissioner for Human Rights, urged the Bulgarian government to enact a law that "would finally recognise [people's] human dignity and treat them as equal with other citizens."²⁸

The Stanev case is an example of where a judgment allowed civil society to build a framework to hold the government to account. It sparked others to campaign for permanent structural reform, and by combining domestic and intergovernmental mechanisms, a legal capacity bill has been laid before the Bulgarian Parliament.

Jurisprudential osmosis?

For the first time in international human rights law, the 2006 CRPD has articulated the right to live independently and be included in the community, and the right to legal capacity. Those rights did not previously exist – or at least have not been so clearly articulated elsewhere. The CRPD has created a universe parallel to the ECHR, other UN treaties and their treaty bodies, the European and global torture prevention bodies. NGOs negotiating the CRPD with States wanted to combat widespread human rights violations, and they urged the pendulum to swing heavily to the other side, which explains the recommendation by the CRPD Committee to prohibit all substituted decision making in all circumstances.²⁹

²⁶ S. Moyn, Human Rights and the Uses of History (New York City, Verso, 2014), p.141.

²⁷ Committee of Ministers, "Stanev group v. Bulgaria (Application No. 36760/06), Supervision of the execution of the Court's judgments, Item H46-8, 1259th meeting, 7-8 June 2016.

²⁸ N. Muižnieks, "Steps forward in protecting persons with disabilities in Bulgaria" (6 July 2016, Council of Europe, Strasbourg).

²⁹ UN Committee on the Rights of Persons with Disabilities, "General comment No. 1 (2014): Equal recognition before the law", UN Doc. CRPD/C/GC/1, 19 May 2014.

so that the conversation moves beyond norms and personal testimonies. Lord Goff warned against a "temptation of elegance", the compulsion to state principles in so succinct a way as to bar the possibility of qualifications or exceptions as yet unperceived,³⁰ and this warning should be heeded here.

The CRPD poses a challenge for Strasbourg litigation too. I recently researched all of the Strasbourg cases that have cited the CRPD. Once I removed the cases where the CRPD appeared simply in a footnote or was otherwise irrelevant to the case, there were 34 cases. This is a tiny number compared to the Court's overall output. During the period that the CRPD has been in force the Court has delivered 11,050 judgments, so 34 judgments is 0.3% of total output. There has been a slow-uptake on disability rights cases in which applicants' lawyers feel that the CRPD has something to add because it takes up to six years for the Court to adjudicate a case,³¹ and the CRPD only entered into force in 2008. We have to bear in mind also the point made by Judge Bratza, about the myriad access to justice barriers preventing arguable cases from ever reaching the Court's in-tray.

Putting the homeopathic concentration of disability cases to one side, is there any evidence of an ECHR-CRPD "jurisprudential osmosis"?³² In the research, I found a Court reluctant to engage with the CRPD, citing the text without integrating it into the legal reasoning. If the Court disagrees with the CRPD or its interpretation by the CRPD Committee it is less inclined to rely upon it, or even cite it.³³

Bringing this back into the themes of argumentation and activism, I found something that came as quite a surprise, namely the majority of the CRPD-cited cases were those where civil society played a role either as a representative or as third party intervenor. The number of times a case is cited by other cases is a proxy indicator of the importance of that case. Recall that my dataset was the 35 Strasbourg judgments that have cited the CRPD. And recall too how the 2008 case of Shtukaturov was the first legal capacity case in the post-CRPD era. That judgment did not cite the CRPD, but is the most cited disability judgment by dataset cases: twelve out of the 34 cases cited it. In second place is Stanev, which did cite the CRPD: it was cited by eleven of the 35 dataset cases. The tentative conclusion is that an investment into Strasbourg test case litigation is having some impact on the development of the Court's boutique disability jurisprudence.³⁴

Anguish, activism and argument

Strategic litigation is a multi-disciplinary venture that uses norms, evidence and emotion. It aims to achieve legal victory but aims also to shift the attitudes and behaviours of others. As

³⁰ Lord Goff, Maccabean lecture, 1983.

³¹ Rusi Stanev submitted his claim in 2006. The Grand Chamber issued its judgment in 2012.

³² Judge Wildhaber, then President of the European Court of Human Rights, used this term in a speech on the occasion of the opening of the judicial year on 23 January 2003, as noted in A. Mowbray, "The Creativity of the European Court of Human Rights" (2005) 5(1) Human Rights Law Review 57, 65.

³³ See Lewis, O. "The UN Convention on the Rights of Persons with Disabilities in Council of Europe Jurisprudence" in Lawson A and Waddington L (eds) Interpreting and Domesticating the UN Convention on the Rights of Persons with Disabilities: A Comparative Analysis of the Role of Courts, OUP forthcoming 2017. ³⁴ O. Lewis "The UN Convention on the Rights of Persons with Disabilities in Council of Europe

Jurisprudence" in A. Lawson and L. Waddington (eds) Interpreting and Domesticating the UN Convention on the Rights of Persons with Disabilities: A Comparative Analysis of the Role of Courts (Oxford, OUP, forthcoming 2017).

such, I suggest that it has a certain aesthetic. In 1973 the composer and conductor Leonard Bernstein gave a lecture in Harvard on Gustav Mahler's terrifying, otherworldly 9th symphony, remarking that, "[a]ll of the truly great works of our century have been born of despair or of protest or of a refuge from both, but anguish informs them all." ³⁵

I have despaired at Valkla, at Pastra, at cage beds, shackles, abandonment and violence. And I have been distressed by the incompetence of governmental representatives as I have been frustrated with the weakness of international accountability for human rights violations. This anguish poses a dilemma. We can walk away and ignore other people's despair: it is actually not our problem. Or, we can channel our anguish into a creative work: perhaps not always a great work, but something of beauty nonetheless. Recall how the Dalits' battle for justice was for Ambedkar, "a matter of joy" and the "reclamation of human personality".

Working for MDAC, I lived in the Jewish quarter in Budapest for twelve years where I became quite affected by the music of Gustav Mahler. His work laid out his own battles as well as the contradictions in his environment. He identified as a Jew and a Christian, used influences from the west and the east, produced soaring melodies and despairing discord and created intimate chamber music and massive orchestral sound in the same piece. His work signalled the end of classicism and opened up modernism, a radically different worldview for which there was no blueprint, no method, no detail.

Law lends itself to easy binaries: guilty not guilty, claim counter-claim, win lose and so on. But there is a more delicate balance, an altogether finer line, a quiet, single, sustained note between segregation and inclusion, between loneliness and support, between poverty and justice. Like Mahler, today's social justice agitators are both observers and co-creators of a profound historical transformation. We are calling for the civilising force of the law to embrace the full spectrum of humanity, not just the privileged, abled valid. That is a big ask.

The phrase "paradigm shift" has become somewhat hackneyed in the disability rights discourse, and we should not expect a moment like Mandela walking out of prison signalling the end of apartheid or the fall of the Berlin wall bringing an end to communism. Change to disability segregation – like other areas of social justice – comes as incrementally as it does unexpectedly. We owe it to the sustainability of own mental wellbeing to guard against shouldering a responsibility for such a profound social shift, and we should punctuate the arc of as-yet-unwritten history with celebrations of small successes. The loudest symphony is made from small, silent notes.

The title of this article is "disabling legal barriers" and I have suggested that rummaging in the legal toolbox can equip activists with the things we need to demolish barriers to equality, inclusion and justice. These are important tasks, as destruction clears the path for renewal and regrowth - another Mahlerian theme. But advocates for social justice must do more than dismantle barriers. Someone needs to provide the evidence about what works, someone needs to establish the reasonable measures that governmental authorities and others have to take, someone needs to work with local communities and someone needs to monitor process.

Law can be an instrument to secure human rights institutionally, but is rarely enough to change human behaviour. Other social arrangements are required for full realisation of rights including public policy and social pressure. So, building something from the rubble of

³⁵ L. Bernstein, Lecture Series entitled "The Unanswered Question", Harvard University, 1973.

injustice requires a multi-disciplinary effort. Social scientists, health experts, economists, as well as those from education, media, business can all play a part in litigation and advocacy initiatives.

I have suggested that concerns of social justice can be addressed by the exchange of ideas through legal activism, by engaging in critical conversations: in the corridors of power with decision-makers, in coffee shops with potentially helpful allies, and in UN buildings with their yellow sleep-inducing lighting. Judicial accountability will remain an important last resort, so critical courtroom conversations will remain crucial.

The post-war human rights project enjoins us to prefer persuasion over violence. We must therefore listen to and understand the concerns of our opponents. We need not be afraid of convening diverse opinions. And we must interrogate that which has worked and that which has not, and find out the reasons why. We know from Pavel Shtukaturov and Rusi Stanev and many others about the consequences of failing to enable and support people to live in the community with choices equal to others. We need to argue the point that governments have a duty to create systems that take into account the wildly differing contexts, cultures, traditions, resources and practices across the world. And as much as we may disagree about the detail, we can ground our demands in the principles agreed through international consensus to guide operational behaviour: inclusion, respect for diversity, non-discrimination, accessibility, support and dignity.³⁶

Rusi Stanev put it in a less convoluted way. On the way to Strasbourg for the Chamber hearing in 2010 he said to his lawyer in Bulgarian, "I'm not an object. I'm a person. I need my freedom". The deprivation of his legal capacity had reduced his destiny to his diagnosis. Under guardianship his personhood had been stripped bare and as a result he was denied his freedom. Reversing the discrimination embedded in legal systems requires many critical conversations: about our motivating anguish, about what it means to author our own lives and about the activism needed to establish a more just and inclusive society.

These conversations have begun, but they've only just begun.

³⁶ See art.3 (General Principles) of the CRPD , a point made by Paul Hunt (op cit)..