

Editor's foreword

When the Convention on the Rights of Persons with Disabilities (CRPD) was negotiated between 2000 and 2006 in New York, legal capacity was one of the major points of conflict among members of the Ad Hoc Committee, the body that drafted the treaty. Universal legal capacity for all persons with disabilities has remained the major challenge for States Parties regarding the implementation of the CRPD. It goes to the heart of the problem with the medical model of disability, which the CRPD seeks to replace with the human rights model of disability. Denial or restriction of legal capacity based on an impairment or disability is enshrined in almost every legal order in this world. While most governments and legislators have at least understood that accessibility of the physical environment and accessible communication and information are preconditions for equal opportunities for persons with disabilities, the level of understanding regarding legal capacity remains minimal. Neither the 1948 Universal Declaration of Human Rights nor any other core human rights treaty has ever pronounced that a certain health status or functional ability is a requirement for human rights. On the contrary, human rights theory is based on the assumption that human rights cannot be gained or merited. We become human rights holders *qua* birth, simply by being members of the human family. Yet, in practice and in law, persons with disabilities, especially those with psychosocial or cognitive impairments, have traditionally been denied their legal capacity or have been restricted therein and their civil death has been legitimised by their impairments. Adult guardianship laws, and many mental-health laws that infringe upon the right to legal capacity, are based on the conviction that it is just to deny or restrict human rights on the basis of disability. The stereotype of the unable, because disabled, citizen is so deeply entrenched in our legal tradition, that courts, legislatures, guardians and family members can claim this violation to be a form of protection – a form of caretaking.

Against this background, it was perhaps naive for the CRPD Committee to take up this issue in its first general comment. When General Comment No. 1 on Article 12 CRPD was finally adopted in 2014, the Committee had worked on it for five years, which gives an indication of how complicated matters were in this regard. The working group on General Comment No. 1 was chaired by several members of the Committee and I had the honour to guide it in the final round as the last chair. I am very grateful to Eilionóir Flynn and Anna Arstein-Kerslake, who acted as my consultants during that time. General Comment No. 1 ends with a call for further 'research and development of best practices respecting the right to equal recognition of the legal capacity of persons with disabilities and support in the exercise of legal capacity' (Committee on the Rights of Persons with Disabilities, 2014, para. 48). It also reminds States Parties that persons with disabilities and their representative organisations need to be involved (Committee on the Rights of Persons with Disabilities, 2014, para. 26). The Voices of Individuals: Collectively Exploring Self-determination (VOICES) project, a Starting Grant funded by the European Research Council, hosted by the Centre for Disability Law and Policy at the National University of Ireland Galway, is one such project.

The VOICES project brings together researchers, disability activists, practitioners and policy-makers to develop collaborative responses to the challenges posed by recognition of universal legal capacity. This project places the lived experiences of people with autism, dementia, intellectual and psychosocial disabilities at the heart of efforts to develop inclusive and sustainable law reform. It is documenting the narratives of persons with disabilities who recount their experiences in exercising, or being denied legal capacity, in a wide range of legal, political, social, cultural and economic contexts. Storytellers with disabilities have been paired with

researchers, activists, practitioners and policy-makers to demonstrate how law and policy can better reflect the principles of universal legal capacity in practice. As part of the VOICES project, fifteen pairs made up of individuals from thirteen different countries are currently exploring the right to legal capacity in the context of criminal responsibility, contract law, consent to medical treatment, and relationships and sex. Their stories and responses will be published in an edited collection at the end of the project in 2018.

This project takes a radical new approach to researching law reform. It is based on two insights. First, historically, disability law, and especially legal-capacity law, has been drafted by non-disabled persons with no experience of living with a disability. This may explain why substituted decision-making laws were first introduced. The black-and-white approach of totally or partially denying legal capacity has very little to do with what life with a psychosocial or cognitive impairment is about. In fact, it is hardly an adequate reflection of human decision-making which takes many forms and shapes. Incapacity law in today's world is based on an outdated medical model of disability and completely ignores that there are many different ways to make autonomous decisions. Secondly, implementation of the right to equal recognition before the law faces many challenges, and many questions need to be resolved when substituted decision-making regimes are replaced by supported decision-making regimes. What kinds of acts or omissions should be regarded as exercises of legal capacity? If the state must recognise the legal capacity of all persons with disabilities, can it restrict or deny the legal capacity of any adult and, if so, when? How can we prevent state intrusion into personal autonomy from indirectly discriminating against persons with disabilities? And finally, if we are to do away with assessments of mental capacity as the basis for granting or denying legal capacity, how are we to ascertain whether individuals are giving free and informed consent where such consent is required to make an action legally binding? These questions cannot be answered without listening to persons with disabilities who are subject to denial restrictions of legal capacity. Their lived experiences and their expertise need to be the starting point for finding adequate answers to questions in relation to legal capacity.

However, the voices of persons with disabilities are rarely recognised or listened to in law or in practice. I have recently returned from a training session with one of Germany's largest service providers in the disability field. The training included over 1,000 professionals providing services to 3,000 persons with disabilities in group homes, sheltered workshops, special schools and kindergartens. The company is very modern and takes account of the UN CRPD and tries to implement it by decentralising residential facilities, creating sheltered jobs outside workshops, and making their educational facilities more and more inclusive. There is no doubt that steps are taken in order to overcome the results and effects of segregation and isolation. However, all these efforts – whether they can be called truly inclusive or not – are taken without consultation with the persons with disabilities who are the service users, or the representative organisations of persons with disabilities. For example, more than 100 persons with disabilities have been placed outside sheltered workshops in so-called sheltered placements within the open labour market. When I asked the staff responsible for these steps how these decisions were made and whether at any point the affected person with a disability was asked and involved, the answer was very disappointing. All decisions within this process, such as who will be placed, in what kind of job, under what circumstances, were made solely by the staff members. The only time during the entire one-day training session that staff members cited the wishes and preferences of the service users was when it came to defending segregated institutional services: 'Our persons with disabilities want to remain in sheltered workshops, they want to remain in their group homes, they want to remain in special schools! Surely the UN CRPD must provide rights in this regard.' When I responded with the question of whether they would find that the UN Convention on the Elimination of all Forms of Discrimination Against Women should give women a right to choose

prostitution or that the UN Convention on the Rights of Children should give children the right to choose child labour, they could not follow my thoughts.

Similarly, in a recent case decided by the Federal Constitutional Court of Germany, the voice of the person with a disability was simply dismissed by taking an incapacity approach to persons with psychosocial disabilities. The sixty-four-year-old woman, who was diagnosed with schizoaffective psychosis and dementia, was hospitalised by her guardian in order to treat some auto-immune disease. When further examination showed that she had also developed breast cancer, a court order was sought in order to apply forced treatment. In response to questions from the court, the woman repeatedly stated that she did not wish to be treated for her cancer, either surgically or with chemotherapy. While the court described her as being mentally capable of expressing 'her natural will', her will was dismissed as 'unfree' because of her impairment. In cases like this, where courts find the person with a disability to be legally incapable of giving informed consent, the Federal Constitutional Court of Germany ruled that the state has a protection duty to save the health and life of the person with a disability. German law did not allow for compulsory treatment in this case because legislation following recent reforms has reduced forced medical treatment to situations of institutional commitment. This woman could not be committed since she was already in hospital and too weak to leave. The Federal Constitutional Court of Germany declared the existing law, with its restrictions, unconstitutional. It did not go as far as calling forced medical treatment a benefit or a privilege, as some legal scholars do, but it called it an 'option' which must not be denied to a person deemed to be incapable of forming a 'free will'.¹ The approach taken by the Court is not new – the concept of 'unfree will' has been developed previously under German guardianship and mental-health laws. It is the back-door option for guardians, doctors and judges when persons with disabilities are capable of expressing their will but this will is contrary to medical expertise. While legal scholars, as well as judges, acknowledge that, in general, there is a right to take risks and the Federal Constitutional Court of Germany has previously recognised a 'right to disease'² as part of a person's right to self-determination, this right is not applied if a person is characterised as incapable of taking a decision based on 'free will'. Furthermore, the Federal Constitutional Court of Germany found that its decision did not violate international law, notably the UN CRPD. Taking note of Article 12, General Comment No. 1 and our concluding observations relating to Germany's first state report, the court realised that the UN CRPD Committee holds completely different opinions on this matter. However, our jurisprudence was characterised as unspecific or ambiguous in relation to the cases before the Court.³ This characterisation was made even though General Comment No. 1 clearly says that there is no such a thing as legal incapacity and that forced treatment cannot be justified under any circumstances using impairment or disease (Committee on the Rights of Persons with Disabilities, 2014, paras 8, 25). The Court went even further and pointed out that the views of a committee that has competence to interpret a human rights treaty are to be given weight but are not binding on international or national courts under international law.⁴ Thus, dismissing the views of the CRPD Committee, the court noted General Comment 35 of the Human Rights Committee, which allows for deprivation of liberty on the basis of impairment under the International Covenant on Civil and Political Rights.⁵

1 Bundesverfassungsgericht (BVerfG), Beschluss vom 26.juli 2016–I BvL 8/15, para. 58.

2 BVerfGE 128, 282 <304>.

3 BVerfG Beschluss vom 26.juli 2016–I BvL 8/15, para. 91.

4 BVerfG Beschluss vom 26.juli 2016–I BvL 8/15, para. 90.

5 BVerfG Beschluss vom 26.juli 2016–I BvL 8/15, para. 90.

Such dismissal of the voices of persons with disabilities, whether as parties to judicial proceedings, or as experts in human rights treaty bodies (all but one member of the CRPD Committee was a person with a disability when General Comment No. 1 was adopted) by legal scholars and judges of the modern world, can only be explained by the deeply entrenched medical model of disability in our (legal) culture. Gerard Quinn has recently described this as follows:

'In the esoteric domain of ethics – well, esoteric, if you are a lawyer like me – you will be amazed to see that persons with intellectual disabilities are not altogether embraced. Ethicists have long disputed whether persons with intellectual disabilities are 'morally considerable' or possess 'full moral status' to be considered the fitting subjects of justice. Why? This is so for one very simple reason. Rather unlike the biologists, the ethicists tend to consider cognitive capacity to be the key to 'full moral status'. That is to say, they used the indicator of cognitive ability to distinguish between those entities with full moral status, those with lesser moral status, and those with no moral status (like a rock). . . . This tells you lot. If our underlying understanding of ethics is one that effectively excludes persons with intellectual disabilities from the 'moral community' then can it be any surprise that the law has followed suit?' (Quinn, 2016, p. 7)

The UN CRPD has codified the human rights model of disability (Degener, 2016) and the doctrine of universal legal capacity is part of it. Many countries have taken considerable legal reforms in order to align their legislation with the UN CRPD. Often these countries do not come from the wealthy parts of this world. For example, Peru has completely abolished substituted decision-making from its civil and mental-health law following our recommendations in our concluding observations on its first state party report (Committee on the Rights of Persons with Disabilities, 2012). Other countries have gone in similar directions. Those legal reforms are only the first tiny steps in the realisation of the rights enshrined in Article 12 UN CRPD. Many questions are yet unresolved. Some of these questions are taken up by the VOICES project. The papers in this edition seek to give some answers. They were developed as a starting point for the theoretical framework of the project. They seek to address three foundational questions:

- 1 What constitutes an exercise of legal agency from an individual within the right to legal capacity protected by Article 12 CRPD?
- 2 What are justifiable limits on individual agency which can be imposed by the state and apply to everyone, regardless of disability or decision-making ability?
- 3 How can we ascertain whether an individual is giving free and informed consent (necessary to make an action legally binding), without engaging in a functional assessment of that person's mental capacity?

Prior to addressing these questions, the first paper, by Clíona de Bhailís and Eilíonóir Flynn, provides an overview of selected literature on Article 12, its origins and development in international law, and the emerging literature since the publication of General Comment No. 1 by the UN CRPD Committee. It explains why Article 12 is identified as one of the main catalysts for change in international human rights law. Starting with a brief history of the right to equal recognition before the law, it clarifies some key terms appearing across the literature in this area. It examines the development of Article 12 during the negotiation of the treaty by the Ad Hoc Committee, and explains the legal impact of General Comment No. 1 and reviews a selection of literature responding to General Comment No. 1.

The following paper, by Anna Arstein-Kerslake and Eilíonóir Flynn on the right to legal agency, explores the concept of legal agency and what exactly Article 12 protects. It provides a definition of legal agency and applies it to the context of cognitive impairment and various case-studies. Applying a theory of domination in relationships of dependency, the authors argue that individuals with

disabilities experiencing domination are forced to exert legal agency at a higher rate than people not experiencing domination. They also argue that mental-health law and legal-capacity law in general provide hardly any protection against domination. The paper represents an important step forward in the scientific of debate around legal capacity by contextualising it within the wider political theory and philosophy.

The same authors reflect in the following paper on state intervention in the lives of people with disabilities and argue for a disability neutral framework in this regard. The paper provides some guidance on the nature and quality of state intervention which are to be regarded as permitted and non-discriminatory and how the state can respond to emergency situations in a manner that continues to respect the individual's legal agency. Drawing on feminist literature on state intervention in relation to domestic violence, the authors develop an interesting roadmap for non-discriminatory, socially justified and effective state intervention in the context of disability.

Eilionóir Flynn and Liz Brosnan explore and discuss the concept of consent in relevant human rights frameworks and theories of consent. They propose to apply a 'freedom to negotiate' standard in order to avoid some of the pitfalls in existing law. They further elaborate upon legal capacity, freedom to negotiate, and provision of accessible information, respect for women and preferences and voluntariness as the essential ingredients for reframing consent. The paper also identifies those conditions which need to be abolished or minimised to ensure valid consent. It draws on feminist thinking on freedom to negotiate consent to sex and applies this to freedom to negotiate consent to medical treatment.

Finally, Tina Minkowitz and Amita Dhanda, renowned scholars and activists, and both members of the International Advisory Committee for the VOICES project, have generously provided their insights and critical analysis of the arguments made throughout the Special Issue. Their central involvement in the negotiations of the CRPD, and in particular on Article 12, makes their perspectives all the more valuable in the ongoing discussion about how best to achieve universal recognition of legal capacity.

All the papers in this Special Issue carry the legal debate on legal capacity in the context of disability further. They provide original and groundbreaking food for thought relating to the implementation of Article 12 UN CRPD and give answers to questions which remained open during the first ten years of the existence of the UN CRPD. The volume thus entails significant subject matters and is timely and well written.

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