Inaugural lecture

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Barely out of bed

1. Convened to create a country-wide lobbying group on Dalit rights, the "All-India Depressed Classes Conference" took place in Nagpur in July 1942. In a famous 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".[1]

2. Ambedkar was talking about reversing the injustices faced by Dalits, the Untouchables, who faced widespread discrimination. He, a Dalit himself, 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.

3. In dictatorships and in democracies, throughout history and around the world today, we can see laws that treat minorities differently, laws that remove rights from the marginalised, and laws that promulgate prejudice. My focus has been children and adults with labels of mental health issues or intellectual disabilities. Oftentimes their discrimination, segregation and injustice is accepted by the public more than they are.

4. This evening I'd like to talk about this anguish, but about two other things as well. Activism: how lawyers – from law student to law firm partner – can use their knowledge and power to engage in the struggle for social justice. And argument: how ideas are advanced and battles won through critical conversations, robust disagreement, deployment of norms, evidence and emotion.

5. Modern human rights activism started in the 1970s and I was born bang in the middle of that decade. Fifteen days after my, the European Commission of Human Rights accepted the case of *Winterwerp v. the Netherlands*, which was to become the first European mental health case. That was not one of my cases.

6. Oliver Thorold took the cases of *Ashingdane* in the 80s and *Johnson* in the 90s to Strasbourg, but there was very little else from any European country. Sir Nicolas

[1] Keer D, *Dr. Ambedkar, Life and Mission*, Bombay: Popular Prakashan, 3rd ed. 1971, p: 351.

Bratza is the former UK judge at the European Court of Human Rights. In a foreword to a book that Oliver, Peter Bartlett and I wrote ten years ago, he noted 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 went on to explain that, "[t]his gap is 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."[2]

7. As you may expect, the US was more litigious, but even cases by the prestigious Bazelon Center for Mental Health Law in Washington DC neither drew from nor contributed to the development of international human rights law. It's only really been since the turn of the century that mental health, disability and international human rights law have come together in any serious way, and the regional cases have pretty much all happened in Europe. So it does seem strange that in the library you'll find recent books by Stephen Hopgood called the "Endtimes of Human Rights" and Eric Posner's "Twilight of Human Rights Law". Last week I was at a conference and so was Paul Hunt, the former UN Special Rapporteur on the Right to Health. He exclaimed, "Twilight? Dawn has just broken and we're barely out of bed."

8. We are indeed at the early stages of this subject's intellectual and operational journey. Yet there have been advances already, such as the UN Convention on the Rights of Persons with Disabilities – the CRPD. This was driven by people with disabilities themselves. The emerging body of case-law, however, exists in large measure as a result of a programme of sustained innovation by human rights litigators with whom my organisation has worked. It is with humility and huge gratitude that I dedicate my inaugural lecture to them.[3]

Discovery

9. The Mental Disability Advocacy Centre (MDAC) was founded by George Soros's Open Society Institute to disrupt a system of disability segregation. It started in Estonia in the spring of 2001 when I was doing pupillage in London. By some fluke I had been appointed the organisation's first legal director and fifteen years ago to the day, I

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

[3] 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, 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.

landed in freezing Tallinn. I planned to return to the bar a couple of years later. The best laid plans…

10. In my first week in Estonia, I visited my first social care institution, in the town of Valkla, half an hour's drive east of Tallinn. We were greeted by the director, a psychology student who was a former Estonian Air flight attendant. She had been brought in following a scandal involving the previous director who ran an institution that the European Committee for the Prevention of Torture – the CPT – characterised as, "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".

11. Valkla was my first taster of how victims of human rights violations were used as political pawns. The CPT had issued its report on Valkla and other places of detention to the Estonian government in 1997 but the government only authorised publication in late 2002, right before Estonia was to accede to the European Union, thus denying the public the chance to leverage change out of the system in those precious pre-accession years.

12. By the time of my visit, there was less violence but no shortage of neglect and abuse. We entered the building, and it reeked of urine and detergent. Valkla housed 300 people who slept in bedrooms with four or five others, beds tightly packed together. Residents wore multiple layers of old clothes as it was cold inside and sub-zero outside. They shared their clothes, as well as soap and toothbrushes. They were allowed to wash once a week in a communal room that reminded me of concentration camp movies. To enter the dining room residents had to pass a nurse and swallow a pill before getting food. "Medication time, gentlemen!" Survival was contingent on compliance with medication: a Foucauldian field trip. Just slop was served: people had no teeth. There was a locked seclusion room with a highly sedated person inside. A group of around 20 men with intellectual disabilities were locked together in a room with green walls and wooden benches. A resident told us in fluent English how he had been placed in the institution several years ago because of a family dispute. He appreciated that he had somewhere to live but want to live there.

13. The institution was clearly horrible but it was less clear to me how it related to the law. I had been asked to relocate to Budapest in early 2002 and I spent that year visiting each of the eight eastern European accession which were to accede to the EU in 2004, marked in orange, plus Bulgaria and Romania which were to accede in 2007. I pooled the experts I knew: Jill Peay, Peter Bartlett, Oliver Thorold and our current chair Phillippa Kaufmann and one of them joined me on each mission. In each country we spent two days conducting site visits to social care institutions, hospitals, children's homes and prisons, and spoke to as many civil society and governmental people as we could. The two Olivers wrote a short training pack on the ECHR and mental disability which was translated to the relevant languages and guided two-day seminars for lawyers and NGOs. These were often the first public events that had brought a rights based perspective to mental disability. We still work with many of the NGOs that carried out the local organisation of those seminars: the NGO Zelda in Latvia, the

Polish Helsinki Federation for Human Rights, the Centre of Legal Resources in Romania.

14. Our lens was ECHR and my knowledge was limited to a book written by star Leeds alumnus Keir Starmer, who opened the Liberty Building and is now doing a rather different job. Keir write the book to build the capacity of UK lawyers as the 1998 Human Rights Act came into force. The book was helpful to this lawyer exiled in eastern Europe too. So how did the European Convention on Human Rights – the ECHR – illuminate what we saw and heard during that year? Well, the right 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.

15. And outside 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 we had a couple of little known UN instruments like the 1971 declaration on the rights of the mental retarded, the 1991 mental illness principles, and a more promising Council of Europe recommendation on incapable adults from 1999. But the titles spoke for themselves.

16. Standing back from the sea of individual rights, what I saw, and what we still see today across Europe, are three interlocking systems: mental health, social care and guardianship.

Mental health

17. Mental health systems operate under the aegis of containment. People receive medication, often old style with obvious side effects, but no talking therapies. Mental health is a closed system and shrouded in secrecy: “It’s better if we don’t tell the patients their diagnosis, they wouldn’t’ know how to cope”, a Latvian psychiatrist told me, withholding clinging on to both information and power. Patients must comply with rigid treatment models that meet the needs of the institution but ignore those of the patient. The system is dominated by the medical model approach that favours chemistry over psychology, regime over recovery, coercion over consent, segregation over inclusion, and paperwork over justice.

18. Law theoretically regulates the psychiatric system: admission, discharge, complaints, reviews. But in reality, service providers can safely ignore pesky legislation. Lawyers and judges had never demonstrated that they added value. After the transition to democracy in central and eastern Europe, well-intentioned American lawyers had consulted governments to redraft their mental health laws, but writing in legal safeguards was doomed to failure in countries where there was no culture of checks and balances. Requiring a judge to glance at papers unsurprisingly results in zero change to the patient’s experience. All it does is add a veneer of legal legitimacy, worse, in my view, than a system of arbitrariness. I remember discussing the new Romanian mental health law with a senior psychiatrist there. He had no idea what the

legal basics were, yet this was the law designed specifically to regulate his every-day practice.

19. In psychiatry, people are inpatients for a few weeks or months, but it was the social care system in which we find a set of altogether different problems.

Social care

20. During my tour a powerful image emerged of institutionalised people hidden from the public's gaze who had been neglected for a very long time. No official data exists, but we estimate that within the Council of Europe region there are upwards of two million people with mental health issues or intellectual disabilities who are warehoused for life. The policy focused on children, and countries like Romania made great strides in reducing the numbers of *non*-disabled institutionalised children, perhaps because, as arch human rights sceptic Stephen Hopgood has suggested, the suffering child "embodies the central figure of liberal humans," where "innocence is a proxy for naturalness (guilessness, blamelessness)". In this way "both compassion and justice can be anchored on the child".[4]

21. Not so for adults, who were and are seen by the public as defectives, deviants, unpredictable and invalid invalids. There is nothing social, caring or homely about social care homes. Now we see the phenomena of creating smaller institutions as if they are better. We see institutions that have been renovated: yes a plastered wall is better than an un-plastered one, but the point is that people never leave. I have seen several institutions with a room at the end of the corridor of bedrooms used to lay out a body when a resident dies so that others can pay their respects. The person is then buried in the institution's grounds. Even in death, liberty is denied.

22. Social care institutions are characterised by regimes of endless empty days, boredom leading to frustration to punishment, helplessness and hopelessness. I always ask management about how many people could live in the community: 20% or 30% they say, betraying a defensiveness of the status quo and a crushing lack of creativity. These institutions pose a huge challenge to litigators: cases mostly require victims, yet residents are still under the thumb of the regime and the risk of retribution is high. Plus, most residents are all under the elephant in the continent: guardianship.

Guardianship

23. In modern international law the legal authority to act is called "legal capacity", but deprivation of legal capacity through the device of guardianship has its roots in Roman law.[5] In those days, guardianship was a mechanism to benefit others: if an 'insane

[4] Hopgood S, *The Endtimes of Human Rights*, 2015, Cornell University Press, p 71.
[5] For a summary of a connection, see Sherman C P, "Debt of the Modern Law of Guardianship to Roman Law", Michigan Law Review, Vol. 12, 1 January 1913.

person' was to inherit property, a sandal-wearing guardian was appointed, and if there was none, the person's relatives had to take charge of his property.[6] Insane people were equated with children: they could choose which toga to wear, but were considered 'incapable' of making more important decisions.[7] The history explains why law professors as well as judges, beloved of ancient and useless concepts as they are, have been the chief blockers of reform in Czech Republic, Hungary, Bulgaria and elsewhere. Bloody law professors!

24. Thomas Hammarberg, the former Council of Europe Commissioner for Human Rights and now MDAC's Honorary President nailed it in 2012 when he said that, "Without legal capacity, we are nonpersons in the eyes of the law and our decisions have no legal force."

25. How does the system work across most member states of the Council of Europe? Statutes are incredibly broad: if you cannot manage your daily affairs you shall be placed under guardianship. The opinion of one doctor is needed. A judge declares the person incapable. The supposedly incapable person is not always invited to attend court or is otherwise heard. No counter evidence is presented, and there's no probing of the medical evidence. The person need not be informed of the proceedings or the court's decision. Some jurisdictions have partial guardianship, but most laws assume that the person is completely incompetent in all areas, so the consequences of being placed under guardianship are that the guardian can decide to place the person in a far-away institution, can block court proceedings if the person wants to get out of guardianship, and the guardian can block a complaint even against himself.

26. Their signatures being invalid, people under guardianship are prohibited from working. Or they're placed in sheltered workshops where their skills are not developed and they don't earn a proper wage. Even the right to vote is removed, reducing political visibility and making it harder to imagine political progress on more substantive rights.

27. Guardianship protects money and power. An outdated normative framework conspires with the very worst of psychiatry to anaesthetise human agency. One of MDAC's impactful achievements was to call this system out, and put guardianship on the human rights map through our litigation and a series of reports that we conducted eight years ago. But even with this evidence-base, we knew that wishful thinking alone would not change the plight of the people under guardianship we met. It became obvious that guardianship was the slip-road to segregation and we went after this as a strategic priority.

[6] Law VII of Table V of the VII Tables: "When no guardian has been appointed for an insane person, or a spendthrift, his nearest agnates, or if there are none, his other relatives, must take charge of his property."
[7] Law VI of Table V of the VII Tables: "When the head of a family dies intestate, and leaves a proper heir who has not reached the age of puberty, his nearest agnate shall obtain the guardianship."

Shtukaturov v. Russia

28. Pavel Shtukaturov was a 24-year old man with a diagnosis of schizophrenia who lived with his mother in St Petersburg, Russia. One day at home he found a piece of paper – a court order, dated the previous year placing him under the guardianship of his mum. It was the first he heard about it. He went to Google and searched for help (do you see how incapable he was?), finding Dmitri Bartenev, a smart lawyer in St Petersburg who works with MDAC. Dmitri met with Pavel and they signed a power of attorney.

29. 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 ask Dmtri to get him out. I happened to be in town, so went with Dmitri on one of his multiple attempts to meet Pavel late one afternoon.

30. It was cold and dark and frankly quite spooky. The hospital's mortuary was signposted on the ground floor. The security guard's Alsatian dog looked decidedly more deadly than Anna's dog Uffy. While the security guard dozed off, probably drunk, the dog roamed around unleashed. 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" she replied. The law was that a guardian could authorise the so-called voluntary detention and forced treatment, bypassing the legal process that also then provides a court review. It was a legal fiction, and however comic it looked from the outside, we knew that Pavel was being forcibly treated inside.

31. When the authorities block access between a lawyer and their client, alarm bells go off. So we applied to the European Court of Human Rights to grant interim relief, which they did, faxing an order to the infuriated Russian authorities ordering – not asking – them to let Dmitri speak to Pavel in private. This made mini legal history as the first interim order in a non-deportation and non-brink-of-death case. The authorities failed to comply and Dmitri was kept out. The St Petersburg bar council threatened to disbar Dmitri for so outrageously binging disrepute to the integrity of mother Russia's mental health system. We ploughed on, winning the case in Strasbourg some months later.

32. It was the Court's first big guardianship case. It ruled that guardianship amounted to a "very serious" interference with Pavel's right to private life under Article 8 of the ECHR, and found the system where one person could authorise the detention of another to violate the Convention. Back in Russia we litigated this point at the Constitutional Court which quashed three areas of Russian law, including the ability of a guardian to authorise detention. This was the first higher court legal capacity judgment in the former Soviet Union, so through a combination of international and domestic legal action we caused a change of the law.

33. Soon afterwards, a notification from the St Petersburg Bar Council landed on Dmitri's desk. He opened it to find a note explaining that they were so proud of their star member that they have bestowed upon him a special award in recognition of his

outstanding achievements in advocating for the rights of people with mental disabilities.

34. This case wrested power from the fading nobility of Soviet psychiatry and was a re-imagining of a just mental health system. It did so without a vibrant movement of activists behind the litigation, and this has been a problem for us. While travelling around the region, I spoke to some NGO people who told me 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, who were represented by their parents: well-meaning but with different viewpoints than their adult children. Civil society was precarious and fragile. People under guardianship were prohibited in law from establishing or joining NGOs so were barred from organising to challenge their oppression. The plight of human rights defenders is now worse: in Russia internationally-collaborating NGOs are labelled foreign agents and shut down. Today Amnesty International's Moscow office was raided and sealed off by the authorities. Many NGOs Europe that receive funding from the State to run services do not advocate for change; their self-censorship resulting from fear of losing funding.

Strategic litigation

35. The Shtukaturov case is an example of strategic litigation, so what is this? Otherwise known as impact or test-case litigation, it's 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. Strategic litigation plays a documentation role: judicial findings are seen as balanced and unbiased and carry more weight than reports of NGOs or national human rights institutions.

36. Our strategy has always been to frame "disability rights" within mainstream civil and political rights like fair trials and freedom from ill-treatment deploying concepts such as arbitrariness, proportionality and discrimination. These claims help challenge the unhelpful view held by many policy-makers and lawyers that disability is just a social issue, or that it belongs to the UN's disability convention, and has nothing to do with other specialist treaties concerning civil and political rights economic and social rights or the conventions on torture or women or children.

37. The beauty of human rights litigation, which I will come back to, is that it creates an asymmetric battle which I find somewhat wonderful. The otherwise passive and helpless "victim" role transforms into one of strength. The person becomes emblematic of others' plight, starring in a universal narrative 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.

38. Litigation has a trickle out effect too, by creating an invitation to the policy table where none existed and by being a catalyst for law and policy reform. Litigation protects and defends the space in which social movements operate, and can inspire

nascent movements to organise. An example is our case of *Stanev v. Bulgaria* which I'll explain.

39. By the way, these two case examples both concern men. Gender-based violence is rife, and our litigators everywhere have found it more difficult to convince women to sign up as litigants. We are implementing a strategy funded by the UN Voluntary Fund for Victims of Torture to address this. Last week's conviction in Moldova of a psychiatrist who raped 16 of his female patients over the course of a decade is an example.

Stanev v. Bulgaria

40. When he was in his mid 40s Rusi Stanev was living at home. He had a mental health diagnosis, as one in four people worldwide do, but was coping fine. In 2002 on 12 December – ironically World Human Rights Day – he was taken from his home and driven 400km away to an institution called the Pastra care home for adults with mental disorders. Like Pavel, Rusi had, behind his back, been placed under guardianship and his guardian had arranged a transfer to this institution. There he found terrible conditions. Freezing winters resulted in a ten percent mortality rate. Rusi had to share a 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. But he survived.

41. Fortunately for him, an NGO, the Bulgarian Helsinki Committee was carrying 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 effectively said: "Get out of my courtroom, you are under guardianship so you lack legal standing." We applied to the European Court of Human Rights in 2006. A few years later there was, unusually, an oral hearing before the seven-judge Chamber, and we flew Rusi over to Strasbourg. The Chamber sensed the importance of this case as it challenged the set-up of social care systems in most European countries, so it bumped up the determination to the seventeen-judge Grand Chamber which also held oral hearing.

42. Six years after we applied, the Court delivered its judgment in 2012. It found a violation of Article 3 of the ECHR (freedom from torture and 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 Article 5, the first ever violation in a social care case.

43. We had argued that Rusi's right to a fair trial under Article 6 of the ECHR and his right to respect for private life under Article 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*.

44. In her dissent, 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." This is code for Article 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.

45. Ruth Bader Ginsberg, Associate Justice of the US Supreme Court, has said that "dissents speak to a future age", and I am confident that the Court will in a future age – next year I hope! – find violations on the substance of guardianship and institutionalisation, not just the procedural points.

46. 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. The Court told 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.

47. The human rights historian Samuel Moyn has suggested that, "Agendas for the world are argued in terms of morality".[8] We've also found that non-normative arguments clinch arguments too (sorry law students), so courts are only ever going to be part of the answer. So how have we combined litigation with advocacy?

48. After a judgment, the file is transferred across the road to the Agora Building which houses the Committee of Ministers secretariat. Last year the government responded by submitting 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 this year we met with several government officials and judges in Sofia to do our bit to support the draft law which at that time was bring opposed by the Ministry of Social Affairs. We are fortunate to have an amazing lawyer Aneta Genova in Bulgaria, and she and we have been working Nadia Shebani of the Bulgarian Centre for Nonprofit Law and Valentina Hristakeva of GIP-Sofia to disrupt the system from within the country.

49. In March this year, we met with diplomats on 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 the Committee of Ministers published its report, drawing from our submission. It encouraged the government to, among other things, take steps to

[8] Moyn S, *Human Rights and the Uses of History*, Verso, 2014, p 141.

give people under guardianship direct access to courts. In July Nils Muiznieks, the Council of Europe's Commissioner for Human Rights urged the Bulgarian government to take action to pass a law that "would finally recognise [people's] human dignity and treat them as equal with other citizens."

50. 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, I'm pleased to say that a legal capacity bill has been laid before Parliament.

Jurisprudential osmosis

51. For the first time in international law, the 2006 CRPD articulated the right to live independently and be included the community, and the right to legal capacity. Those rights don't really exist or at least haven't been articulated like that 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.

52. 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. Academia can, I think play a role in widening out this debate by providing an evidence base, so that the conversation moves beyond norms and personal testimonies. The jurist Lord Goff has 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.[9]

53. What does this mean for strategic litigation? How is the European Court of Human Rights integrating the CRPD? I recently researched all of the Strasbourg cases that have cited the CRPD. Once I removed the cases where the CRPD appeared in an irrelevant footnote, there were 34 proper 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. It takes up to six years for the Court to adjudicate a case,[10] so given that the CRPD entered into force in 2008, and bearing in mind the myriad access to justice barriers preventing arguable cases from ever reaching the Court's in-tray, it is understandable that there has been a slow-uptake on disability rights cases in which applicants' lawyers feel that the CRPD has something to add.

[9] Lord Goff, Maccabean lecture, 1983.

[10] Rusi Stanev submitted his claim in 2006. The Grand Chamber issued its judgment in 2012.

54. Leaving the homeopathic concentration of disability cases to one side, is there any evidence of an ECHR-CRPD "jurisprudential osmosis"?[11] What I found was a Court reluctant to engage with the CRPD. Where it cites the CRPD, it does so without any integration in its 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. Explaining the reasons would take me on a tangent, so read my chapter in Anna Lawson and Lisa Waddington's book when it comes out next year.

55. Bringing this back into the themes of argumentation and activism, I found something that came as quite a surprise: 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 34 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 it is the most cited disability judgment by dataset cases: twelve out of the 34 cases cited it. And remember that the dataset contains cases that have nothing to do with mental health. In second place is *Stanev*, which *did* cite the CRPD: it was cited by eleven of the 34 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.

Anguish, activism, argument

56. Strategic litigation is a multi-disciplinary venture because it uses not only norms but empirical evidence and emotion. It aims to achieve legal victory but aims also to shift the attitudes and behaviours of others. As such I suggest that the enterprise 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. Bernstein remarked that, "All 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."

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

58. I lived in the Jewish quarter in Budapest for twelve years and became quite affected by the music of Gustav Mahler. His work laid out his battles and the contradictions in

[11] Judge Wildhaber (then President of the European Court of Human Rights), speech on the occasion of the opening of the judicial year on 23 January 2003, as noted in Mowbray A, "The Creativity of the European Court of Human Rights," *Human Rights Law Review* 5, no. 1 (2005): 57–79. at 65.

his environment: he used influences from the west and the east, he produced soaring melodies and despairing discord, he identified as a Jew and a Christian, he 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.

59. Of course, law lends itself to easy binaries: guilty / not guilty, claim / counter-claim, win / lose and so on. But there's a much more delicate balance, an altogether finer line, a quiet, single, sustained note between segregation and inclusion, between loneliness and support, between poverty and justice. I would suggest that today's social justice agitators are, like Mahler, observers and co-creators of a profound historical transformation. It is after all, a big ask for the civilising force of the law to embrace the full spectrum of humanity, not just the privileged, abled valid.

60. The hackneyed phrase "paradigm shift" is overused in the disability rights discourse. We cannot possibly 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 comes incrementally and unexpectedly. *Viva la evolution!* My point is that we owe it to the sustainability of own mental wellbeing to guard against shouldering a responsibility for such a profound social shift. And my point is also that we should punctuate the arc of as yet unwritten history with celebrations of small successes. The loudest symphony is made from small, silent notes.

61. The title of this lecture is "disabling legal barriers" and I've suggested that by rummaging in the legal toolbox we can find things to dismantle barriers to equality, inclusion and justice. Destruction clears the path for renewal and regrowth, another central Mahlerian theme. But we need to 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 the process.

62. Law can be an instrument to secure human rights institutionally, but it's rarely enough to change human behaviour. Other social arrangements are required for full realisation of rights including public policy and social pressure. Building a structure from the rubble of injustice requires a multi-disciplinary effort. So, I am particularly looking forward to working with colleagues from across the University, with Angharad Beckett and others from the Centre for Disability Studies, with John Baker from health, as well as colleagues from economics, education, media, business – domains that litigation and advocacy initiatives can work with more effectively.

63. In the new year MDAC be rebranding and relaunching, and we will be in a position to engage students in our work as we move several staff from Budapest to be based here. Shifting our headquarters to the University marks a significant milestone in our charity's development and I would like to thank Peter Bartlett, Felicity Callard, and Phillippa Kaufmann, three successive chairs, and all of the other trustees – including Jean Barclay our newest trustee here today – for steering us this far.

64. I am hugely grateful to the leadership of the School of Law: Alastair Mullis, Joan Loughrey, Michael Thomson, Julie Wallbank and colleagues in the Centre for Law and Social Justice for extending an invitation for me to join the School, for believing in the institutional collaboration and for being such supportive and motivating colleagues.

Robert Louis Stevenson said that we shouldn't judge each day by the harvest we reap but by the seeds we plant. I have been teaching a course on mental disability law and advocacy to postgraduate law students at the Central European University in Budapest for thirteen years. At least seven of my former students are now leading mental disability rights advocates. They are as impressive as their names are unpronounceable: Ines Bulic, Emina Ćerimović, Constantin Cojocariu, Oana Girlescu, Eyong Louis Mbuen, Barbara Méhes and Marcin Swed. As proud as I am of them, I look forward to incubating more agitators-to-be in Leeds by teaching a new LLM module on global human rights advocacy, and picking up a few classes on the LLM and LLB disability law modules.

65. I'm humbled to join such a supportive and collaborative teaching and learning environment headed up by Nick Taylor. This year we launched a Disability Law Hub under Anna Lawson's leadership, and I look forward to spending more time with her and fellow hubbists Luke Clements, Gauthier de Beco, Beverley Clough, Louise Ellison, Amanda Keeling, David Pearce and Cesar Ramires-Montes, as well as the LLM students and PhD candidates. Thank you all for the work you do and for giving me an opportunity to work alongside you.

66. I would like to pay massive tribute to *my* teachers and mentors, many of whom are here today: Jill Peay, Genevra Richardson, Oliver Thorold, Peter Bartlett, Michael Bach and Aart Hendricks: thank you for your support, wisdom and for buying the drinks. Thanks to my family – my mother Sylvia met Alan as they were shutting down learning disability institutions in Bristol. With service provider intrapreneurs, change happens faster as it need not be provoked from outside. And thanks too to István for many things, including today's powerpoint.

67. Finally, to students past, present and future. Your life can have meaning even if you become commercial lawyers! Whatever field chooses you, you can – *and you better* – support social causes that you care about. Insist on your firm allowing you time to provide pro bono services. Be an active alumnus. Help your favourite charities by setting up a thoughtful direct debit. Provide strategic advice. Become a trustee. Be an ambassador. Do not hide behind what it says on your business card: use your privileged position to contribute to social impact, because the true measure of your character is how you treat the poor, the disfavored, the accused, the incarcerated, and the condemned.[12]

68. I've suggested today 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 dreadfully boring UN meetings too. Judicial accountability will remain an important last resort, so critical courtroom conversations will remain crucial.

[12] Stephenson B, *Just Mercy*, 2015.

69. 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 hasn't, and find out the reasons why.

70. We know from Pavel and Rusi 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 arguments to help create systems that take into account the wildly differing contexts, cultures, traditions, resources and practices across the world. And as much as we can have legitimate arguments about the detail, let us be grounded in the principles agreed through international consensus to guide operational behaviour: inclusion, respect for diversity, non-discrimination, accessibility, support and dignity.

71. Rusi Stanev put it in a less convoluted way. On the way to Strasbourg for the Chamber hearing in 2010 he said 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.

72. 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. Please join in! Those conversations have begun. But they've only just begun.