

WHAT MAKES A 'GOOD' CONFERENCE FROM A SERVICE USER PERSPECTIVE?

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I. INTRODUCTION

This article started with a question from one academic wearing an editor's hat to another academic wearing an academic service user's hat¹: conversing about a conference both had attended, the question asked was about the features that make conferences 'good' from a service user perspective. The question led to the comments that form Part II of this article. We then decided that we should combine resources and examine what the Convention on the Rights of Persons with Disabilities 2006 (CRPD)² has to say about the matter, identifying the normative framework of rights in the context of academic conferences that belong to those who attend in the context of experiencing psychosocial/mental impairment which in interaction with attitudinal and environmental barriers cause them to experience disability; and the corresponding obligations on conference organisers and/or those who regulate the situation and so might be required to impose obligations on conference organisers. This material, in Part III, is followed by some final reflections and thoughts as to good practice.

The context in which our arguments are framed is academic conferences on mental health and mental capacity law. Although our reference to 'service user' is therefore limited, some of our contentions can no doubt be applied to people experiencing other forms of disability and to conferences of a different type. These wider points are not a concentration in this article, but only because it was conceived and written with a more specific focus. Naturally, we are not suggesting that persons experiencing psychosocial or intellectual disabilities will only be interested in conferences on mental health and mental capacity matters, or that people experiencing other forms of disability will not have an interest in such conferences.

II. INITIAL COMMENTS

When Kris first asked me to write something on this topic I felt a bit indignant – what makes you think it would be any different to what you think makes a 'good' conference – presentations that provide new knowledge and/or perspectives on existing knowledge that are delivered well, and engagement with others, resulting in personal development through learning, reflection and networking. Having gotten over my initial indignation, I came to appreciate that maybe there are some matters concerning conferences that

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¹ 'Service user' is the term primarily used, throughout the present article, to describe people with personal experience of mental distress. This is for no other reason than it is the self-titled descriptor of one of the authors; and for many others in similar roles internationally at the present time. It is acknowledged that language itself is a matter of inclusion and a wide range of preferred self-descriptors exist.

² (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13 Dec 2006, (Opened For Signature) 30 Mar 2007, [Entered Into Force] 3 May 2008.

are particularly important from a service user perspective and that ought to be discussed.

A. Inclusion/exclusion

Recently I was involved in some research into the concepts of social inclusion and exclusion – as they relate to discrimination particularly – from the subjective and cross-cultural perspectives of people who experience mental distress in Aotearoa/New Zealand.³ As a subjective phenomenon, social exclusion is the sense of “Otherness”, as if one is an alien. Whereas, the subjective phenomenon of social inclusion is feeling you are exactly where you should be, with the people who you should be with, and as the person you really are. This resonated with me in terms of the present article. Generally at conferences I do feel the sense of being ‘other’. However, I have now had the opportunity to attend a number of service user conferences, namely the Nutters conference which was held in New Zealand in 2006 (although I was initially loathe to go because I don’t like the term ‘nutter’) and the service user academia symposiums;⁴ and I can’t communicate it any better than by saying that at those I feel I am exactly where I should be, with the people who I should be with, and as the person I really am.

Does that mean that we are unable to come together to conference in a way that is inclusive of all of us? I hope not but there is work still to be done, with some conferences requiring more work than others.

B. Nothing about us without us

Not long after I started in my first service user role – consumer advisor – I attended a mental health service conference in 1998. I think there may have been three of us coming from a service user perspective who attended. We went to everything, cringed a lot, didn’t say anything and engaged with no-one. The mantra of ‘nothing about us without us’ applies equally to conferences as it does to anything else concerning mental health. What’s more, that must extend to all aspects of the conference in order to be meaningful – organising committees, key-note and concurrent session presentations, posters, attendees, panellists.

Some conferences responded to the mantra of ‘nothing about us without us’ by facilitating a critical mass of service users to be in attendance. In some situations one may have been forgiven for thinking that a bus had been taken around all the local inpatient units to collect all the service users for a day trip. This practice seemed to overlook the importance of the ‘advisor’, ‘activist’, ‘worker’, ‘academic’ part of the role

³ Gordon, S., Davey, S., Waa, A., Tiatia, R., & Waaka, T. (In press). *Aotearoa/New Zealand: Social Inclusion and Exclusion, stigma and discrimination, and the experience of mental distress*. Auckland: Mental Health Foundation.

⁴ This event originated in Auckland in 2011 and has subsequently been held annually via collaborations between universities in Australia and New Zealand. This symposium is for service users holding academic, education or professional development positions or aspiring to do so, and those (usually non-service users such as health professional academics and carers) who promote, support and advocate for these roles in academia and service settings.

description. Often these masses were visibly unwell and/or bombed out on medication and would spend the day either smoking or eating. In my opinion, this was not meaningful or respectful involvement for those service users in attendance, apart from perhaps in terms of a good feed and peer socialisation, or for others in attendance.

'Consumer days' were initially another popular way to involve service users at conferences. In my experience these were a mixed bag. Often they were facilitated more as a therapy session or an opportunity to spend hours debating the language we used to refer to ourselves, which whilst important, did get rather tiresome. In my opinion a good 'consumer day' is run similarly to any other professional body meeting where you discuss the issues and opportunities facing the *work* that you do. Of course, it is important that there is then provision for that information to be shared with the wider constituency.

Nowadays, I think many conferences do encourage and support the engagement of service user advisors, activists, workers, and academics in a manner that certainly has the potential to facilitate meaningful involvement. However, one of the things that has struck me recently is that there often remains an element of segregation, particularly in terms of service users engaging with service users, and others engaging with others, including by way of attendance at presentations – service users go to service user presentations, others go to what I perceive them to believe are the 'real' presentations. I think this could be partly addressed by having service-user presentation only streams.

C. Experiential-based knowledge

In terms of new knowledge and/or perspectives on existing knowledge, lived experience needs to be valued; and the lack of appreciation for that value is, in my opinion, the biggest barrier to 'good' conferences from a service user perspective. I find this perplexing. Perhaps it is a confounding of favourable perspectives on my part but the presentations people most often cite as having had the most immediate and lasting impact are those based on personal experience. Obviously not all personal experience based presentations have this level of impact. Like most things, there is an art to crafting and delivering such presentations. It is not simply a matter of sharing your story. Experience-based presentations must be tailored and relevant to the focus of the conference, its theme and audience. Often these presentations involve contesting 'dominant' paradigms and it is important that that is done in such a way that the audience will be receptive to (e.g. challenging but not attacking). It is also important to identify how the personal experience being shared applies in terms of new knowledge and/or perspectives on existing knowledge. Sometimes I feel presenters get distracted or daunted and feel the need to play-down their personal experience and come from a more 'academic' or traditional knowledge focused perspective. I can understand this but it is vitally important that if our role is to deliver a service user perspective, then that requires us to maintain a focus on the import and value of experiential-based knowledge. It is not a good idea to craft and deliver your presentation when unwell: been there, done that, got the stunned audience reaction to prove it. This can be difficult to manage if you get unwell in the intervening period between acceptance and delivery of a presentation however, this is no different to anyone else – there are a number of reasons why people are unable to fulfil their

commitments on the day and good conferences should have contingencies in place. At the service user symposium we have a couple of extra presentations on stand-by.

D. A recent experience

Some 18 years after I attended my first conference in a service user capacity, I was stunned when in 2016 I attended a conference that completely and utterly flew in the face of 'nothing about us without us'. To my knowledge there were only two people from a service user perspective in attendance and I was the only one that presented to the 20 or so people – out of the 200 in attendance – that chose the service user option. Admittedly I wasn't that well going in (note to self: take own advice) and I am not great at small talk at the best of times and so my sense of being 'other' was exacerbated until acute alienation set-in and grew into full blown paranoia – I even thought the conference organising company didn't want me there! I spent the majority of the conference in my room and most definitely did not attend the conference dinner. However, on the final day of the conference I had to check out of my room in the morning – by that time I was exhibiting some rather bizarre behaviour. Where is the quiet room when you need it? Well, definitely not here. So, I went to the hotel bar, wrapped my coat around my head, and started rocking. And then something extraordinary happened – the hotel staff inquired as to what they could do to help me; they turned the music down, they bought me tissues and a hot lemon, ginger and honey drink, they asked if I would be most helped by them sitting with me or leaving me alone, they attempted to change my flight so I could get home sooner. The irony: 200 psychiatrists one level above discussing the intricacies of disorders, diagnoses and medications whilst the basics of human kindness and compassion were being extended to me to support me out and away from one of the worst examples of doing nothing about us with us that I have ever encountered. I suppose the lesson being that a 'good' conference from a service user perspective is not just an academic exercise, it extends to being and keeping safe.

The remainder of this article focuses on human rights imperatives that support inclusive conferences and a series of suggestions and guidance that could transform this type of conference experience from being exclusionary and unsafe, to being inclusionary and safe for service users and of benefit to all.

III. THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES 2006

The human rights framework that has developed over the last 70 years provides a legal obligation that supplements the moral force and simple decency of conferences being designed to be inclusive. At the same time, the existence of a framework that brings with it legal obligations, provides an easier justification for why an approach should be adopted: 'because it's the law' is a simple response to anyone who might doubt the sense of something. The framework is one that matures, and has seen the bringing into force of specific protections for persons with experience of disabilities. In this part, we set out first the place of non-discrimination as a core component of the human rights regime, then outline both the core principles behind the CRPD and specific rights it contains that, together, allow for the contention that creating a 'good' conference for service users is a matter of legal obligation.

A. Inclusivity as a part of non-discrimination: introduction

We are both based in Aotearoa New Zealand, where conferences and public events are invariably opened with te reo Māori speeches and songs. But New Zealand sign language – also an official language – is present less regularly. However, s 7 of the New Zealand Sign Language Act 2006 provides a right for parties, their representatives and members of the tribunal to use sign language in court proceedings. Naturally, there is a consequence to this, namely that there must be interpretation.⁵

The official recognition of sign language reflects an ethos of inclusivity backed by a legal framework, and is called for regularly by the Committee on the Rights of Persons with Disabilities,⁶ the body established under article 34 of the CRPD to carry out various functions, namely considering reports from states as to the progress in their obligations to put the Convention into effect (articles 35 and 36), reporting to the UN and making suggestions and recommendations (article 39), and, in relation to states that have signed the Optional Protocol,⁷ considering complaints. At the time of writing, the Committee has issued a few decisions on complaints, four general recommendations about the meaning of aspects of the Convention, and considered reports from a significant number of countries. This allows a growing confidence as to how the Convention will be interpreted.

The context of the Convention is that it is part of the UN's human rights regime, which centres around the International Bill of Rights, namely the Universal Declaration of Human Rights 1948 (UDHR),⁸ the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR)⁹ and the International Covenant on Civil and Political Rights 1966 (ICCPR).¹⁰ The motif of equality is a core standard: the UDHR opens with

⁵ Te Ture mō Te Reo Māori 2016, the Māori Language Act 2016, confirms (under section 5) the status of the Māori language as an official language of New Zealand and the right (under section 7) to use it in legal proceedings.

⁶ This is discussed below.

⁷ Optional Protocol to the Convention on the Rights of Persons with Disabilities (United Nations [UN]) 2518 UNTS 283, UN Doc A/61/611, Annex I, GAOR 61st Session Supp 49 vol 1, 80, (Adopted) 13 December 2006, (Opened for signature) 30 March 2007 [Entered Into Force] 3 May 2008.

⁸ (United Nations [UN]) UN Doc A/810, 71, UN Doc A/RES/217(III) A, GAOR 3rd Session Part I, 71 (Adopted) 10 December 1948 the text is available at <http://www.un.org/en/universal-declaration-human-rights/index.html>. See also Charter of the United Nations (done at San Francisco, United States, on 26th June 1945) (United Nations [UN]) 892 UNTS 119, 59 Stat 1031, TS 993, 3 Bevans 1153, 145 BSP 805, (Adopted) 26 June 1945, (Signed) 26 June 1945, [Entered Into Force] 24 October 1945, available at; <http://www.un.org/en/charter-united-nations/index.html>. Its preamble refers to the determination of the states "to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women ..." The purposes of the UN are set in article 1 as including ".... To achieve international cooperation in ... promoting respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language, or religion ..." Noticeably, the grounds on which discrimination is improper is more limited and does not have the catch-all reference to "other status" that appears in the UDHR a short time later.

⁹ (United Nations [UN]) 993 UNTS 3, CTS 1976/46, S Exec Doc D, 95-2 (1978), GAOR 21st Session Supp 16, 49, UN Doc A/6316, UN Doc A/RES/21/2200, (Adopted) 16 Dec 1966, (Signed) 16 Dec 1966, [Entered Into Force] 3 Jan 1976.

¹⁰ (United Nations [UN]) 999 UNTS 171, UN Doc A/6316, UN Doc A/RES/2200(XXI), Annex, UN Reg No I-14668, (Signed) 16 December 1966, [Entered Into Force] 23 March 1976.

the indication in its article 1 that “All human beings are born free and equal in dignity and rights”, and makes the point in its article 2 that the rights it goes on to set out are to be enjoyed by all “without distinction of any kind” based on the status of the person. In short, the recognition of equality and prohibition of discrimination are features of the first two articles of this opening document of the International Bill of Rights. Article 7 supplements this with the indication that:

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 2(2) of the ICESCR specifies that the rights it contains have to be guaranteed “without discrimination of any kind” arising from status; article 2(1) of the ICCPR is to similar effect, albeit that it refers to the absence of “distinction” rather than referring to “discrimination”. The ICCPR contains the equivalent of article 7 of the UDHR: its article 26 notes:

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

In short, protection against discrimination in relation to anything set out in law is itself a civil and political right. The need for “equal and effective protection” is to be noted.

Supplemental treaties have been developed that explain the application of this and the other substantive standards in the context of various groups of people who have often been subject to discriminatory treatment on account of various features (race, gender, youth, migrant worker status and disability). The CRPD is designed to counter, as it identifies in its preamble, the fact that, despite the standards set out in these human rights instruments “persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world”.¹¹ It does not seek to define ‘disability’, noting that it is “an evolving concept ... that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.¹² However, article 1 of the CRPD confirms that included within the Convention are “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder

¹¹ Convention on the Rights of Persons with Disabilities (United Nations [UN]) 2515 UNTS 3, UN Doc A/RES/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13 Dec 2006, (Opened For Signature) 30 Mar 2007, [Entered Into Force] 3 May 2008, preamble para (k). A Handbook for Parliamentarians on the Convention, *From Exclusion to Equality, Realizing the rights of persons with disabilities*, issued by the High Commissioner for Human Rights, the Department of Economic and Social Affairs of the UN, and the Inter-Parliamentary Union, <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html>, last accessed 19 July 2017 - contains the comments that “Persons with disabilities remain amongst the most marginalized in every society. While the international human rights framework has changed lives everywhere, persons with disabilities have not reaped the same benefits” (Foreword, piii).

¹² Convention on the Rights of Persons with Disabilities 2006 preamble para (e).

their full and effective participation in society on an equal basis with others”.

The specific problem of attitudes is summed up in a Handbook for Parliamentarians on the Convention, namely that:¹³

Persons with disabilities are still primarily viewed as “objects” of welfare or medical treatment rather than “holders” of rights. The decision to add a universal human rights instrument specific to persons with disabilities was borne of the fact that, despite being theoretically entitled to all human rights, persons with disabilities are still, in practice, denied those basic rights and fundamental freedoms that most people take for granted.

Accordingly, note the authors:¹⁴

The Convention is a complement to existing international human rights treaties. It does not recognize any new human rights of persons with disabilities, but rather clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities.

This reference to the lack of new rights is an accurate but understated summary of the aims of the Convention. In particular, since rights are concepts that have meaning, a change that elucidates a meaning more accurately may properly be said to create a new concept. Moreover, since the human rights framework is designed to be “practical and effective”,¹⁵ the high-level statements of rights found in the overarching International Bill of Rights will often require more specific elucidation. Treaties such as to the CRPD provide examples of what this specificity means. Hence, as Harpur has commented:¹⁶

... the CRPD does not merely re-state existing human rights. The CRPD re-states existing rights and then creates incidental rights to ensure that existing rights are realized. Through this process existing rights are provided greater clarity, which provides disability advocates and scholars with a powerful tool to hold states accountable.

In fact, the power of the CRPD is that it compels a shift in attitudes that secure what has been described as a paradigm shift. Glen, speaking in the context of guardianship arrangements for people with intellectual disabilities, has noted that the concept of a paradigm shift, involving a development that alters or reorients a historical

¹³ *From Exclusion to Equality, Realizing the rights of persons with disabilities*, above n 10, p4.

¹⁴ *From Exclusion to Equality, Realizing the rights of persons with disabilities*, above n 10, p5.

¹⁵ This phrase is used by the European Court of Human Rights in relation to its decisions under the European Convention on Human Rights, Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols No 11 and 14 (Council of Europe) 213 UNTS 222, ETS No 5, UN Reg No I-2889, (Opened For Signature) 4 November 1950 [Entered Into Force] 3 September 1953 [Amended] 1 June 2010; available at <http://conventions.coe.int/treaty/en/treaties/html/005.htm> (last accessed 17 August 2017). For example, in *Airey v Ireland*, Merits, App No 6289/73, A/32, IHRL 23 (ECHR 1979), [1979] ECHR 3, (1980) 2 EHRR 305, [1979] EuGRZ 626, 9th October 1979, European Court of Human Rights [ECHR], it commented at [24], “The Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective”. The context was the Court’s conclusion that legal aid had to be made available if it was necessary to secure a fair trial in a civil matter even though the Convention is express as to legal aid only in relation to criminal charges.

¹⁶ Paul Harpur “Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities” (2012) 27:1 Disability and Society 1, 2.

perspective,¹⁷ is a “framework” that is “helpful in moving us from what has become a comfort zone to a new way of thinking about people with intellectual disabilities and their capacities”.¹⁸ The Committee on the Rights of Persons with Disabilities has endorsed the idea that there is a new paradigm in various Concluding Observations to states parties.¹⁹ Accordingly, we turn to the rights of persons experiencing psychosocial/mental impairment, which in interaction with attitudinal and environmental barriers cause them to experience disability, who attend conferences to present or participate and suggest what they should be understood to mean. This involves first understanding the core obligation arising.

B. The core obligation under the CRPD

The basic general obligation undertaken by the CRPD in order to set right the ongoing failure to secure equality of enjoyment of rights, and thereby secure the new paradigm involved, is set out in article 4: “ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability”.²⁰ The key question of what amounts to “discrimination on the basis of disability” is defined in article 2:

“Discrimination on the basis of disability” means any distinction, exclusion or restriction on the basis of disability which has the purpose *or effect* of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation. (Emphasis added.)

¹⁷ Kristin Booth Glen, “Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond” (2012) 44 *Columbia Human Rights Law Review* 93, 96-99; the phrase describing the concept is credited to Thomas S Kuhn *The Structure of Scientific Revolutions* (University of Chicago Press, Chicago, 1962).

¹⁸ Kristin Booth Glen, “Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond” (2012) 44 *Columbia Human Rights Law Review* 93, 98. Kristin notes that the view of people with limited capacity being treated as objects of charity and placed under guardianship in their best interests was being replaced by a supported decision-making approach – an “emerging paradigm” which “challenges our perceptions and our understanding of when, how, and even *if* the state may intervene in a person’s life”.

¹⁹ See the concluding observations on Belgium UN Doc CRPD/C/BEL/CO/1 (28 October 2014), para 17, dealing with the Committee’s concerns as to inadequate steps to comply with the need for awareness-raising to comply with article 8: “The Committee is concerned that there is no sign that a paradigm shift has occurred following ratification of the Convention, whereby persons with disabilities are recognized as basic rights holders taking part in decisions affecting them and asserting their rights in society”; Slovakia UN Doc CRPD/C/SVK/CO/1 (17 May 2016), para 4, under the heading “Positive aspects”: “The Committee welcomes the recognition of the paradigm shift required to realize the rights of persons with disabilities in the State party as well as the efforts to adopt a human rights-based approach to disability”; Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 34(b), in the context of the Committee’s concerns that article 12 was breached because of the failure to move from substituted decision-making processes, it recommended that Cyprus “Allocate adequate human, technical and financial resources to support the transformation from the present paradigm to a new paradigm that is in line with the Convention, and being guided by, *inter alia*, general comment No. 1 (2014)”.

²⁰ It is to be noted that article 4.4 makes it plain that the Convention is not to be used as a justification for reducing the impact of any provisions of domestic law (or any other provisions of international law binding on the state) “which are more conducive to the realization of the rights of persons with disabilities”; nor can there be any restrictions on human rights that exist under the law, conventions, regulation or custom of domestic law on the basis that there is lesser protections guaranteed in the Convention.

The “denial of reasonable accommodation” is also defined in article 2 in the following terms:²¹

“Reasonable accommodation” means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

The Convention sets out various specific obligations that supplement the general obligation to promote rights: states have to:

- “adopt all legislative, administrative and other measures” to implement the Convention (article 4.1(a)),
- take “all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities” (article 4.1(b)),²²
- mainstream consideration of matters of disability by ensuring that the rights of persons with disabilities are taking into account “in all policies and programmes” (article 4.1(c)),
- ensure that all public bodies comply (article 4.1(d)),
- regulate to prevent private sector discrimination on the basis of disability (article 4.1(e)),²³
- promote “universally designed goods, services, equipment and facilities” (article 4.1(f)), which picks up a further concept set out in article 2 – namely “Universal design”, which is defined as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design”;²⁴
- promote research into and the availability of new assistive technologies (article 4.1(g)), and accessible information on technologies and support services (article 4.1(h)), and
- promote the training of those who work with people with disabilities as to what their rights entail (article 4.1(i)).

These features can be seen as examples of steps that have to be taken by the state to comply with the general principles behind the terms of the Convention, which are set out in its article 3 and are worth reproducing in full:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The focus is full integration and respect for autonomy, which may require additional consideration to overcome the impact of any disability or the perception of others as to

²¹ See also the concept of “Universal design”, described below.

²² This has to involve consultation with and the involvement of persons with disabilities: article 4.3.

²³ This reflects the concept of “horizontal effect”, namely that breaches of rights caused by private persons or bodies can be the responsibility of the state if the latter has not handed down legislation or taken other measures within its powers to control private sector behaviour in order to safeguard rights.

²⁴ It is also made clear in article 2 that “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed”.

its impact, so as to ensure true equality.

This account of the general features of the CRPD allows the following points to be made about its consequences in the specific context of conference organization. Firstly, in light of article 4.1(d) and (e), whether a conference is organised by a public or private sector body, the obligations that flow from the CRPD should apply. The state is under a duty to ensure that appropriate mechanisms are in place. Those who organise conferences, whether they are state-funded or entirely commercial, can voluntarily ensure respect for the rights of attendees who experience disability (which consequently may avoid the need for legislation) if that means there is no need for corrective state intervention.

Secondly, the core of ensuring non-discrimination includes ensuring that reasonable accommodation is made, since denial of reasonable accommodation amounts to discrimination on the basis of disability. In short, such proportionate and non-burdensome steps as can be taken to ensure that a conference can be enjoyed equally by persons with experience of disability must be taken: this will, naturally, turn on the facts, including the information available as to the needs of those with experience of disability who wish to attend a particular conference.

Thirdly, and in fact before one gets to the need for reasonable accommodation, there is the important concept of universal design, the definition of which is set out above and in the conference setting means the use of “environments, programmes and services” that can be used by all. Essentially, the starting question in terms of conference design, including the facilities at which the conference will be held, should be whether the arrangements are disability-friendly in that they can be used by all people, whether impaired or not. The obvious point to make, and the reason why universal design should be the opening motif, is that the greater the level of universal design, the less need there will be for separately-required reasonable accommodation. This reflects an important feature motivating the concept of universal design, namely that it prevents inclusion being a supplemental task, or one that puts the inclusion of persons who experience disabilities as something of an end-thought: this is self-evidently not an appropriate approach.

C. Relevant specific rights in the CRPD

Various of the specific rights that have to be guaranteed by virtue of the various provisions of article 4 (noted above) are of obvious relevance to the context of academic conferences: namely article 9 (accessibility), article 21 (freedom of information and access to information), and article 24 (education). It is important to understand the breadth of their coverage to appreciate their potential value; it is also important to read them together with the core obligation described above.

1. Accessibility

The right to accessibility in article 9 (and the supporting principle in article 3(f)) covers not just the physical environment and transport facilities (important though that is, including in the context of conferences, given that people have to get to an event and

be able to get into lecture halls): it also covers “information and communications ... and ... other facilities and services open or provided to the public” (article 9(1)). The purpose of this is set out as “To enable persons with disabilities to ... participate fully in all aspects of life” (article 9(1)). Obviously, academic conferences are often linked to the promulgation of public of research, which is information and so within the coverage of article 9(1).

The state must ensure that practical effect is given to this by reason of article 9(2), which points to the need for monitoring, facilitation and promotion, including through the training of “stakeholders”. When combined with the general obligation in article 4(1) to take steps to change laws and practices, this means that failures by those involved in conferences to meet the needs of accessibility should be dealt with by way of relevant regulation. Indeed, article 9(2)(b) requires the state to ensure that “private ... facilities and services which are open or provided to the public” take accessibility needs into account. Other relevant specific obligations set out in article 9(2) include the provision of relevant interpreters and intermediaries so as to facilitate accessibility. This obligation as to provision is state-wide, which will allow entities that arrange conferences (or other examples of relevant services within article 9) to hire them.

The Committee on the Rights of Persons with Disabilities has expanded upon the impact of article 9 in its General Comment No 2.²⁵ It makes the point that as “[a]ccessibility is related to groups, whereas reasonable accommodation is related to individuals”, “the duty to provide accessibility is an *ex ante* duty” which does not turn on the receipt of a complaint of non-accessibility.²⁶ This means that there should be a review of relevant laws to ensure universal design and accessibility standards, backed up by sanctions for non-compliance.²⁷ Moreover, the Committee indicates that there should be accessibility action plans, together with monitoring mechanisms to ensure implementation.²⁸ The Committee thereby makes it clear, perhaps particularly through the requirement for sanctions, which might be achieved via regulatory criminal law, that it takes seriously the need to ensure that organisations take suitable steps to comply with this aspect of inclusivity as an aspect of non-discrimination. Conference organisers can take the necessary steps to ensure participation: or public welfare regulation to require it will

²⁵ Committee on the Rights of Persons with Disabilities, General Comment No 2 (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014).

²⁶ (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [25]. In para [26], it is stated that “The duty to provide reasonable accommodation is an *ex nunc* duty, which means that it is enforceable from the moment an individual with an impairment needs it in a given situation, for example, workplace or school, in order to enjoy her or his rights on an equal basis in a particular context”.

²⁷ (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [28]. Indeed, it is also suggested that denial of access should be defined as amounting to discrimination: para [29]. The need for sanctions or penalties as part of the monitoring process has been a regular feature of concluding observations issued since the General Comment: see, for example, the concluding observations on Mexico UN Doc CRPD/C/MEX/CO/1 (27 October 2014), para 20(b) and (e); Germany UN Doc CRPD/C/DEU/CO/1 (13 May 2015), para 22(a); Ethiopia UN Doc CRPD/C/ETH/CO/1 (4 November 2016), para 20; Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 26. In relation to Kenya reference is made the need to implement regulations under its Persons with Disabilities Act No 14 of 2003 that include the making of “adjustment orders” for non-compliance: UN Doc CRPD/C/KEN/CO/1 (30 September 2015), para 18(b).

²⁸ (2014), Article 9: Accessibility [UN Doc CRPD/C/GC/2] (22 May 2014), para [33].

follow.

2. *Expression and Information*

Article 21 is the right to freedom of expression and opinion, and also the right of access to information. As such, it is phrased so as to include not just passing on views but also “the freedom to seek, receive ... information and ideas on an equal basis with others”.²⁹ This cannot be construed other than as including a right to attend conferences (both as a speaker and as an audience member) on equal terms, and hence with the requirements of universal design and accessibility to assist at the group level and reasonable accommodation to facilitate the needs of any particular individual.

The text of article 21 gives further assistance as to what this should entail in practice. States must take “all appropriate measures” to ensure people with experience of disability can exercise the right on an equal basis and, as part of this must, respect the communication of choice of the person with experience of disability. This is also defined in article 2, in which it is noted that:

Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology ...

In light of this, it is noted in article 21 that states have duties to provide public information in accessible formats and allow people with experience of disability to use their choice of communication in interactions with state machinery, but also are required to encourage the use of accessible formats in the mass media and by “private entities that provide services to the general public” (article 21(c)). Such specific references to the need for action by private entities reinforces the general point made above that the legal system has to be used to ensure that rights are respected within both the public and private sectors.

There is a specific obligation to both recognise and promote the use of signing (article 21(e)). In making recommendations for change as part of the concluding observations issued to states, the Committee on the Rights of Persons with Disabilities has regularly called for the recognition of sign language where it is not officially recognised, and for improvements in relation to its use in other instances, often in the form of additional training or funding to allow additional hiring of interpreters. Examples of calls for official recognition (which would no doubt prompt additional use and, naturally, empower users to remind others of its importance) include various wealthy nations such as Australia,³⁰ the Republic of Korea,³¹ Italy,³² and Canada (with a reference to both American and Quebec Sign Language to reflect the two main language cultures of the country).³³ In addition, there were instances where there was recognition but the law

²⁹ In this regard, it follows the structure of its equivalent in the ICCPR, Article 19.2, which expressly includes both imparting information and receiving it.

³⁰ Concluding observations Australia UN Doc CRPD/C/AUS/CO/1 (21 October 2013), para 44.

³¹ Concluding observations Republic of Korea UN Doc CRPD/C/KOR/CO/1 (29 October 2014), para 42.

³² Concluding observations Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 50.

³³ Concluding observations Canada UN Doc CRPD/C/CAN/CO/1 (8 May 2017), para 40.

was not properly implemented: this was recognised in the case of Costa Rica³⁴ and Croatia.³⁵ An interesting dynamic was noted in the context of Denmark, in relation to which there was a call for the recognition of Faroese sign language but also for people to have a right to use sign language even after a successful cochlear implant.³⁶

As has been noted above, human rights should be made “practical and effective”,³⁷ which in turn means that resources have to be in place to secure the implementation of a right. Hence, the Committee, whilst congratulating various countries for the recognition of the right to sign language nevertheless called for the taking of practical steps such as the provision of resources for training interpreters. Accordingly, for example, New Zealand was commended for recognising sign language as an official language and establishing a Sign Language Board to promote its use,³⁸ but was told that it needed to do more to promote the training and employment of sign language interpreters, particularly for Maori and Pacific peoples.³⁹ Similarly, the Czech Republic⁴⁰ and Ukraine⁴¹ were congratulated for official recognition but reminded that that was not the sum total of the obligation: the Czech Republic was informed of the obligation to provide resources for the training and hiring of interpreters to give effect to the right to use sign language,⁴² as was Ukraine.⁴³

The clarity of the calls for ensuring participation for those who make use of signing can be seen as an instance of a more general need. In relation to various countries, the call made was a more general one for use to be made of accessible formats of communication, and particularly in relation to public information. For example, in the case of Brazil, the call made was more generally for “resources and training” to be provided to allow information aimed at the public to be published “in accessible formats and technologies” (and in timely fashion);⁴⁴ in relation to Colombia, it was noted that there was a need for relevant resources “to facilitate access to information in accessible modes, means and formats of communication”;⁴⁵ and in the EU report, a reference to sign language was made in the context of it being one of the various “accessible languages, formats and technologies”.⁴⁶ Other examples include Denmark, which was encouraged to promote “augmentative and alternative modes of communication that are accessible to people with intellectual and mental disabilities”;⁴⁷ Cyprus, in relation to which it was noted that a right to use tactile communication would ensure its users

³⁴ Concluding observations Costa Rica UN Doc CRPD/C/CRI/CO/1 (12 May 2014), para 42.

³⁵ Concluding observations Croatia UN Doc CRPD/C/HRV/CO/1 (15 May 2015), para 32.

³⁶ Concluding observations Denmark UN Doc CRPD/C/DEN/CO/1 (30 October 2014), para 45.

³⁷ See text to fn 14 above.

³⁸ Concluding observations New Zealand UN Doc CRPD/C/NZL/CO/1 (31 October 2014), para 4.

³⁹ *ibid* paras 42/44.

⁴⁰ Concluding observations Czech Republic UN Doc CRPD/C/CZE/CO/1 (15 May 2015), para 4.

⁴¹ Concluding observations Ukraine UN Doc CRPD/C/UKR/CO/1 (2 October 2015), para 4(a).

⁴² Concluding observations Czech Republic UN Doc CRPD/C/CZE/CO/1 (15 May 2015), para 42.

⁴³ Concluding observations Ukraine UN Doc CRPD/C/UKR/CO/1 (2 October 2015), para 39.

⁴⁴ Concluding observations Brazil UN Doc CRPD/C/BRA/CO/1 (29 September 2015), para 39.

⁴⁵ Concluding observations Colombia UN Doc CRPD/C/COL/CO/1 (30 September 2016), para 51. This was a report that did not mention sign language or Braille specifically: but clearly they are included within the more general description.

⁴⁶ Concluding observations EU UN Doc CRPD/C/EU/CO/1 (2 October 2015), para 55.

⁴⁷ Concluding observations Denmark UN Doc CRPD/C/DEN/CO/1 (30 October 2014), para 49.

“their participation and recognition in all spheres of life on an equal basis with others”;⁴⁸ and Moldova, which was encouraged to use accessible formats for all public services, especially for children in inclusive education.⁴⁹

The more general point of principle of which these are illustrations, is that the Committee wishes that states take seriously the obligation to ensure that information can be passed and received: the obvious consequence of this is that publicly accessible information has to be provided in a way that allows equal access to people who experience disability. This will include information for which a conference registration is necessary. Whilst this most obviously includes supplemental methods of communication for the hearing and vision-impaired, what is needed will depend on the nature of the impairment, and so if participation in a conference requires a supportive environment, that is what is mandated.

The link between article 9 and article 21 is noted by the Committee, which comments that, “Without access to information and communication, enjoyment of freedom of thought and expression and many other basic rights and freedoms for persons with disabilities may be seriously undermined and restricted”.⁵⁰ In its concluding observations to Italy, the Committee makes specific reference to the need for the educational sector to ensure accessibility. It notes the need for an audit leading to an action plan:⁵¹

to ensure the provision of live assistance and intermediaries, including guides, readers and professional sign language interpreters, and augmentative and alternative communication across all public sectors. In particular, augmentative and alternative communication must be provided free of charge in the education sector.

Along similar lines, in its concluding observations relating to Jordan, the Committee expressed its concern about the difficulties of access to various aspects of life owing to limitations in communication,⁵² and so recommended that various steps be taken, including:

the provision of live assistance, intermediaries, guides, readers, accessible information kiosks, ticket vending machines, websites, mobile applications and professional and certified sign language interpreters to facilitate access to public buildings, facilities, transportation and information and communication services...

This language is suitable to cover the provision of information in the form of conference lectures and seminars.

3. *Education*

The final right of obvious application to academic conferences is the right to education,

⁴⁸ Concluding observations Cyprus UN Doc CRPD/C/CYP/CO/1 (8 May 2017), para 46.

⁴⁹ Concluding observations Moldova UN Doc CRPD/C/MDA/CO/1 (18 May 2017), para 41(c).

⁵⁰ Committee on the Rights of Persons with Disabilities, General Comment No 2, CRPD/C/GC/2, 22 May 2014, para [21].

⁵¹ Concluding observations to Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 24.

⁵² Concluding observations to Jordan UN Doc CRPD/C/JOR/CO/1 (15 May 2017), para 21.

as set out in article 24.⁵³ This expressly includes, in article 24.1, “an inclusive education system at all levels and life-long learning”. The importance of the right to education is noted, including such matters as developing human potential and personality, self-worth and dignity, and enabling effective participation in society. Article 24(5) deals more specifically with post-school education, indicating that:

States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Academic conferences should be considered to constitute part of lifelong learning. As has been noted already in relation to access rights, this obligation on states is to be combined with the general obligation of enforcement and as such, means that the failure of providers of lifelong learning to adopt relevant policies should lead to the imposition of regulation.

The Committee on the Rights of Persons with Disabilities has emphasised the value of the right to education in its fourth General Comment.⁵⁴ It comments that the changed perception of people who experience disabilities (as rights holders rather than as recipients of welfare) means that there is a recognised right to education, which has to be inclusive to ensure that people with experience of disability receive education of the same quality:⁵⁵ this seems obvious when one recalls the unimpressive history of the separate but equal motif in the context of racial discrimination.

The core components of inclusive education are enunciated by the Committee and include:⁵⁶

- (e) Respect for and value of diversity: all members of the learning community are equally welcome and must be shown respect for diversity ... All students must feel valued, respected, included and listened to ...
- (f) A learning-friendly environment: inclusive learning environments are accessible environments where everyone feels safe, supported, stimulated and able to express themselves ...

In relation to the right to tertiary and lifelong learning set out in Article 24(5), the

⁵³ Note should also be taken of article 29, the right to participation in political and public life, which will also include matters of law reform; academic conferences may include papers relating to law reform in the area of law that particularly affects persons who experience disability. This article will reinforce the need to steps to ensure equal participation in such a situation.

⁵⁴ Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016.

⁵⁵ Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, paras [1]-[3]. There is an older UNESCO Convention against Discrimination in Education (United Nations Educational, Scientific and Cultural Organization [UNESCO]) 429 UNTS 93, UN Reg No I-6193, (Adopted) 14 December 1960, (Signed) 14 December 1960, [Entered Into Force] 22 May 1962, which New Zealand ratified in 1963: it prevents separate systems or institutions for different groups save for permitting single sex schools and ones based on religion or language (Articles 1(c) and 2).

⁵⁶ Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [12].

Committee notes:⁵⁷

Attitudinal, physical, linguistic, communication, financial, legal and other barriers to education at these levels must be identified and removed in order to ensure equal access. Reasonable accommodation must be provided to ensure that persons with disabilities do not face discrimination. States parties should consider taking affirmative action measures in tertiary education in favour of learners with disabilities.

Just as there is a link between articles 9 and 21, so there is a link between articles 21 and 24. In particular, article 24(3) requires the development of suitable modes of communication in the sphere of education, with specific reference being made to the need to facilitate the learning of “Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills”, as well as sign language and making use of “peer support and mentoring”. Article 24(4) in turn recognises that this requires teachers who are able to use these modes of communication and have disability awareness training.⁵⁸ Article 8, which requires awareness-raising as to the rights and abilities of people with experience of disability, is worth noting. In its concluding observations to El Salvador, the Committee's recommendations included “promoting disability education as a cross-cutting theme in university courses”.⁵⁹

Reference can also be made to the UN's Sustainable Development Goals, as adopted by the General Assembly in September 2015.⁶⁰ The vision behind the 17 SDGs and accompanying 169 targets includes a vision of, inter alia, a “world with equitable and universal access to quality education at all levels”,⁶¹ and a commitment to “inclusive and equitable quality education at all levels” and to “life-long learning opportunities”, including for people who experience disabilities, which are viewed as having utilitarian skills-building purposes but also as reflecting participation in society.⁶²

Goal 4 is “Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all”, and the specific elements of this include, in Target 4.5:

By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations.

⁵⁷ Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [38].

⁵⁸ Accordingly, in the concluding observations to Australia UN Doc CRPD/C/AUS/CO/1 (21 October 2013), para 44, relating to article 21 freedom of expression, the Committee noted that it was necessary to facilitate alternative modes of communication in light of articles 24(3) (education) and also 29(b) (participation in public life). Going further, in the concluding observations to Azerbaijan UN Doc CRPD/C/AZE/CO/1 (12 May 2014), para 35, a similar point was made in the comments under article 21 but with a citation of article 9 as well as articles 24(3) and 29(b). Note also that in the concluding observations to the Dominican Republic UN Doc CRPD/C/DOM/CO/1 (8 May 2015), para 42, the Committee encouraged the use of sign language in educational institutions, starting in primary institutions.

⁵⁹ Concluding observations El Salvador UN Doc CRPD/C/SLV/CO/1 (8 October 2013, para 22.

⁶⁰ UN General Assembly *Transforming our world: the 2030 Agenda for Sustainable Development* A/Res/70/1 (25 September 2015).

⁶¹ *ibid* para [7].

⁶² *ibid* para [25].

Supplementing this, Goal 4(a) refers to the building and upgrading of “inclusive and effective learning environments for all”. UNESCO, working with other bodies, has developed a programme for the implementation of Goal 4, the Incheon Declaration and Framework for Action.⁶³ It builds on past commitments which have some references to education and people who experience disability. The World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs,⁶⁴ from 1990, set out the need for equity in Article III of the Declaration, including in Article III.5:

The learning needs of the disabled demand special attention. Steps need to be taken to provide equal access to education to every category of disabled persons as an integral part of the education system.

This led to the Dakar Framework for Action of 2000,⁶⁵ and the Muscat Agreement of 2014.⁶⁶ The latter set the provision for all of equitable and inclusive education (including lifelong learning) as the target for 2030,⁶⁷ to which fuller effect is given through the Incheon Declaration. It includes the indication in its paragraph 7 that:

Inclusion and equity in and through education is the cornerstone of a transformative education agenda, and we therefore commit to addressing all forms of exclusion and marginalization, disparities and inequalities in access, participation and learning outcomes. No education target should be considered met unless met by all. We therefore commit to making the necessary changes in education policies and focusing our efforts on the most disadvantaged, especially those with disabilities, to ensure that no one is left behind.

As with the rights already discussed, there is supplemental supporting material in Concluding Observations issued to states. For example, the Committee commended Austria for offering sign language interpretation at the tertiary level, but also expressed its disappointment that there had only been 13 students by the time the matter was considered and only 3 had graduated and recommended that more efforts be made;⁶⁸ Ecuador was encouraged to “Step up efforts to implement models of inclusive education for persons with disabilities at the university level by encouraging adaptations to the curriculum and premises of universities for the various courses they offer” as a response to the concern that the lack of adjustments meant that there was limited access;⁶⁹ Germany was encouraged to “[e]nsure that reasonable accommodation is provided at all levels of education and that the right to such accommodation is legally enforceable and justiciable before the courts” and to ensure that sign language was available in all

⁶³ UNESCO, Education 2030 – Incheon Declaration and Framework for Action, available at <http://en.unesco.org/education2030-sdg4>.

⁶⁴ UNESCO, World Declaration on Education for All and Framework for Action to Meet Basic Learning Needs, the outcome of the World Conference on Education for All – *Meeting Basic Learning Needs* at Jomtien, Thailand, 5-9 March 1990, UNESCO, Paris, 1990.

⁶⁵ UNESCO, The Dakar Framework for Action – Education for All: Meeting Our Collective Commitments, the outcome of the World Education Forum, Dakar, Senegal, 26-28 April 2000 (and several regional meetings), UNESCO, Paris, 2000. Specific reference to the needs of disabled people is made in declarations from the regional meetings.

⁶⁶ UNESCO, The GEM Final Statement – The Muscat Agreement, outcome of the Global Education for All Meeting, Muscat, Oman, 12-14 May 2014.

⁶⁷ *ibid*, para 10.

⁶⁸ Concluding observations Austria UN Doc CRPD/C/AUT/CO/1 (30 September 2013), paras 41 and 43.

⁶⁹ Concluding observations Ecuador UN Doc CRPD/C/ECU/CO/1 (27 October 2014), para 37.

institutions, "including at the post-doctoral level";⁷⁰ Croatia was encouraged to provide access at the tertiary level and provide reasonable accommodation, with the additional recommendation to establish "the principle that exclusionary and segregated education is discriminatory";⁷¹ and Italy was encouraged to ensure equal access and also "build and upgrade education facilities that are disability sensitive and safe".⁷²

The recommendations in relation to Chile provide a good example of a comprehensive approach. It was encouraged to take various steps to respond to concerns about "the lack of action by government authorities to promote inclusive higher education",⁷³ in addition to the general point relating to the link with the SDGs, namely:

- "(a) Implement a plan for transitioning towards inclusive education at all levels up to higher education, which provides for the training of teachers, the roll-out of comprehensive awareness-raising campaigns and the promotion of a culture of diversity;
- (b) Provide personalized instruction and the necessary support and resources, such as Braille and sign language, to foster inclusion, in particular of students with intellectual or psychosocial disabilities;
- (c) Ensure the accessibility of higher education institutions, including by facilitating reasonable accommodations in the admissions process and all other aspects of higher education; ..."⁷⁴

The Committee has indicated that the Convention approach to the right to education, picking up the paradigm changing motif, involves a "transformation in culture, policy and practice".⁷⁵ This may be over-stating it, since it will often be a matter that involves just some basic thought about inclusivity that will help to ensure that a conference is able to meet this need. Mainstreaming of a disability perspective, invariably by ensuring the involvement of people with experience of disability in the process of organising a conference and starting from the principles of universal design and, where necessary, reasonable accommodation, will provide an easy method of compliance with the obligations that exist.

IV. SUGGESTIONS AND GUIDANCE

The material in Part III indicates that persons who experience psychosocial/mental impairment which in interaction with attitudinal and environmental barriers cause them to experience disability, whether acting as academics or members of the public, have the right to attend academic conferences on mental health and mental capacity law on the same terms as those without that experience. It arises from the width of the right to access, which extends to information; the right to impart and receive information; the right to education, including lifelong education; and the more general right to equal treatment, the elements of which include the use of universal design and reasonable accommodation. These are elements of the inclusivity programme that is key to recognising the rights of people with experience of disability to full participation in life.

⁷⁰ Concluding observations Germany UN Doc CRPD/C/DEU/CO/1 (13 May 2015), para 46.

⁷¹ Concluding observations on the initial report of Croatia UN Doc CRPD/C/HRV/CO/1 (15 May 2015), para 36.

⁷² Concluding observations Italy UN Doc CRPD/C/ITA/CO/1 (6 October 2016), para 56.

⁷³ Concluding observations Chile UN Doc CRPD/C/CHL/CO/1 (13 April 2016), para 49.

⁷⁴ *ibid* para 50.

⁷⁵ Committee on the Rights of Persons with Disabilities, General Comment No 4 on the right to inclusive education, CRPD/C/GC/4, 25 November 2016, para [9].

This means that conference organisers have a corresponding duty, which has to be regulated for by the state if conference organisers do not have appropriate processes to ensure respect for this right.

Naturally, the starting point for conferences on mental health and mental capacity issues is that it cannot be considered relatively unimportant to consider service user participation and engagement, given the impact on service users of the law in this area. To deny this starting point would be akin to holding the view that the identification and amendment of "all legislation which contained provisions that reflected the stereotypical assumption that a person was incapable of performing certain public or fiduciary roles because they were mentally disordered"⁷⁶ is a minor and technical matter. However, any and all areas of exclusion are problematic, and are often experienced cumulatively by persons with experience of disability so as to make social exclusion both prolific and pervasive. Hence we must be prepared to consider and address all aspects of our endeavours.

Naturally, no-one will suggest that resources be wasted by making arrangements that are not going to be needed, meaning that it is proper to require an advance indication of needs. At the same time, universal design ideas should be to the fore, since they will not diminish the conference experience for those that do not need those extra services. Applying this approach to conferences that will, or may well, involve the participation of service users, those who want to facilitate conferences that are 'good' from service user perspectives, and in accord with the obligations of the CRPD, must focus on the question: What needs to be done to enable the full and effective participation and inclusion of people with experience of disability? In accord with the social model of disability the answering of this question is about addressing the attitudinal and environmental barriers that hinder service users' full and effective participation in conferences on an equal basis with others.

To our mind, the starting points of inclusion and universal design lead to two essential components:

Involving service users in all stages of the planning of the conference from the outset and through to the culmination of the evaluation.

Valuing the knowledge and perspective that service users bring to any mental health related subject and event – service users must feel valued, respected, included and listened to.

Full and effective participation means consideration and facilitation of meaningful service user participation in all aspects of the conference – whether as key-note presenters, as concurrent session presenters, as poster presenters, as panel members, as active audience members, and as social and networking event attendees, supporting the enjoyment of freedom of thought and expression through all avenues and in all capacities.

⁷⁶ Mental Health Foundation of New Zealand. (2008). *Submission to the Universal Periodic Review Relating to the Situation in New Zealand of People Living with Mental Illness*. Retrieved from <http://www.mentalhealth.org.nz/file/Policy-Advocacy-etc/Documents/Submission-Universal-Periodic-Review-10-November-2008.doc>.

In order to do this, attitudinal and environmental barriers must be considered and addressed. These can include travel, cost, feelings of being 'other' and/or a 'token', out of place, overwhelmed, isolated, and over-stimulated, and alcohol related events.

The principles of universal design that can address these barriers and support full and effective participation of service users at the group level include, but are not limited to, the availability of scholarships to support attendance, 'live-streaming' options for presenting, flexibility of presentation times, presentations on stand-by (to fill in if people become unwell), early provision of conference information, quiet rooms, regular breaks, water available at all times and in all venues, preferential seating, screening out of external (environmental) stimuli, conference 'buddies', asking service users if they would be prepared to be called upon to provide a service user perspective (prior to the start of any session), and 'dry' options at social events.

In addition, conference organisers should promote through conference communications that reasonable accommodations are available and involve a process for service users to advise and be supported with any particular needs.

Organising of conferences based on these suggestions and guidance would mean, at the very least, that the recent experience of one of the authors, and the significant harm that resulted from that, could be avoided. The fact is that with relatively little effort service users can be supported to fully and effectively participate in conferences and the benefits of that, to all involved, will be immense. That's why these small steps are a good idea, beneficial to all. If you have colleagues and conference organisers that do not accept this, then you can fall back to the indication we have sought to demonstrate via the analysis of the CRPD: it's also a requirement of international human rights law.