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Rethinking and Advancing a ‘Bottom-up’ Approach to Cultural Participation of Persons with Disabilities as Key to Realising Inclusive Equality

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Abstract

Debates about cultural participation of persons with disabilities within legal and socio-legal scholarship and within disability studies tend to remain disconnected. This article brings legal analysis and other academic disciplines into a critical dialogue. It sheds light on how the right to cultural participation is understood from the bottom up, building on a study carried out across Europe. Participants in this study perceived opportunities to participate in, and to contribute to, arts and culture in ways that are consistent with the human rights approach to disability as expressed in the UN Convention on the Rights of Persons with Disabilities, and as central to the concept of inclusive equality. Cultural participation was also understood as intrinsic to the humanity of all people, as vital to inclusion in mainstream life, as capable of communicating experiences or identities not otherwise represented, and as potentially transformative of art-forms and ultimately, of society.

Keywords: international disability law; socio-legal research; disability studies; right to participate in cultural life; UN Convention on the Rights of Persons with Disabilities

1. Introduction

Recent decades have witnessed growing debate on cultural participation by people with disabilities¹ both among scholars within disability studies and other disciplines, such as in law, cultural studies, museum studies, art studies – and, to an extent, amongst cultural institutions, disability activists and society at large (amongst others, Tatic, 2015; Arengi, Garofolo and Sørmoen, 2016; Eardley *et al.*, 2016; EASPD, 2020; Acesso Cultura, n.d.). The cultural construction of disability is a core concern of what is termed ‘critical or cultural disability studies’ (Waldschmidt, 2018; Goodley *et al.*, 2021). In particular, Goodley’s (2013, p. 634) review of what is encompassed within the term ‘critical’ includes a range of perspectives, and he suggests that they all emphasise the ‘cultural, discursive and relational undergirdings’ of the disability experience.

¹In this Article, we use person-first language (‘persons/people with disabilities’) for consistency with the terms used in the UN Convention on the Rights of Persons with Disabilities (CRPD). They are also the preferred terms of many activists especially from outside the UK. We recognise also the alternative and different histories associated with the term ‘disabled people’, which tends to be the preferred term in the UK and associated with the development of the social model of disability.

These critical approaches analyse disability as a social and cultural phenomenon (Ferrucci, 2004; Goodley and Bolt, 2010). Scholars from a range of disciplines have also addressed cultural participation of persons with disabilities by way of contribution to broader studies on the positive effects of cultural participation on health and well-being (Fancourt and Finn, 2019; Zbranca *et al.*, 2022; Voices of Culture, 2023). This research also comes at a time of wider scholarly and policy discussion on emancipatory approaches to cultural participation and audience development (Hadley, 2021). The latter strand of studies engages with issues of ‘democratisation of culture’ or ‘cultural democracy’, which are intended to represent ‘an approach to arts and culture that actively engages everyone in deciding what counts as culture, where it happens, who makes it, and who experiences it’ and refers to a ‘range of approaches to widening involvement in arts and culture’ (Arts Council England, 2018a, p.2). ‘Audience development’ helps foster ‘relationships with new and existing audiences [which] ... can include aspects of marketing, commissioning, programming, involvement in decision making, education, customer care, and distribution’ (Cuenca-Amigo and Makua, 2017; Arts Council England, 2018b, p.3). Traditionally audience development initiatives focused on the removal of barriers to participation associated with an assumption that the people being targeted might be interested in the arts (Kawashima, 2000; Hadley, 2021). Within legal and socio-legal scholarship, the increasing debate on cultural participation of people with disabilities is, on the one hand, linked to a more general renewed attention to disability rights prompted by the entry into force of the UN Convention on the Rights of Persons with Disabilities (‘CRPD’ or ‘the Convention’) in 2008. In fact, the CRPD is said to have removed the invisibility of persons with disabilities within international human rights law (Quinn, 2009). It is commonly acknowledged to be a groundbreaking treaty (Perlin, 2009) in that it has reframed civil, political, social, economic and cultural rights in light of disability (Kayess and French, 2008). On the other hand, such debate has been driven by the need to interpret and implement Article 30 CRPD, which provides for the right of persons with disabilities to participate in cultural life. As discussed by Bantekas *et al.* (2018, p. 876) ‘[t]he emphasis on “participation” implies that the right to take part in cultural life is not confined to the freedom to enjoy (read: “consume”) culture, but also the freedom to pursue and contribute to every aspect of cultural life’.

However, thus far, these multifaced debates on cultural participation of persons with disabilities have remained somewhat disconnected from one another. While contributions from scholars and artists emphasise the potential transformation of mainstream culture through involvement of people with disabilities in the arts (Sandahl, 2018, p. 84), cultural participation itself remains a hazy concept. From a disability studies perspective, the field of disability arts has become recognised as ‘a powerful source of aesthetic innovation’, although participation can require a number of different components of access, which are not always present (Hadley, Paterson and Little, 2022, p. 74). From a human rights perspective, it has been highlighted that the right to participate in cultural life is key to realising the human rights model of disability envisaged by the CRPD (Ferri and Leahy, 2023). Yet, despite the flourishing of commentaries (see, amongst others, Della Fina, Cera and Palmisano, 2017), the right to participate in culture remains ‘one of the least studied human rights in the international literature’ (Bantekas *et al.*, 2018, p. 865). Veal (2022) also suggests that this right is largely neglected by the relevant UN treaty bodies and in the reporting process by states. Its content ‘remains contested’ (Bantekas *et al.*, 2018, p. 865) and it has been described as the ‘Cinderella of human rights’ (Xanthaki, 2015). This is particularly true with regard to the right to culture of persons with disabilities, and Article 30 CRPD has so far attracted much more limited attention compared, for example, to the right to education (De Beco, Quinlivan and Lord, 2019) or the right to work (Steele, 2023).

Against that background, this article connects different disciplinary perspectives, revisiting them in light of an empirical study conducted between 2021 and 2023 in Europe as part of a larger

multi-method project called DANCING.² Bringing legal analysis and other academic disciplines that have engaged with cultural participation into a critical dialogue with each other, it articulates a new understanding of the right to cultural participation that is rooted in experiences of disability. It, therefore, propounds a 'bottom-up' approach to the interpretation of Article 30 CRPD, which does not replace scholarly analysis based on legal sources nor theoretical approaches within other disciplines, but re-interprets them together, informed by the perspectives of study participants drawn from organisations representing persons with disabilities.

Overall, this article shows that opportunities to participate in and to contribute to arts and culture are perceived by participants as intrinsic to the humanity of all people and as vital to self-expression and/or to communicating a sense of identity/identities, and hence to the human rights of people with disabilities. These perceptions make evident that persons with disabilities support the view that the right to cultural participation is inherent in a human rights model of disability, in line with legal analysis. This is so even if participants do not articulate it in exactly those terms or by reference to legal or human rights concepts. The article also explicates how such participation contributes to realising the model of inclusive equality embedded in the CRPD with its four overlapping dimensions (which we outline below) (UN Committee on the Rights of Persons with Disabilities (CRPD Committee), 2018). Moreover, not only was cultural participation understood as intrinsic to the humanity of everyone, as vital to inclusion in mainstream life, as capable of communicating experiences or identities otherwise under-represented in society, but also as potentially transformative of art-forms and ultimately of society, something that echoes scholarship on disability arts/aesthetics.

Following these introductory remarks, this article is divided into four parts. We first outline cultural participation as a human right, discussing the approach of legal scholarship to the right to culture and highlighting, *inter alia*, the most relevant aspects of the CRPD. We then examine how cultural participation is apprehended within other areas of scholarship, including critical/cultural disability studies, especially within scholarship on disability art. The fourth section discusses the findings from our empirical study. After outlining the methodology employed, the section presents our findings based on an analysis of participants' understandings of cultural participation. We present our findings organised into four themes relating to understandings of cultural participation (1) as human right and expression intrinsic to humanity, (2) as inclusion in society, (3) as challenge to what constitutes arts and culture and as to what disability is and (4) as assertion of identity in separate events outside the mainstream. These themes are discussed in light of relevant scholarship, highlighting ways they should inform the interpretation of Article 30 CRPD. We finish with some concluding remarks.

2. Cultural participation of persons with disabilities as a human right and a cornerstone of inclusive equality

It is recognised that the right to participate in cultural life is well-established in international human rights law. Article 27 of the Universal Declaration of Human Rights (UDHR) states that 'everyone has the right to freely participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits'. Article 15(1)(a) of the International Covenant on Economic Social and Cultural Rights (ICESCR) recognises 'the right of everyone to take part in cultural life' (O'Keefe, 1998). Other international provisions guarantee, to different extents, the right to participate in culture and articulate collective cultural rights of minorities and indigenous peoples (Stamatopoulou, 2007). Human rights law has generally referred to culture in its broadest meaning as the 'set of distinctive spiritual, material, intellectual and emotional features

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of society or a social group, [which] encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs' (UNESCO, 2001; UN CESCR, 2009). In that regard, the Independent Expert on cultural rights, in June 2010, in a report submitted to the Human Rights Council (Independent Expert in the Field of Cultural Rights, 2010) argued that cultural rights are generally multifaceted, relating to: the expression and creation of material and immaterial forms of art; information and communication; language; identity and belonging to multiple, diverse and evolving communities; development of specific world visions and the pursuit of specific ways of life; education and training; access, contribution and participation in cultural life and the conduct of cultural practices; as well as access to heritage in its tangible and intangible manifestations. Specifically, the right to participate in cultural life is considered as encompassing a two-fold individual dimension and a collective aspect. The two-fold individual dimension entails, respectively, the right to access cultural activities, goods and services, and the right to active involvement in culture, which includes engaging in the creation of cultural products (Romainville, 2015). In this respect, the right to participate in cultural life has been mostly associated with the right to participate in and practice creative arts (i.e. different art forms, including literature, dance, music, theatre and visual arts) and to enjoy heritage as forms of cultural expression (Caust, 2019). The collective aspect of the right refers to cultural communities being recognised, protected as well as enabled to enjoy their cultural expressions (including their language and traditions).

Along with other international provisions, Article 27 UDHR and Article 15 ICESCR do apply to persons with disabilities without discrimination, but they failed to address their specific needs. This gap has been filled by Article 30 CRPD which articulates the right of persons with disabilities to participate in cultural life, alongside the right to participate in sport, leisure and recreation, while listing a number of obligations to be complied with by states parties to the Convention (Manca, 2017).

Article 30 CRPD encompasses the two-fold individual dimension and the collective aspect of the right to participate in culture. As with economic and social rights, cultural rights must be realised progressively. The CRPD Committee, most recently in *Henley v. Australia* (CRPD Committee, 2023, para. 10.7), recalled that 'each State party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of those rights'. Further, the CRPD Committee highlighted that states parties 'have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of rights' (CRPD Committee, 2023, para. 10.7). Notably, Article 30(1) CRPD protects and promotes the right of persons with disabilities to participate in cultural life, in its two-fold individual dimensions, as mentioned already, involving both the right to access or consume culture and the freedom to pursue and contribute to every aspect of cultural life (Bantekas *et al.*, 2018, p. 876). It requires states parties to take all appropriate measures to ensure that people with disabilities have access to cultural materials, television programmes, films, theatre and other cultural activities, as well as to cultural spaces, including places where cultural performances are held, monuments and sites of cultural importance. While the Committee's jurisprudence, thus far, has only highlighted the importance of audio-description on tv programmes (CRPD Committee, 2023), access measures mentioned in its Concluding Observations as well as in General Comment No 2 (CRPD Committee, 2014) include subtitling, sign language interpretation and the provision of a variety of accessible formats of printed materials (encompassing Braille, audio and easy to read formats). In fact, Article 30(1) CRPD tallies with the principle of accessibility articulated in Article 9 CRPD, as highlighted by the CRPD Committee both in its General Comment No 2 (CRPD Committee, 2014) and in *Henley v. Australia* (CRPD Committee, 2023, para. 10.8 *et seq.*). Further, this provision needs to be read as entailing a duty to reasonably accommodate persons with disabilities, i.e. a duty to provide any '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' (Article 2 CRPD). Article 30(2) CRPD obliges states parties to take appropriate measures to enable persons with disabilities to develop their creative, artistic and intellectual potential. Furthermore, Article 30(3) CRPD requires states to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access on the part of people with disabilities to cultural materials. The latter obligation relates primarily to copyright, which may constitute a barrier preventing cultural materials in accessible formats from being made available (Sganga, 2015). The CRPD Committee has consistently linked this obligation to the ratification and implementation of the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled ('Marrakesh Treaty'), which was approved by the World Intellectual Property Organization (WIPO) in 2013 (Bantekas *et al.*, 2018). Article 30(4) provides for the recognition and support of the specific cultural and linguistic identity of people with disabilities, including sign languages and Deaf culture. It complements Article 21(e) CRPD, which requires states parties to take measures 'recognizing and promoting the use of sign languages', and Article 24 CRPD addressing the linguistic identity of Deaf persons in the context of education (Murray, De Meulder and Le Maire, 2018). Article 30(4) does not explicitly conceptualise Deaf people as a linguistic minority, even though it acknowledges the existence of Deaf culture (Ball, 2011) highlighting the collective dimension of such provision. In its Concluding Observations, the CRPD Committee has generally recommended that states enact laws that protect and promote sign languages (Leahy and Ferri, 2022a), but has not engaged in depth with Deaf culture. In *Sahlin v. Sweden* (CRPD Committee, 2020), which concerned a Deaf lecturer who was not recruited by a Swedish University because the provision of sign language interpretation was deemed too expensive, the CRPD Committee focused on the right to employment and on reasonable accommodation. The Committee highlighted that:

State authorities did not take into account the positive impact that hiring a deaf lecturer could have had on the attitude of students and co-workers to promote diversity and reflect the composition of society, but also for possible future candidates with hearing impairments. (CRPD Committee, 2020 para. 8.10)

However, the Committee did not engage with the cultural or linguistic rights of Deaf people, nor with the concept of Deaf culture.

To date, legal scholarship has emphasised how cultural participation (including in the arts) is an 'essential dimensions of life, both for persons with disabilities and for those without disabilities' (Tatic, 2015, p. 6), and how the implementation of Article 30 CRPD is essential in furthering 'the CRPD's transformative vision of persons with disabilities' full-fledged membership in an inclusive society' (Smith and Stein, 2020, p. 287). Arts participation at all levels is also considered to play a critical role in realising human rights for people with disabilities (Ferri and Leahy, 2023) and speaks particularly to the model of inclusive equality of the CRPD (CRPD Committee, 2018). The CRPD – while embracing a social-contextual understanding of disability (Broderick and Ferri, 2019) and being underpinned by the 'human rights model of disability' (Degener, 2016; 2017; Beckett and Lawson, 2021) – which emphasises the human dignity of persons with disabilities and 'encompasses both sets of human rights, civil and political as well as economic, social and cultural rights' (Degener, 2017, p.44) – puts forward a capacious conception of equality. This is defined as 'inclusive equality' by the CRPD Committee (2018). Inclusive equality goes beyond the dichotomy of formal versus substantive equality and encompasses four overlapping dimensions: a fair redistributive dimension, which requires that socio-economic disadvantages are addressed and redressed; a recognition dimension, which necessitates the combatting of stigma, stereotyping, prejudice and violence, and the recognition of the dignity of human beings and their intersectionality; a participative dimension, which aims to reaffirm the social nature of people with disabilities as members of society; and an accommodating dimension, which entails making 'space for difference as a matter of human dignity' (CRPD Committee, 2018). The latter dimension

is underpinned by the idea of the diversity of individuals with disabilities from one another and refers to reasonable accommodation. This fourth dimension may also be linked with accessibility as a precondition for the effective implementation and the full enjoyment of all the rights set out in the CRPD.

Article 30 CRPD speaks particularly to the recognition of participatory and accommodating dimensions of inclusive equality. Culture is the expression of human nature. Hence, the right to access cultural activities on an equal basis is central to the human dignity of persons with disabilities. Second, and from an interconnected perspective, given the prevalence of limited and often negative cultural representations of disability (Shakespeare, 1994; Mitchell and Snyder, 2000; Hadley, 2015), the contribution of artists with disabilities is indispensable to the recognition of the inherent dignity of all disabled people.

Even though scholarship on the right to participate in cultural life is relatively scant, and somewhat mirrors the limited engagement of the CRPD Committee with cultural rights, there seems to be a recognition that enjoying culture is a vital part of being a member of society. Further, culture is recognised as having the potential to promote fuller enjoyment of human rights, including by championing the universality of human rights and dignity, embodying and embracing cultural diversity, challenging discrimination and contributing to reconciliation (Bennoune, 2018).

3. Cultural participation of persons with disabilities as transformative engagement

Discussion of a changed role for museums and heritage sites in the twenty-first century is a feature of museum studies (Black, 2005), which has led to an increased debate on access for people with disabilities (Confino-Rehder, 2010; Argyropoulos and Kanari, 2015). Hadley (2015) posits that cultural industries have displayed a growing focus at the level of logistical access (that is, ramps, interpretation and other access measures), although even logistical or physical access continues to be problematic in many settings (Leahy and Ferri, 2023). Disability access is considered critical also by a range of scholars in disability studies, as ‘disabled people [artists, arts-workers and audiences] literally cannot enter certain spaces, even when granted “permission”’ (Sandahl, 2002, p. 24). In that regard, most recent socio-legal research has evidenced a range of ongoing barriers to participating in culture, both as audience and as practicing artists (Ferri *et al.*, 2022; Leahy and Ferri, 2023), although often scholarly work focuses on one type of disability or is confined to a single or limited number of venues (Leahy and Ferri, 2022b).

Academic discussion of access and of barriers to access and inclusion exists alongside scholarship that looks at the transformative function of cultural participation. A lively scholarly debate on audience-development initiatives exists, including arguments that they can perform a ‘legitimizing function’ by discursively suggesting that an undemocratic cultural policy is in the process of being democratised in light of how people who attend the subsidised arts are predominantly a particular demographic, supported by taxpayers who subsidise but do not consume the arts (Hadley, 2021, p. 233; Hadley, Heidelberg and Belfiore, 2022). This literature, while not focusing specifically on disability, emphasises that cultural sectors are still not fully representative of their consumers and the wider society (Hadley, Heidelberg and Belfiore, 2022). While change may be happening in the cultural sectors, it is taking place in a slow and piecemeal fashion, largely due to the efforts of ‘minoritized groups’ (Hadley, Heidelberg, Belfiore, 2022, p. 16). Arguably, ‘without transformational and structural changes, increased surface level representation is meaningless’ (Hill and Sobande, 2019, p. 109; Hadley, Heidelberg and Belfiore, 2022). Such transformational change is advocated within interdisciplinary scholarship engaging with disability arts. For Allan (2005), disability art has flourished as a particularly powerful genre which enables exclusionary barriers within a disabling society to be exposed. Within museum studies there are also developments such as an ‘activist museum practice’, intended to communicate alternative, progressive ways of thinking about disability (Sandell and Dodd, 2010, p. 3).

Disability art emerged in association with the disability rights movement (Darke, 2003; Solvang, 2018) and was originally associated with expressions of disability experiences, often for audiences comprised of people with disabilities, but, more recently, is characterised by artists with disabilities wanting to attract mainstream audiences (Solvang, 2018). For Darke (2003, p. 132) disability art is ‘not to be seen as an equal opportunities issue’, but as part of a process of re-presenting a more accurate picture of ‘society, life, disability and impairment and art itself’, and it is based on legitimising the experience of people with disabilities ‘as equal within art and all other cultural practices’. While medicalised (Bang and Kim, 2015; Gratton, 2020) and charitable perceptions of disability continue to hamper creation by artists with disabilities (Darke, 2003, p. 133), people with disabilities use cultural interventions in order to subvert and query the meanings given to disability (‘tragedy, loss, dependency’), and ‘disability culture emerges as a counterculture’ (Kuppers, 2003, p. 6). For Hadley and McDonald (2019, p. 2), the growing field of disability art, culture and media studies engages with the stories told about what it means to be disabled in drama, dance, film, literature, media and other artforms, and also with how workers in these industries ‘are developing new accounts of what it means to be disabled’. Thus, scholars and artists within these perspectives emphasise the potential for transformation of mainstream cultures, suggesting, for example, that disability arts function as a highly effective form of ‘ideological critique’ (Allan, 2005, p. 32). Sandahl suggests that ‘[i]nstead of adapting to the way a mainstream art form has been created . . . disability art starts with disability experiences and disabled bodies just as they are’ (2018, p. 85). This comes against a backdrop in which, as Hadley (2015) argues, disabled characters are still too rarely written or played by people with disabilities, which is coupled with how the distinctive corporeality of people with disabilities has been a means of symbolising corruption, innocence or suffering, presenting a metaphor for the problems people have to overcome. This recalls the famous characterisation by Mitchell and Snyder (2000, p. 51) of the deployment of representations of disability, not as approximations to the lives of people with disabilities, but as ‘props’ or ‘prostheses’ that serve the narrative practices of Western canonical theatre, cinema and literature – ‘a contrivance upon which many cultural and literary narratives rely’. Instead, as Sandahl (2002, pp. 18–19) puts it, disability can be ‘generative’ and the ‘unique somatic experiences’ of people with disabilities provide ‘doors of perception’ to space that can sometimes radically differ from that of non-disabled people and allows ‘us to envision an enormous range of human variety—in terms of bodily, spatial, and social configurations’.

In a recent work, Hadley, Paterson and Little (2022) suggest that at least three types of access are required, which intersect and reinforce each other. They characterise these as logistical access (including ramps, hearing loops, interpreters and other access technologies), ideological access (stories, characters, discourse, disability inclusive language, and rehearsal and production contexts) and methodological access, which embodies disability culture in training, rehearsal, production and presentation processes, including the modes of collaboration that prevail in them. They suggest that the first tends to be the focus within industry policies, while the second is a key focus within scholarly accounts of disability arts practice, but that the third, methodological access, involving inclusion of disability culture relationships and concepts, has yet to be understood within mainstream arts sectors even though it is as essential as other types of access like ramps and inclusive language (Hadley, Paterson and Little, 2022). In making this argument, the authors somewhat bring together the concept of access with ideas related to the transformative power of disability art.

4. Empirical Findings: Cultural participation of persons with disabilities for persons with disabilities

4.1. Methods

Before engaging with how cultural participation is experienced by people with disabilities, as perceived by participants in our study, we present the methods used. We draw on our qualitative

study carried out between 2021 and 2023. For this study we recruited representatives from at least two organisations from twenty-eight European countries (twenty-seven EU countries and the UK) drawn from three types of organisations: (1) organisations of people with disabilities working at national level who, for the most part, represent people with a range of disability types, (2) nationally representative organisations of Deaf people and (3) organisations that work on disability and arts/culture.

A purposive sampling process was pursued, whereby we ultimately recruited representatives of sixty-four organisations, comprising twenty-eight organisations of people with disabilities, twenty-five organisations working on arts and disability and eleven organisations of Deaf people. Participants received information on the study in advance related to issues such as anonymisation, data protection and data storage. Participants gave informed, written consent to participate. Ethical approval for the study was obtained from the relevant Maynooth University Ethics Committee.

The majority of participants engaged in semi-structured interviews, most of which were conducted online. The alternative of completing a written qualitative questionnaire (which sought open-ended or free-text answers) was offered as a form of reasonable accommodation to include participants who might otherwise not have been able to participate. Interviews were transcribed verbatim, and transcripts and questionnaires were analysed using a reflexive approach to thematic analysis involving familiarisation; systematic coding; generating initial themes; developing and reviewing themes; refining, defining and naming themes; and writing up (Clarke and Braun, 2017; Braun and Clarke, 2021). When quoting extracts from interviews/questionnaires we identify from which country they were drawn, using EU country-codes, and the type of organisation involved (organisation of people with disabilities – ‘DPO’; organisation working on arts and disability – ‘A&D’; organisation of Deaf people – ‘D’).

4.2. Findings

Our study suggests that participation in culture is often seen by organisations representing people with disabilities as an intrinsic part of life for people with disabilities, as it is for all people, and a human right because, not least, it is inherent in active participation in society. This is presented as the first theme drawn from findings focusing on the nature of arts participation, and it underlies all the other themes in the discussion that follows. Our findings also show perceptions among study participants that participating in culture, both as audience and as performers/artists, provides opportunities for integration and being part of the mainstream of life in general, which constitutes our second theme, and something that again embodies the idea of participation as human right. Making art or engagement at a professional level could challenge stereotypes and representations of disability and, in essence, communicate an alternative version of the world in which disability is intrinsic to culture, which is our third theme. This is consistent with the provisions of Article 30 CRPD, which recognises the right not only to consume culture but also to contribute to it. By way of our fourth theme, we discuss perceptions that participation by people with disabilities or Deaf people often happens in separate events that are just for people with disabilities, or certain groups amongst them, and there were different reactions to these forms of participation.

4.2.1. Cultural participation as human right and expression that is intrinsic to humanity

Participants often articulated the importance of cultural participation in a general sense as intrinsic to the humanity of all people, as an expression of human nature, and essential to self-expression and to representation. They sometimes mentioned the CRPD explicitly for its contribution to changes in cultural participation. For example, a Greek participant felt that the ‘human-rights based approach’ to disability enshrined in the CRPD was the ‘key element’ in

promoting the right of persons with disabilities to participate ‘in the production/creation of culture’ (EL DPO). Participants felt that participation in arts and culture has not traditionally been seen as an intrinsic issue for people with disabilities due to the focus on care or on ‘needs’, but that, in line with moving away from medical model understandings of disability, cultural issues were beginning to be recognised as of more central concern. Even when they did not specifically mention the CRPD, participants often expressed views consistent with scholarly works suggesting that cultural participation is essential to respecting the inherent dignity of persons with disabilities. In that connection, they also echo arguments from literature on disability art about expressions and representations of human variety (see, amongst others, Sandahl, 2002). For example, as an Irish participant put it:

The whole job of arts and culture is to help people with meaning-making and with processing their own life journeys. So if we are not seeing our lives being reflected in culture, we are at a loss to process our own lives (IE DPO)

Again, echoing key tenets of the CRPD (specifically Article 30(4)), participants also linked artistic expression to expressions of identities and to offering what we might call ‘doors of perception’ to others (Sandahl, 2002, p. 18). For example, a Swedish participant said: ‘I mean, to be an artist is to express your identity, in many ways, and giving people the opportunity to do that, giving people a voice, is also expressing someone’s identity’ (SE A&D). As another participant put it, art helps other people to enter their ‘world’, to ‘speak the same language’, ‘which is an important component of integration and socialisation’ (BG A&D).

Participants sometimes also highlighted a stark picture for people with disabilities in their countries that included poverty or lack of income, of supports or of healthcare, and, in some countries, extreme exclusion across all areas of life experienced by certain groups who continued to be institutionalised. These issues could mean that cultural participation was ‘a luxury’ for many (CY DPO), reinforcing the ‘Cinderella’ status of the right to participate in culture. That was, for example, the view of a Cypriot participant, who felt that this was so especially for people with severe levels of impairment (CY DPO). Somewhat similarly, a Bulgarian artist from a network of disabled artists felt that there was much to do in her country relative to the rights of people with disabilities (highlighting issues in healthcare, employment, education and infrastructure), and that ‘even if we don’t like to state this, the participation of people with disabilities in our cultural life is a very last problem of our country’ (BG A&D). However, participants could also argue that cultural participation should be seen as a central issue, notwithstanding that other issues also need attention. As a Finnish participant articulated it, ‘every aspect of life can be part of a disability discussion’. She suggested that if disability were understood as a social and cultural issue (not just a medical one) and as just ‘one way of being [a] human being’ then ‘art is of course part of that’ (FI DPO). Similarly, for a Polish participant, ‘invisibility’ continued to be a problem. While she acknowledged that it might be argued that basic needs should be provided for before ‘we can think about additional stuff’, that wasn’t how she saw it:

But I don’t think it works like this really because we know that we should take care of many [things] as humans ... I think that we should take care and especially persons with disabilities should feel that they can take care of all of the areas of their development of their lives and also about ... participating in culture (PL DPO).

On the whole, ideas of participating in culture were associated with disability rights. While not always articulating it precisely in these terms, participants referred to the two-fold individual dimension of the right to participate in culture, and to its collective aspect. In doing so, they highlighted the yet unfulfilled potential for greater expression and communication of disability experiences and identities. For some participants, the fact that disability art remains somewhat

‘invisible’, that ‘disability’ has been confined to a narrow range of issues and to medicalised framings, only underlines the importance of cultural participation at all levels as a way of expressing and representing human dignity. Overall, participants saw cultural participation as an essential part of being a member of society, which calls for the implementation of Article 30 CRPD in conjunction with all other rights, and as an essential aspect of the principle of participation provided in the CRPD. Findings evidence views of cultural participation as essential to realise the recognition and participative dimensions of inclusive equality (CRPD Committee, 2018).

4.2.2. *Cultural participation as inclusion in society*

Linked to the foregoing, participants felt that forms of cultural participation, including taking part in cultural events as audience members, as well as engaging in professional processes that included both people with disabilities and non-disabled people, were ways of achieving inclusion in society. This was an area where overall improvements were often perceived. For example, a representative of a Deaf organisation from Germany stated that:

It is true that cultural participation contributes to social cohesion within the Deaf community and is an important motor of integration in our society . . . and participation also enables integration into community structures and, in particular, to establish contact with all people with different cultures, in Germany, in Europe and worldwide (DE D).

In a way that links, or sometimes confirms, findings of interdisciplinary work on access and barriers to access, participants discussed many examples of innovation in access measures on a logistical level that enabled people with disabilities to be integral to cultural events. While it is often implicit, they evoke the realisation of the ‘accommodating dimension’ of inclusive equality within cultural institutions. However, participants usually perceived access measures as aimed at accommodating audiences rather than performers/artists. They also suggested that such access measures remain somewhat patchy or intermittent in their availability even for audiences. For example, an Estonian participant (EE DPO) talked about access measures – such as sign language, audio description and tactile cards – having in recent years facilitated people with disabilities to take part in major cultural events (national singing festivals and national dance festivals). These events are highly culturally significant in Estonia, with a huge proportion of the general population participating in them, but people with disabilities have traditionally been excluded. However, now, as that participant articulated it, various access measures have brought ‘this participation more close’ (EE DPO). A Lithuanian participant talked about an approach to theatre for blind audience members, explaining how she had been invited on stage to experience a play through her senses. Her account suggests that she found this enjoyable, innovative, and that it somewhat changed the art-form for the performers and the experience for other audience members:

When some of the spectators are being used as part of the story is also very interesting because the story or the vibe of the theatre play changes according to the people that came . . . and also the work of the actors changes (LT DPO).

That participant’s perceptions echo Hadley’s (2015) suggestion that the negotiations that occur in a disability-inclusive space mean that spectators are conscious of other spectators’ approaches to perceiving, interpreting and meaning-making. These findings also suggest that what Hadley (2015, p.168) calls ‘new modes of spectating’ are developing and deserve more attention in research as well as in practice.

Participants often stressed the need for integrated events, not separate ones. In that way they emphasised a sense of having an equal right to participate in cultural opportunities, and to be part

of a mainstream culture that accommodates them. For example, a Polish participant talked about a large and growing festival that provides opportunities for cultural participation that are accessible for everyone (including not only physical access but audio descriptions, subtitles, induction loops, sign language translations, quiet hours and other amenities for neurodiverse people, workshops and events for people with intellectual disabilities as well as the involvement of assistance from volunteers). This participant stressed that not all those taking part in the festival were people with disabilities and the importance of integrated opportunities:

The thing that you should work towards is just an event that is accessible for everyone who wants to participate in it. So it isn't marketed towards a group, it is just an event and if someone needs something it has to be provided for them (PL A&D).

She added, 'this is a natural environment that we want to create for everyone to see that there shouldn't be events that are only for people with disabilities'.

Inclusion could also be sought in professional engagement, as, for some participants, having people with disabilities and non-disabled people on stage together was a way to send a message about integration and about what was 'normal'. As a Greek participant said, for example, 'I don't believe in ghettoisation', and he outlined how he seeks opportunities to perform in mainstream productions: 'we are professional actors and we can collaborate and we co-exist with all other actors' (EL A&D). Likewise, a Cypriot participant (CY A&D) talked about the integrated performance company to which she belongs, suggesting that her company does not address itself 'only to disabled people because we need all people to have inclusion so we will never have something that will exclude the not-disabled people'. She felt that this kind of integrated approach was new in her country where participation in cultural events by people with disabilities, and especially professional engagement, was very limited and where cultural participation opportunities were often segregated by impairment/illness types. Specifically, without her professional arts practice, she considered that her opportunities would be confined to outings with people with the same condition as she has. One might conclude, to echo the words of Koppers (2003, p. 4), that these participants 'understand the pervasiveness and persuasiveness of medical knowledge and social differentiation based on medically and culturally controlled difference ... and they turn to subversion' through being artists/performers.

Participants' perceptions discussed in this section (both regarding attending and making art) point to the rights articulated in Article 30(1) and (2) CRPD. They can also be seen as an aspiration towards the accommodating dimension of inclusive equality and as an expression of its participative dimension, which necessitates appreciation of the social nature of people as members of society (CRPD Committee, 2018). It shows how participants resist segregated opportunities and seek involvement on an equal basis with others. In that regard, perceptions of overall improvements occurred in a context in which participation opportunities for artists with disabilities, and even for visitors/audiences, were limited, available only on an intermittent or patchy basis, or sometimes ill-conceived due to lack of input by a range of people with disabilities in planning processes. Amongst the issues identified were logistical barriers, such as buildings that continued to present physical barriers (especially for performers/employees with disabilities), or practices that provided a different experience or separated, say wheelchair users, from others at venues. Participants also highlighted intermittent offering of accessible opportunities (such as tours or performances) or offering them only at specific times that were not always suitable. As one participant said, 'fragmentation does not favour ... enjoyment of this what is offered' (EE A&D). Thus, one might say that the realisation of Article 30 CRPD is indeed rather distant: developments predicated in policy-making and expounded in approaches to democratisation of culture or audience development have yet to become fully impactful.

4.2.3. Cultural participation as challenge to what constitutes arts and culture and as to what disability is

Study participants also echoed, to varying degrees, the concept of cultural participation as transformative engagement. In particular, those working in the area of arts and disability perceived that making art is a way of challenging the cultural mainstream. Making art could be seen as means whereby people with disabilities can challenge what constitutes an art-form and put forward an alternative view about disability, culture and, indeed, life itself, in the public domain. As noted above, cultural participation was perceived as both the exercise of a human right and indispensable to combatting stigma, and, thus, as conducive to realising the recognition dimension of inclusive equality, and also as potentially transformative of society.

Several participants pointed to greater visibility of artists with disabilities in different art-forms in their countries, sometimes highlighting instances where performers with disabilities were cast in ordinary roles where ‘disability’ was not the issue – or not, as it is often traditionally depicted, as an ‘inciting incident or point of crisis in the drama’ (Sandahl, 2002, p.19). For example, a participant from Spain (ES A&D) pointed to decision-makers within certain cultural institutions who now cast people with disabilities in mainstream roles – not simply roles where disability was an issue – and, similarly, one from Portugal pointed to performances at a major theatre involving actors with and without disabilities in a play that was not about disability. The latter participant stated that ‘to see those people on the main stage of the National Theatre in an amazing production’ was ‘a big moment in Portugal’ (PT A&D). Participants from the UK, in particular, were positive about changes that had occurred in participation both as audiences and as artists, and about the attitudinal changes which this had started to filter into attitudes more generally. As one said:

You are seeing greater integration of the disabled experience on stage and also on television and on film ... And these films and TV works are also filtering more deeply into the national culture. So whilst there are barriers absolutely in place there is also more and more opportunities opening up as well. It is quite a nuanced picture (UK DPO).

Thus, these developments change whose stories are told and how they are told, and contribute to ‘ideological access (stories, characters, discourse and language)’ (Hadley, Paterson and Little, 2022, p. 74). However, it is also worth noting, that even participants who instanced positive developments perceived that more needed to be done, including the need for more influence by people with disabilities in decisions made within cultural organisations and in national policy-making.

Several participants referred to having to stress the artistic merit of their work and to distinguish it from therapeutic, charitable or social endeavours to funders and others. Some felt that the artistic work of people with disabilities tended to be less valued. Participants also suggested that what they were doing did not just replicate mainstream artistic approaches but fundamentally changed them in a way that echoes scholarship about disability arts/aesthetics. This is because of, to use Sandahl’s (2002, p. 18) terms, the unique ‘doors of perception’ that they brought to it. For example, a Czech participant working with an integrated company reported that they were often assumed to be a ‘social group’. He saw this as at odds with his own view that his theatre provided a way to communicate with audiences as ‘a real platform, a real artistic platform’, adding too that their approach ‘is a little bit different than the mainstream’ and that they were trying to ‘overstep just the field of theatre as an art[istic] tool’ (CZ A&D). Similarly, a Finnish participant explained that they were not operating as therapy or as a social endeavour (‘that is not our point – we are a theatre’), suggesting too that facilitating access in a range of ways was central to the artistic processes of her company – an ‘inspiration’ – and ‘not something you add on later’ (FI A&D). In this way, these, and other participants, reflect what Hadley, Paterson and Little (2022, p. 74) call ‘methodological access’, embodying ‘disability culture in training, rehearsal and

production processes'. That participant from Finland went on to say that their approach helped the non-disabled people that they came into contact with to think about things 'in a new way', through 'getting to know artists with disability and their ways of working'.

Thus, consistent with arguments made about disability art, participants talked about the value of difference ('it is a creative invitation and a creative opportunity' (IE A&D2)) and about the potential for change within art-forms. This was articulated by a Croatian participant from an integrated dance company who suggested that when people with disabilities access the 'tools of high creativity', they 'can push the field . . . they change the discipline, they change the artform' (HR A&D). Similarly, as a Greek participant suggested, they were not trying to 'adapt' to the norms within theatre, suggesting instead that when people with disabilities perform 'there is no normal, there is a new world' (EL A&D) and, as an Italian participant put it, 'because beyond these borders you can see new things' (IT A&D).

Overall, however, as already mentioned, perceptions of greater inclusion of professionals working in arts/culture, often occurred in a context where neither the general public nor people who work in arts and culture expected people with disabilities to be artists/ performers – or in some cases had not done so until recently. This meant that engaging in the arts could also be perceived as activism, even though the main aims were artistic ones – as, of necessity, it could challenge not just ideas about what was appropriate within art-forms but also ideas about disability, people with disabilities, or society more generally. For a participant from the UK, for example, 'theatre is the best way to challenge and change perceptions of who we are'. She said that people 'don't expect disabled people to be on stage' and 'if the work is good' everything changes when people with disabilities are visible in performances, which have thus far tended to be told from the perspective of non-disabled people. This offered, she suggested, ways of 'telling the same story but with different physicality, different intentions, different ways of communication' (UK A&D). Another example comes from a Greek (EL A&D) participant who suggested that when you are on stage 'that is an activist act':

When you are a disabled person, when you are on stage this is an activist act . . . first of all I am an artist and the first goal is artistic, the goal is the art . . . you have to see . . . How you can abolish all these stereotypes and this is a very important thing. For this reason we believe extremely about inclusion and accessibility in art (EL A&D).

Thus, participants echo what Sandahl (2002, p. 24) argued relative to disability arts decades ago, that if disabled bodies were to participate fully in our theatres, we would not only 'alter the ideology of our performing space, but we would . . . serve as a model for change to the larger social order'.

4.2.4. Cultural participation in separate events outside of the mainstream as assertion of identity

Several participants highlighted that cultural participation by people with disabilities continued in many cases to take place outside of the mainstream of cultural life in self-organised events/festivals/settings for specific groups or, alternatively, within social projects or care settings of one kind or another. There were different reactions amongst participants to these 'segregated' approaches – which to some extent depended on whether these were self-organised by people with disabilities, on the one hand, or organised by service providers or promoted out of therapeutic or charitable motives, on the other.

Thus, some participants spoke positively about separate events, sometimes organised by groups of people with specific impairment types. For example, a Finnish participant mentioned classes run by disabled artists for other people with disabilities, with people participating with different levels of ambition, including as a hobby. She felt that these classes were popular and suggested that they provided role models, as they are run by people who are 'disabled artists', adding that 'they

can be quite a good example for someone who hopes to be [an artist]' (FI DPO). Somewhat similarly, a Lithuanian participant spoke about a tradition continuing since the Soviet era of artistic creation in different art-forms by blind people, 'that are non-professional but still very actively producing their art' and who were considered 'very strong', and she associated this with a traditional identification with a community of blind people (LT DPO). One could argue that participants perceived these modes of participating in culture to embody the recognition and participative dimensions of inclusive equality. At the same time, that Lithuanian participant (who herself identified as blind) suggested that nowadays what many blind people wanted, instead, was a 'culture without segregation, or inclusive³ culture, culture for everyone' (LT DPO). A Bulgarian participant put it even more strongly, rejecting the idea of 'culture for disabled people or by disabled people only', which she characterised as 'a sort of a show-off thing' associated with charitable donors (BG DPO). She said that 'if we want inclusion, we want to see disabled people's creativity along with everybody else' (BG DPO). In that regard, perhaps unsurprisingly, participants sometimes critiqued available cultural opportunities that are confined to medicalised or therapeutic settings or to social projects, especially for some groups such as people living in or attending care settings or institutions. Arguably, these participants echo the contention of Darke (2003, p. 133) that events that are 'pseudo-therapy' are sometimes presented as disability art.

The Polish participant mentioned already who favoured integrated events that included people with disabilities and non-disabled people acknowledged that separate events were sometimes preferred by some groups, instancing people with intellectual disabilities who sometimes preferred closed events/workshops (PL A&D). She also referred to 'a surge' in activity amongst organisations of Deaf people, which are sometimes only offered in sign language. That participant felt that 'this is a great step', which she linked to the fact that Deaf people in Poland are still fighting to be 'recognised as a culture and language minority' (PL A&D). In fact, separate cultural events were most often mentioned favourably in the context of Deaf people and Deaf culture, which is perhaps not surprising given the 'somewhat separatist ideology' sometimes pursued by Deaf activists (Bagenstos, 2009, p. 3), and given the specific mention of 'sign-languages and deaf culture' in Article 30(4) CRPD. Thus, these positive perceptions occurred in the context of a distinctive language and Deaf culture where arts and culture were considered an important means of consolidating a sense of community and of communicating that culture, albeit largely amongst Deaf people themselves. For example, a representative of a Deaf organisation from Hungary felt that 'Keeping in mind their distinct linguistic identity, Deaf persons mostly attend cultural events organized by the Deaf community, such as theatre performances with Deaf actors, pub quizzes, trips, galleries.' A representative of an Irish organisation of Deaf people enjoyed performances by a Deaf theatre group aimed at Deaf audiences and perceived them to be of high quality (IE D). Sometimes participants stressed methodological or process issues in this context. For example, a Finnish participant described as 'a positive step' the fact that there are now more theatre productions and art exhibitions that provide sign language interpretation, distinguishing between mainstream cultural offerings that translate performances into sign language and ones that 'maintain sign language culture' and that are created in sign language from the outset, saying:

It is highly important to make a difference between performances that are produced straight to sign language from those performances that are first produced, for example, in Finnish and then interpreted into sign language. These organisations [led by Deaf people] maintain sign

³Although a distinction is made between 'inclusive arts' (bringing disabled and non-disabled artists together to undertake work with a strong social inclusion agenda), and 'integrated arts' (bringing people together without amplifying boundaries, binaries, and power relations between disabled and non-disabled arts) (Hadley and McDonald, 2019, p. 6), this was not a distinction that participants always made. In fact, when they talked about 'inclusion' in a general sense, and, often, in the context of creative work in the arts, it was often in the latter sense of work that did not amplify boundaries and that might or might not specifically address 'disability' issues.

language culture and enable people whose native language [is] sign language to express themselves in their own language (FI D).

The foregoing illustrates perceptions that identity, culture and community can develop through arts and cultural practices among specific groups. Hadley, Rieger, Ellis and Paterson (2022, p. 5) argue that such practices can be important to constructions of positive self-representations and positive ways of relating to self and others, helping to build 'solidarity within community, advocate beyond community, and transform the meaning of their body for themselves and for others in the public sphere'. Overall, however, quite a nuanced picture emerged as to perceptions of separate events for people with disabilities or for specific groups. These ranged from outright rejection of a perceived patronising, medicalised or charitable aspect to this and a preference for an integrated approach, to valuing separate events in terms of community-building and, as it might be put, embodying the recognition and participative dimensions of inclusive equality. Unsurprisingly, positive appraisals were particularly associated with separate cultural events/performances created in the context of Deaf language and culture. By contrast, events that took place in health or social care settings, that were perceived as only ostensibly artistic/cultural, were perceived as not providing opportunities based on equality.

5. Concluding remarks

In this article, bringing together different disciplinary perspectives on cultural participation and revisiting them in light of an empirical study conducted between 2021 and 2023, we have endeavoured to shed new light on the right to cultural participation that is rooted in the experience of disability. In particular, drawing on evidence from this empirical research with people representing organisations of people with disabilities, organisation of Deaf people and organisations working on disability and art/culture, our findings point to the importance of cultural participation as a human right, to the essential nature of the dimensions identified by Article 30 CRPD, and lead to a conception of cultural participation as a key to inclusive equality. Participants perceived opportunities to participate in, and to contribute to, arts and culture in a way that is consistent with a human rights approach to disability as expressed in the CRPD and discussed by legal scholars, insofar as such participation was seen as intrinsic to the humanity of all people, as vital to self-expression and/or to communicating experiences or identities that were otherwise not often represented within their societies, and to integration in the mainstream of life. Participants' perceptions, especially around making art, echo understandings from scholarship on disability art and aesthetics about expressions and representations of human variety and as enabling expressions of a 'more accurate picture of society, life, disability and impairment and art itself' (Darke, 2003, p. 132).

Thus, experiences of disability also point to a very important aspect that is inherent in cultural participation and recognised by scholarship from critical or cultural perspectives - that of disability art and aesthetics as critique of and challenge to mainstream culture (see, amongst others, Allan, 2005; Hadley and McDonald, 2019; Hadley, Paterson and Little, 2022). That is to say, for participants engaging in professional arts practices, their participation was itself potentially transformative of the art-forms they worked in, and ultimately of society, even if there were still many challenges. Participating as an audience member, on an equal basis with others, was also considered important in this regard, and a creative engagement with the access needs of audiences could change mainstream cultural productions and involve new modes of spectating (Hadley, 2015).

Participants who stressed the importance of cultural participation also acknowledged that it might be seen by some people as of minor importance, especially in societies where very basic needs are not met. Linked to this, participants often stressed the importance of integrated events,

for attendees and performers, which were also perceived to represent possibilities for challenge to assumptions that underlie mainstream cultural practices, including challenges to limited, charitable or medicalised representations of disability, and to prejudicial attitudes towards people with disabilities and, in essence, as a means of communicating alternative versions of the world in which disability is intrinsic to culture.

On the whole, an articulation of cultural participation that is rooted in disability experiences is key to the realisation of inclusive equality and needs to embed its four dimensions, but particularly highlighted here are the accommodating, recognition and participative dimensions. Participants reported ongoing instances of segregated arts/cultural events, and expressed a range of reactions to them. Although some participants rejected the idea of segregation in cultural participation outright, others spoke of such events in favourable terms, especially if they were self-organised. Events of that nature could, for example, be perceived of as supportive of a sense of community among groups such as blind people. Most favourably perceived were segregated events organised by groups of Deaf people, considered to be expressive and supportive of Deaf culture, language and community, and highlighting events that were methodologically informed by sign-language and culture. These appraisals might be said to reflect the specific mention of ‘sign-languages and deaf culture’ within Article 30(4) of the CRPD in the context of recognition of cultural and linguistic identity. However, ‘arts’ events that occur within social or care settings – and which are often not driven by artistic goals, but rather therapeutic or social ones – tended to be roundly criticised.

Participants’ views also centre the importance of cultural participation, not only for individual self-determination, but for the potential to challenge perceptions and framings and to communicate alternative ways of being and experiencing the world. Thus, the arts themselves – which are intrinsically bound up with expression – were perceived as potentially creating more awareness that, in turn, could lead to more opportunities for people with disabilities to attend, create and to contribute to culture and, indeed, to be integrated in society more broadly. Crucial to these processes is the visibility of arts professionals and of artists with disabilities.

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