

Article

Implementing the Right of People with Disabilities to Participate in Cultural Life across Five European Countries: Narratives and Counternarratives

Delia Ferri *, Ann Leahy, Neža Šubic and Léa Urzel

Abstract

The UN Convention on the Rights of Persons with Disabilities is a ground-breaking treaty that constitutes persons with disabilities as holders of rights and active members of society, and encompasses civil, political, economic, social and cultural rights. Article 30 of the Convention provides for the right of persons with disabilities to participate in cultural life. The importance of this provision lies in its detailed normative content, and also in that it sheds a light on the need for appropriate policies and practices that enhance cultural participation of persons with disabilities. By investigating the extent to which Article 30 of the Convention has been implemented across five European states (Austria, the Netherlands, Poland, Portugal, Sweden), this article identifies common narratives and counternarratives related to the realization of the right to participate in cultural life. It adopts a socio-legal approach and a blended methodology combining desk-based and empirical research. It contrasts official narratives, which highlight good practices and steps taken to improve access to culture, with counternarratives that reveal a fragmentary approach to cultural participation of persons with disabilities, persisting barriers, limited recognition of artists with disabilities, and the perpetuation of stigma and stereotypes.

Keywords: accessibility; barriers; CRPD; empirical research; right to participate in cultural life

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1. Introduction

The right to take part in cultural life, which encompasses the right of everyone to access, participate in and enjoy cultural goods and services and heritage, is protected by an array of international human rights instruments (Stamatopoulou 2007; Bidault 2009; Chow 2022). Article 27 of the Universal Declaration of Human Rights (UDHR) provides 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 of the International Covenant on Economic Social and Cultural Rights (ICESCR) also recognizes ‘the right of everyone to take part in cultural life’ (O’Keefe 1998). It obliges States Parties to take steps to achieve ‘the full realization of this right’ which is said to ‘include those necessary for the conservation, the development and the diffusion of science and culture’ (Article 15 (2)). Among other core human rights treaties, the UN Convention on the rights of Persons with Disabilities (CRPD or simply ‘the Convention’) articulates the right to participate in culture with particular regard to disabled people in Article 30 (Manca 2017). The importance of this provision lies in its rather detailed normative content, and also in that it sheds a light on the need for appropriate policies and practices that enhance the cultural participation of persons with disabilities. Furthermore, the implementation of Article 30 CRPD is essential ‘for the transformation of how cultures think about disabled people’ (Scully 2012: 73), in furthering ‘the CRPD’s transformative vision of persons with disabilities’ full-fledged membership in an inclusive society’ (Smith and Stein 2020: 287), and in ending the marginalization experienced by persons with disabilities in society (Tatic 2015). The role of culture in the production of disability is also recognized in critical and cultural disability studies (among others, Titchkosky 2000, 2003; Waldschmidt 2018). As Sandahl (2018: 84) argues, ‘the break-through’ work of artists with disabilities ‘tends to challenge, not replicate, mainstream traditions’, and, without experiencing disabled artists’ differences, the mainstream *status quo* may not be able to imagine the ways it could be transformed.

While cultural rights of persons with disabilities are recognized as an emerging area of academic research (Chow 2022), as yet, analysis of the implementation of Article 30 CRPD is scant (Leahy and Ferri 2022). In that regard, this contribution aims to advance current scholarship by investigating the extent to which Article 30 CRPD has been implemented across five European States: Austria, the Netherlands, Poland, Portugal, and Sweden. The choice of countries aims to cover different legal systems, as well as different cultural policy approaches and economic circumstances (Mitra, Posarac and Vick 2013),¹ and to highlight that, even in different contexts, common narratives and counternarratives arise. As will be further discussed later in the article, the construction of the narrative on the implementation of Article 30 CRPD derives from analysis of reports of States Parties to the CRPD and national disability strategies as well as, where feasible, relevant cultural policies, relating to the five countries. Counternarratives emerge to a limited extent from Concluding

1 Although all countries are broadly considered to belong to the Civil Law tradition (Zweigert and Kötz 1998; Glenn 2014; Merryman and Pérez-Perdomo 2020), some of them incorporate remnants of other traditions, such as the Socialist one (e.g. Poland: see Maňko 2013). This choice is also based on the range of European models of cultural policy covered by the countries. Indeed, the five European States represent the majority of cultural policy models that have been identified in the European Union; the Central-Western European Model (Austria, The Netherlands), the Nordic Model (Sweden), the South-Western European Model (Portugal) and the Central-Eastern European Model (Poland) (Rius-Ulldemolins, Pizzi and Rubio Arostegui 2019: 1051).

Observations (COs) made in respect of State reports by the Committee on Rights of Persons with Disabilities (CRPD Committee), the treaty body set up by the CRPD. We also identify them from our analysis of selected shadow reports where available (and where they addressed cultural participation) and from a new qualitative study we carried out with representatives of national disabled people's organizations (DPOs) and organizations working on disability and arts in each of the five countries.² On the whole, this article contends that while the official narratives highlight instances of good practice or steps taken to improve access to culture, counternarratives reveal a fragmentary approach which fails to mainstream the right to cultural participation across the five countries considered. Furthermore, the top-down approach to Article 30 CRPD emerging from narratives of States Parties fails to fully recognize the role of people with disabilities in cultural life, and counternarratives unveil that hidden stereotypes and medicalized views of disability are still a barrier. The overall analysis provides an important theoretical framework for understanding how the legal obligations envisaged in Article 30 CRPD can be best fulfilled.

After these introductory remarks, Section 2 begins with a discussion of the core tenets of the CRPD by way of background, and highlights the key obligations stemming from Article 30 CRPD. Section 3 explains the methodological approach adopted. Sections 4 and 5 provide an in-depth analysis of the development of States' narratives and counternarratives with regard to the implementation of Article 30 CRPD. They look, in particular, at how the realization of the twofold individual dimension of the right to participate in culture (i.e. the right to access cultural activities, goods and services and the right to be a creator of cultural goods and to be involved in culture as a professional artist) is portrayed by the States. It then contrasts these narratives with counternarratives that challenge States' accounts, revealing barriers to cultural participation and gaps in the implementation of Article 30 CRPD. Section 6 provides some concluding remarks.

2. The right of persons with disabilities to participate in cultural life

2.1 The UN Convention on the rights of persons with disabilities

While there is extensive literature describing the content of the CRPD, and it is beyond the scope of this article to examine its complex architecture, it is worthwhile locating Article 30 CRPD within the broader remit of the Convention.

The CRPD constitutes disability as resulting 'from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others' (Preamble, para. 5 and Article 1 CRPD). In this respect, the CRPD rejects the medical model of disability, which focuses on the individual impairment, and has been said to embrace the social model of disability (Kanter 2015: 8), or the social-contextual model of disability, which represents a more refined version of the social model (Broderick 2015; Broderick and Ferri 2019). The CRPD is also considered to embed the 'human rights model of disability' (Degener 2017; Lawson and Beckett 2020), or, more generally, to put forward a human rights approach to disability (Skarstad and Stein 2018). As Degener argues, the human rights model of disability does not focus purely on social and environmental barriers—rather, it emphasizes the human dignity of persons with disabilities and values impairments as part of human diversity,

2 This article is part of a larger pan-European research project, and the results presented in this article represent one of the first outcomes of a broader analysis.

paying attention to intersectional discrimination (Degener 2017: 44–49). In fact, the CRPD Committee in its General Comment No. 6 (CRPD Committee 2018a: para. 9) not only recognizes that disability is a social construct, but conceives of it as ‘one of several layers of identity’.

Article 3 CRPD includes, among the general principles upon which the Convention is based, dignity and autonomy, equality and non-discrimination, accessibility, and participation. These principles are the lens through which every provision of the CRPD must be interpreted, applied and implemented. In that connection, general principles can be regarded ‘as a benchmark against which States Parties should assess the conformity of domestic laws with the Convention’ (Ferri and Broderick 2019: 266). Notably, accessibility, as stated by the CRPD Committee, ‘is approached [in the CRPD] in all its complexity’, and is a ‘precondition for persons with disabilities to live independently and participate fully and equally in society’ (CRPD Committee 2014: para. 10). Article 9 CRPD requires States Parties to:

take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

The principle of participation is also an essential feature of the CRPD and requires ‘engaging with all persons, including persons with disabilities, to provide for a sense of belonging to and being part of society’ (CRPD Committee 2018b: para. 27). In that regard, participation can represent a ‘transformative tool for social change, and promote agency and empowerment of individuals’ (CRPD Committee 2018b: para. 33).

The CRPD encompasses civil and political as well as economic, social and cultural rights. As indicated in Article 4(2) CRPD, the realisation of economic, social and cultural rights is ‘progressive in nature’ (Pyaneandee 2018: xxv), and thus depends on the maximum available resources that each State Party can devote to their implementation. Nevertheless, those rights must be afforded to persons with disabilities on an equal basis with others, and States Parties must address barriers, socio-economic disadvantages, and combat stigma, all of which hamper participation of people with disabilities in society. Although it is generally acknowledged that the CRPD does not establish new rights, the Convention has ‘modified, transformed and added to traditional human rights concepts in key respects’ (Kayess and French 2008: 32). In doing so, O’Cinneide (2009: 164) suggests that the CRPD:

adopts a particular conceptual view of the state’s role in securing individual human rights as involving more than simple abstinence from the abuse of individual civil and political rights. Instead, the state is expected to play an active role in creating the social conditions necessary for individuals to be treated with dignity.

2.2 Article 30 CRPD: re-writing the right to participate in cultural life through the disability lens

In international human rights law, the content of the right to participate in cultural life ‘remains contested’ (Bantekas et al. 2018: 865), but it is generally considered as encompassing a twofold individual dimension and a collective aspect (EPRS 2017: 10, 27; UNESCO 2009). The twofold individual dimension entails respectively the right to access cultural activities, goods, services and heritage, and the right to active involvement in culture, which

includes engagement in the creation of cultural activities, goods and services (Romainville 2015). The collective aspect refers to cultural communities being recognized, protected, as well as enabled to enjoy their cultural expressions (Jakubowski 2016). All those dimensions are covered by Article 30 CRPD, which articulates a range of obligations that are detailed in their normative content, wide-reaching, and cohere with provisions included in other articles of the Convention.

Article 30(1) provides for the right of persons with disabilities to participate in cultural life, echoing the wording of the UDHR (Manca 2017: 544). As noted by Bantekas et al. (2018: 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.

Article 30(1) CRPD requires States Parties to take all appropriate measures to ensure that persons with disabilities have access to cultural materials, to be interpreted, as noted above, in a broad manner encompassing television programmes, films, theatre and other cultural activities, as well as places where cultural performances are held or services are provided, and monuments and sites. This provision must be read in light of Article 9 CRPD on accessibility and in conjunction with Article 21 CRPD on freedom of expression and opinion, and access to information. The ‘cultural dimension’ of Article 9 CRPD (Pyaneandee 2018: 178) is clear as accessibility acts as a precondition to ensuring cultural participation, as highlighted by the CRPD Committee in its General Comment No. 2 (CRPD Committee 2014: para. 4). Furthermore, Article 21 CRPD requires States Parties to the Convention to provide information in accessible formats, to recognise and promote the use of sign languages, as well as to facilitate communication in Braille and other accessible formats. In this respect, the obligations set out in Article 9 and Article 21 CRPD appear to complement and strengthen those of Article 30 CRPD, and reveal the interdependence which ties the right to participate in cultural life of persons with disabilities with the realisation of Articles 9 and 21 CRPD. In line with the social-contextual understanding of disability, and given that the CRPD embraces a broad concept of accessibility (Broderick and Ferri 2019), Article 30 CRPD is underpinned by the understanding that accessibility of cultural knowledge depends on the complex interplay between a specific person’s individual characteristics and the environment (Mastrogiuseppe et al. 2021).

Article 30(2) obliges States Parties to take all appropriate measures to enable persons with disabilities to develop their creative, artistic and intellectual potential. This encompasses the obligation to set up ‘specialized forms of training’ (Bantekas et al. 2018: 886). Smith and Stein (2020: 286), citing Lord and Stein (2009), recall that ‘[i]f fully harnessed, Article 30(2) CRPD (2006) will afford powerful opportunities for persons with intellectual disabilities to “[c]onfront the passivity that paternalistic and non-participatory models of disability typically evoke”’. Echoing the words of Jakubowicz and Meekosha (2003: 190), the promotion of disability culture is essential to revalorize disability experiences and affirm ‘different embodiments through literature, drama, sport and music’.

Furthermore, Article 30(3) imposes on States the obligation of ensuring that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to the access of people with disabilities to cultural materials. In that regard, the CRPD is complemented by the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled (Marrakesh

Treaty), adopted by the World Intellectual Property Organization (WIPO) in 2013, and which entered into force in 2016 (Helfer et al. 2017). The Marrakesh Treaty aims to ensure access to printed materials for persons with disabilities.

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 that addresses the linguistic identity of Deaf persons in the context of education (Murray et al. 2018). It has been highlighted that these provisions, however, entail different types of obligations: Article 24 provides for education to be inclusive, and States Parties ‘are mandated to “facilitate and promote the linguistic identity” of [D]eaf persons on an equal basis, whereas Article 30(4) provides an individual entitlement to “recognition and support”’ (Bantekas et al. 2018: 909). Ball (2011: 785) argues that ‘an essential feature of the CRPD’s model is the emphasis on balancing the preservation of the Deaf individual’s linguistic identity while achieving accessibility to public services for sign language’.

3. Methodology

This article is informed by the human rights model of disability and builds upon legal literature on the right to participate in culture. Notably, it does not engage in a comparative analysis; rather it adopts a socio-legal approach in that it focuses on how Article 30 CRPD has been implemented by States Parties and how this implementation is perceived and experienced by persons with disabilities. It is based on a blended methodology that combines desk-based and empirical research.

We undertook a qualitative document analysis (Wolff 2004; Bowen 2009) of reports of States Parties to the CRPD (CRPD/C/AUT/1; CRPD/C/AUT/2-3; CRPD/C/SWE/1; CRPD/C/SWE/2-3; CRPD/C/PRT/1; CRPD/C/POL/1; CRPD/C/NLD/1)³ and national disability strategies, with reference to Article 30 CRPD or to the right to access culture or to participate in culture as artist or creator, examining whether a common narrative existed. The term ‘national disability strategy/ies’ is used here as an umbrella term to refer to an array of policy documents explicitly termed as strategies, or action plans, or plans that ‘set out how people with disabilities are to be included in domestic society as fully participating citizens through measures to improve access to education, employment, transport, housing, income, personal support, etc’ (Flynn 2011: 1). We focused on strategies adopted after 2008, the year of entry into force of the CRPD, which represent a key tool for the implementation of the CRPD (Flynn 2011; McCallum 2011; Lorion 2019).⁴

3 These reports are available on the website of the CRPD Committee along with Concluding Observations issued by the CRPD Committee: <https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx>.

4 We included the following strategies in our analysis: the Austrian ‘National Action Plan on Disability 2012–2020: Strategy of the Austrian Federal Government for the implementation of the UN Disability Rights Convention’ (Federal Ministry of Labour, Social Affairs and Consumer Protection of Austria 2012); the Dutch ‘Unlimited Participation! Implementation of the UN Convention on the Rights of Persons with Disabilities’, adopted in 2018 (Government of the Netherlands 2018); the ‘Polish Strategy for People with Disabilities 2021–2030’ (Government of Poland 2021); the Portuguese National Disability Strategy 2011–2013 (Government of Portugal 2010), and National Strategy for the Inclusion of People with Disabilities 2021–2025 (Government of Portugal 2021); and

We then looked at and selected shadow reports made by DPOs, civil society organizations and human rights bodies in respect of the five countries, where available, and COs made in respect of those reports by the CRPD Committee to detect counternarratives. Notably, as of 1 February 2022, the CRPD Committee has issued COs with regard to four of the countries under review (Austria, Poland, Portugal and Sweden). As yet, it has not challenged the narrative made by States Parties under Article 30 CRPD, although admittedly it consistently calls on States to improve accessibility, to enhance data collection, and to adopt an approach to disability consistent with Article 1(2) CRPD. However, little is said specifically with regard to cultural participation. A certain restraint from the CRPD Committee had already been noted by [Bantekas et al. \(2018: 873\)](#), and our review confirmed that the most typical recommendations under Article 30 CRPD have a relatively narrow focus, on issues of copyright. This is the case in respect of COs issued for Portugal and Sweden (CRPD/C/PRT/CO/1; CRPD/C/SWE/CO/1), while COs issued in respect of Austria and Poland include no recommendations in relation to Article 30 (CRPD/C/AUT/CO/1; CRPD/C/POL/CO/1).

In order to bolster the counternarratives emerging from shadow reports and COs, the analysis of those documents is augmented by initial empirical findings from a study with organizations working on disability across Europe focusing on the five selected countries and on participants' perceptions of barriers to cultural participation by people with disabilities. In particular, we conducted qualitative research with representatives from ten organizations, two from each of the five countries. Recruited during 2021 by way of a purposeful sampling strategy, the interview participants were drawn from an umbrella organization of people with disabilities ($n = 5$), from organizations working on arts and disability ($n = 4$) and from an organization of Deaf people ($n = 1$). Interviews were semi-structured and the interview guide included, among other things, questions about barriers to engagement in culture by people with disabilities. Answers to those questions are a key focus of this article by way of elaborating the counternarrative. Interviews were conducted by video conference, allowing maintenance of the face-to-face element of interviewing ([Foley 2021](#)). In most cases participants' first language was not English, and, given that qualitative methods are flexible and evolve in response to context ([Foley 2021](#)), we decided to offer some alternative accommodations using qualitative questionnaires, which can be combined in a complementary way with interviews ([McGuirk and O'Neill 2016](#)). We, therefore, provided the option of responding to key interview questions in writing, rather than by way of interview. Thus, our empirical research involved a combination of interviews and qualitative questionnaires (seven interviews and three questionnaires). Participants were provided in advance with information and gave informed consent. Each interview was recorded and transcribed verbatim. All contributions have been anonymized, but we identify which country participants were drawn from and whether they worked with organizations of people with disabilities (DPOs), arts and disability organizations (A&D) or organizations of Deaf people (D). We obtained ethical clearance from the relevant Maynooth University Ethics committee. The analysis process followed the steps for thematic analysis outlined by [Braun and Clarke \(2006, 2020a, 2020b\)](#) and included: familiarization; coding; generating initial themes; reviewing and developing themes; and refining, defining and naming themes.

the Swedish Strategy for the Implementation of Disability Policy, 2011–2016 ([Government of Sweden 2011](#)), and National Goal and Focus of Disability Policy 2017 ([Government of Sweden 2017](#)).

4. Narratives around the implementation of the right of persons with disabilities to participate in cultural life

4.1 Access to culture: a narrative of progress and enhancement

When discussing Article 30 CRPD, the States Parties' reports to the CRPD Committee that we analysed predominantly frame persons with disabilities as audience members and cultural consumers. The narrative that emerges from these States Parties' reports portrays investments to improve accessibility in the area of culture and achievements in ensuring access to cultural goods and services to persons with disabilities (see CRPD/C/AUT/1: para. 335; CRPD/C/SWE/1: para. 285; CRPD/C/POL/1: paras 513, 515; CRPD/C/NLD/1: paras 337–338). In this respect, States' reports often focus on physical accessibility, but also on accessibility of content of arts, cultural products, and heritage designed to be inclusive of a range of people with disabilities, showcasing awareness of the need to implement Article 30 in line with the general principle of accessibility envisaged in Article 9 CRPD.

When focusing on physical access, States' reports discuss a number of measures undertaken, which include the use of subsidies to improve the accessibility of cultural premises (CRPD/C/AUT/1: para. 335; CRPD/C/SWE/1: para. 79; CRPD/C/NLD/1: para. 337), transnational collaboration to address the accessibility of heritage sites and other premises (CRPD/C/SWE/1: paras 289–290) or specific initiatives and programmes to increase the physical accessibility of various cultural venues including museums, theatres, galleries (CRPD/C/PRT/1: paras 526–531). In this respect, the Polish report also notes that a 'majority of cultural institutions (...) are adapted to the needs of disabled people'. However, this statement is followed by mention that, for financial reasons or preservation purposes, not all architectural barriers may be removed (CRPD/C/POL/1: para. 525). Additionally, States' reports highlight a number of measures that have been enacted or planned with the aim of supporting access to cultural content for persons with disabilities. They refer to the use and production of Braille and audio books, audio guides and video guides as well as interpreting devices (in sign language), the accessibility of TV broadcasts and films, digitization and the creation of personal information services in cultural premises (CRPD/C/AUT/1: para. 335; CRPD/C/SWE/1: paras 284–285, 289, 291, 293–296; CRPD/C/PRT/1: para. 273). Reports from Poland and the Netherlands also discuss similar initiatives under other articles, citing, for example, the availability of books in different formats or the subtitling, interpretation and audio description of films, plays and other TV broadcasts under Article 9 and 21 CRPD (CRPD/C/POL/1: para. 268; CRPD/C/NLD/1: paras 103–104, 219).

Further, States Parties' reports also devote attention to copyright laws and/or to ratification of the Marrakesh Treaty (CRPD/C/AUT/1: para. 333; CRPD/C/SWE/1: paras 169, 292; CRPD/C/POL/1: paras 517–520; CRPD/C/NLD/1: paras 218, 339), in compliance with Article 30(3) CRPD. Again, the narrative emerging is that of successful legal reform (either undertaken or forthcoming) that prevents copyright from being a barrier for persons with disabilities.

The narrative evident from these reports aligns with that conveyed by national disability strategies. Very few of the national disability strategies explicitly mention Article 30 CRPD. This is the case, for example, in the Polish Strategy for People with Disabilities (Government of Poland 2021: 129), which refers to Poland's obligation to ensure that persons with disabilities have the opportunity to participate in cultural life, recreation, leisure and sport on an equal basis with others. However, all strategies address culture, to varying degrees, and highlight a series of measures designed to advance access to culture of persons

with disabilities. Interestingly, all national disability strategies reviewed include principled statements on the significance of access to culture, and consistently demonstrate awareness of access to culture requiring both accessibility of the built environment and of cultural content. For example, the Austrian National Action Plan on Disability ([Federal Ministry of Labour, Social Affairs and Consumer Protection of Austria 2012](#): 50) highlights the need for ‘not only ensuring the accessibility of buildings, but to enable people with sensory impairments and those with learning disabilities to experience and understand arts and culture (e.g. by means of tactile, visual and audio presentations)’. Access to cultural content is generally afforded more space and attention than physical accessibility, somewhat suggesting that physical accessibility has already been successfully dealt with (see [Government of Poland 2021](#): 31). Overall, national disability strategies convey a positive narrative of a portfolio of measures being adopted or planned in order to improve access and consumption of culture by people with disabilities. While these measures differ from one strategy to another, they include, among other things, creating accessibility plans, providing funding (for example for assistive technology), establishing and disseminating best practices and technical standards, pursuing digitization, training of staff in cultural institutions, supporting specific projects, guaranteeing free or reduced entry fees, and adopting legislation (in particular to impose obligations on broadcasters in relation to, among other things, providing subtitling, audio description and/or sign language interpretation of a certain proportion of programmes). They highlight the role played by specific measures in facilitating access to media ([Federal Ministry of Labour, Social Affairs and Consumer Protection of Austria 2012](#); [Government of the Netherlands 2018](#); [Government of Sweden 2017](#)), libraries ([Government of Poland 2021](#): 31; [Government of the Netherlands 2018](#): 23); museums and film ([Government of Sweden 2011, 2017](#)).

On the whole, while States’ reports to the CRPD Committee and national disability strategies of the countries reviewed deal with access to culture in different ways, they all convey a narrative of progress achieved in the implementation of all obligations included in Article 30 CRPD, and enhanced access to cultural goods, services and heritage.

4.2 Active participation in culture: a subtle narrative of self-expression, dignity and diversity

References to active participation of persons with disabilities in culture are much more limited, ambiguous and scattered throughout the States’ reports, compared with statements regarding the access to culture from an audience viewpoint. However, some reports recognize in a general fashion the importance of cultural participation. For example, the Swedish report states that ‘[c]ulture should be available to everyone—in the form of educational work, opportunities for personal creation and opportunities to share in professional artistic creation’ (CRPD/C/SWE/1: para. 282). In a similar vein, the Dutch report addresses the recognition of ‘the right to participate on an equal basis in cultural life’ and highlights that ‘culture is by and for everyone’ (CRPD/C/NLD/1: para. 334). These reports also discuss current and forthcoming initiatives with regard to active participation in cultural life, mentioning arts companies of persons with disabilities or the integration of a disability perspective in the granting of subsidies in culture or future studies focusing on the cultural participation of persons with disabilities (CRPD/C/SWE/1: paras 283, 287–288; CRPD/C/NLD/1: para. 336). The Portuguese report only briefly engages with the right to participate

in cultural life, although it clearly refers to the professional engagement of persons with disabilities in culture, mentioning them ‘both as an audience and as artists’ (CRPD/C/PRT/1: para. 273). While disability arts is no longer seen as needing to engage exclusively with disability issues (Solvang 2012) or to be about educating others, in some States Parties’ reports, cultural participation of persons with disabilities is linked to the idea of raising awareness and combating stigma (CRPD/C/AUT/1: para. 98; CRPD/C/POL/1: paras 62–63). The active participation of persons with disabilities in cultural life is also addressed in the broader context of education, albeit less explicitly, with States Parties referring to opportunities for the development of creative skills and potential, as well as opportunities to access cultural education through art schools and lifelong learning (CRPD/C/AUT/1: paras 240, 250; CRPD/C/SWE/1: paras 286, 288). However, in some instances it remains unclear whether States Parties are referring to the cultural participation of persons with disabilities as professionals or as amateurs. For example, the distinction is not quite explicit in the Polish report when it discusses the promotion of artistic achievements of persons with disabilities (CRPD/C/POL/1: para. 515) nor in the Austrian report, which lists arts promotion initiatives under Article 8, including theatre productions, dance projects, festivals or workshops involving persons with disabilities (CRPD/C/AUT/1: para. 98).

A similar approach is visible in national disability strategies of all States considered in this article. For example, the Portuguese National Strategy for the Inclusion of People with Disabilities (Government of Portugal 2021: 17), quite similarly to its initial report to the CRPD Committee, states that inclusion does not encompass only ‘cultural enjoyment, but also the encouragement and increased participation of these citizens as creators, performers or performers of works, thus also fostering diversity in the national artistic panorama and encouraging the emergence of projects led by artists with disabilities’. The Austrian National Disability Plan (Federal Ministry of Labour, Social Affairs and Consumer Protection of Austria 2012: 50) recognizes that ‘active participation of people with disabilities in cultural events should be promoted and the wariness of society with regard to such artistic events reduced’, and the Swedish Strategy for the Implementation of Disability Policy (Government of Sweden 2011: 15) declares culture must be accessible to all, including ‘through opportunities for own creation and through opportunities to take part in professional artistic creation’. However, these statements are not consistently accompanied by concrete measures. For example, the only measure in the Austrian National Disability Plan (Federal Ministry of Labour, Social Affairs and Consumer Protection of Austria 2012: 54) that supports active participation is the funding of Austrian films about and *by* people with disabilities. The Dutch Programme for the Implementation of the UN CRPD (Government of the Netherlands 2018: 21) lists some general measures that, among other things, foster cultural participation of disabled artists, such as sharing knowledge via the National Centre of Expertise for Cultural Education and Amateur Arts, and financing projects in the field of cultural activities via the Cultural Participation Fund.

It is evident that States, in reports to the CRPD Committee and national disability strategies, convey a general awareness of the importance of active participation of persons with disabilities in cultural life, and highlight the (somewhat implicit) attempt to support people with disabilities in developing their artistic potential, as required by Article 30(2) CRPD. However, a rather elusive narrative, which portrays limited measures adopted to support cultural creation and self-expression of persons with disabilities, seem, to emerge.

5. Counternarratives around the (incomplete and patchy) implementation of the right of persons with disabilities to participate in cultural life

5.1 Access to culture: counternarratives of existing barriers, patchy progress and fragmentation

The portrayal of the proactive role of State parties in implementing Article 30 CRPD and narratives about a plethora of measures which are effective in creating the social and environmental conditions necessary for cultural access are challenged by the counternarratives emerging from both shadow reports and our empirical study.

Even if physical barriers to accessing cultural institutions and content are often characterized as having been addressed through an array of different legislative and policy measures in State reports or in national disability strategies, participants in our empirical study from all five countries referred to existing physical barriers and highlighted lack of access for audiences or visitors to cultural institutions. Sometimes this was associated with older buildings, especially buildings of architectural importance, which have not been made accessible to people with physical disabilities. In some instances, physical inaccessibility is reported to be a widespread problem, especially outside major urban areas, and one that continues in buildings hosting cultural institutions or cultural heritage. For example, one participant from Poland talked about her experience as someone using a wheelchair, stating that:

I have only a few places in my city where I can feel safe and I can feel sure that I am going to enjoy the show. So, I think, still those architectural barriers are well preserved in Poland. (PL, DPO)

Another barrier perceived for audiences was that accessible seating is provided within venues in ways that are not user-friendly. A Swedish participant highlighted how an important theatre only has four accessible seats, which are in a special area, 'so if you have a family and some people who don't need accessibility seats you can't sit with your family', adding 'you are only counted as a person with a disability and not as a member of a family or a couple or a mother or father' (SE, DPO).

In a similar vein, shadow reports reference ongoing problems with physical accessibility (see [KSK Foundation \(Poland\) 2015](#): paras 166–167; [Swedish Disability Federation 2011](#): para. 564), conveying a counternarrative of existing barriers. They also sometimes signal that improvements have been made in some cultural venues, but still suggest patchy progress when it comes to accessibility of culture. For example, a Dutch report acknowledges improvements in accessibility of museums but suggests that physical barriers continue in other areas, including theatres and events ([Netherlands Institute for Human Rights 2018](#)).

Lack of accessible cultural content is also highlighted in shadow reports (see [KSK Foundation \(Poland\) 2015](#); [Netherlands Institute for Human Rights 2018](#); [Independent Monitoring Committee \(Austria\) 2018](#)). Consistent with this, participants in our study suggested that cultural organizations sometimes prioritize physical access, which means that lack of accessible content across a range of cultural organizations continues to be a barrier to access. For example, a Portuguese participant commented:

...there are a large number of organisations that are maybe accessible in order to get in from the front door and that is where it stops. I mean the offer itself, either it is the museum exhibition or a performance or...a conference organised by a library, you know, all the programming that

cultural organisations have to present. ...[in museums, they] don't consider at what height we present the objects, where are the labels? What is the size of the letter? What are the contrasts of the panels? If [they] have alternative information in Braille or audio description or sign language tours etc. (PT, A&D)

Similarly, a participant from the Netherlands felt that there was 'minimal' attention to 'communication accessibility, guided tours in sign language or for people with visual disabilities or all kinds of other disabilities or information in easy language' (NL, DPO). A Polish participant perceived that film companies could relatively easily facilitate accessible movie screenings (with audio description and subtitling) but that, instead, where screenings are made accessible, it is done by organizations working on disability who must fundraise to pay the film companies (PL, A&D). The fact that it often falls to NGOs to facilitate access to culture was also highlighted in a shadow report from Poland ([KSK Foundation 2015](#)).

Other accessibility barriers identified by study participants relate to difficulties with information on websites. For example, a Swedish participant commented that, while laws require websites to be accessible, what is provided is poor from a disability perspective, lacking information on accessibility of exhibitions/events or transport, parking, etc. (SE, DPO).

A number of participants felt that existing laws were not effective to counter the barriers encountered, challenging the positive narrative of effective measures conveyed by States reports and national disability strategies. An Austrian participant referred to the Federal Disability Equality Act (*Bundes-Behindertengleichstellungsgesetz BGStG*), which aims to eliminate or prevent discrimination against persons with disabilities, adding that, 'it still doesn't include provisions for injunctive relief ... for the removal of barriers or discriminatory behaviour ([although] in some cases there is a possibility for financial compensation)' (AT, DPO). Talking about access, a participant from the Netherlands suggested that laws left a good deal of discretion to individual organizations and institutions, saying that it made legal accountability difficult as 'these laws and legislation are really like framework and leave a lot of space and interpretation to self-regulation' (NL, DPO). A Polish participant felt that relevant laws were 'a little bit of a grey area' and that they are not consistently enforced (PL, A&D). Similarly, no consequences for non-compliance with laws mandating accessibility were identified by the Portuguese participants, with one commenting:

Our legislation prohibits discrimination and defends accessibility [in] all aspects of life. However, the legislation is not applied in its entirety and there is a lot of permissiveness with the breaches. (PT, DPO)

Knowledge barriers were frequently identified by participants who expressed the view that people working in the arts and cultural sector often do not know how to facilitate access for people with a range of disabilities (something also asserted in other studies, see [Weisen 2012](#); [Constantinou et al. 2016](#)). For example, a Swedish organization felt that cultural institutions do not know 'how to work with universal design and how to implement it. . . So [there] is a gap between the regulations and the reality' (SE, DPO). A Polish participant felt that a recent change in the law meant that many staff were now charged with responsibility for accessibility who lacked the requisite knowledge and that projects were sometimes implemented without the input of people with disabilities. That participant commented that such staff tended to think about physical access to their buildings but lacked knowledge about other access needs (PL, A&D).

Participants also highlighted the existence of financial barriers to accessing cultural goods and services. Sometimes this was talked of in terms of limited incomes or poverty of individuals or lack of support by way of personal assistance to attend cultural events. However, in some cases they highlighted the lack of public support for making cultural organizations accessible. For example, talking about sign language not being provided by cultural organizations, an Austrian organization of Deaf people felt that ‘we are told again and again that there is a lack of money, or that the expenses were not planned in the budget’ (AT, D). Participants from the Netherlands, Portugal and Sweden indicated that employees in cultural institutions sometimes had no or minimal budgets to improve accessibility, which limited what could be done even where they themselves were interested in and open to improving accessibility. These counternarratives deeply challenge the States’ narratives of an array of financial support readily available to cultural institutions.

Finally, a key issue that underlies some of the themes discussed above is the lack of a comprehensive approach to the right to participate in culture. Many participants in the present study talked about how access could be facilitated only at special times, or accessibility was limited to individual projects, or was dependent on the enthusiasm of a key staff-member within a cultural organization. In some instances, participants also highlighted that accessibility of cultural goods and services is deeply affected by the fact that accessibility funds are given for short-term projects, rather than long-term action or with the purpose of embedding accessibility features in all cultural goods and services. For example, one participant from the Netherlands mentioned a government fund for cultural participation which was contributing to positive change, but suggested that cultural organizations need continuous and mainstreamed funds, as otherwise they worked from ‘project to project’ (NL, A&D). Similarly, a Polish participant commented that there have been many ‘smaller projects on culture and people with disability, but not really something that could last’ (PL, DPO). A Swedish participant noted that there are lots of good projects and lots of good ideas about how to increase accessibility, but that accessibility ‘never mainstreams because the project manager or the project group goes on with a new thing and the knowledge disappears then’ (SE, DPO). This lack of a comprehensive approach is characterized as ‘fragmentary’ in a shadow report from the Austrian [Independent Monitoring Committee \(2018: 28–29\)](#), which lists ways in which access to cultural programming is not made accessible in, among other places, theatres, cinemas and museums and suggesting that inclusive guided tours, subtitling and use of Simple German, Austrian Sign language and audio description ‘are mostly non-existent’.

On the whole, a counternarrative of barriers, patchy progress and fragmentation emerges from our qualitative research and our review of shadow reports, which illuminate a reality that is rather different from that conveyed by States reports and national disability strategies.

5.2 Active participation in culture: a long road ahead

As discussed above in section 4.2, although active participation is generally referenced (albeit somewhat elusively) in national disability strategies and in some State Reports, the reality, according to participants in our study and to our review of shadow reports, is that concrete measures to bring this about are often lacking. The subtle narrative of growing awareness about the importance of disability arts and participation of persons with disabilities in cultural institutions is overturned by a rather grim counternarrative of lack of

equitable access to grants/subsidies, lack of employment of people with disabilities within cultural industries, and/or a fundamental problem associated with absence of opportunities to exercise influence in decision-making fora (see [Independent Monitoring Committee \(Austria\) 2018](#); [Netherlands Institute for Human Rights 2018](#): para. 28; [Swedish Disability Federation 2011](#): para. 557). Study participants also pointed out that there is little access to professional arts education or training for people with disabilities, something also highlighted in a shadow report from Sweden ([Swedish Disability Federation 2011](#): para. 564). Furthermore, participants also suggested that, for people wishing to work as artists or to be employed by cultural organizations, physical barriers remain significant. Therefore, it was perceived that even buildings that are accessible for audiences remain inaccessible for performers or artists or staff. For example, a participant from Sweden commented as follows:

The work-places are not created to include everybody. So even if they would hire somebody it wouldn't be possible to, let's say, access the break room or even come up on stage and so on. So the lack of physical accessibility excludes people with disability so in a double sense. . . . (SE, DPO)

Participants sometimes linked this inaccessibility to negative attitudes or stereotypes about people with disabilities, or with traditional segregation in education and lack of awareness that people with disabilities could be professional artists or workers in cultural organizations. This was considered to be a fundamental problem, suggesting the lack of engagement with the human rights model of disability in the cultural sector. For example, a participant from the Netherlands commented:

. . . a lot of our theatres they have . . . places for people with wheelchairs so that you can visit art, but you cannot come on the stage because it is not thought out that you can be an artist in a wheelchair. (NL, DPO)

Participants gave examples of ways in which artists with disabilities were discounted. One gave as an example challenges faced by an actress of short stature to be cast just as a regular person—adding that the problem was about negative ideas about disability – ‘the frame that they are put in’ (NL, DPO). Similarly, another participant talked about a woman with a visible disability working as a stand-up comic but attracting hateful comments and ‘nobody really focused on the way that she was performing’ (PL, DPO). That participant indicated that opportunities for people with disabilities in Poland to make art are confined to ‘special’ events or festivals that remain outside of the mainstream, with societal preconceptions acting as a barrier. She said:

We are not shown that it is also culture, and it is not as valued as the mainstream culture. I think that society isn't really prepared mentally or when it comes to the awareness that it could be something different from the norm. . . . It is not really something that people would expect to see a person with a disability on the stage. (PL, DPO)

That participant's concern with the need for attitudinal change, with separation between art made by people with disabilities and mainstream cultural production was echoed in other interviews, and it could also be linked to a sense of patronization or exclusion from mainstream funding. For example, a Dutch organization perceived that some organizations that create art are ‘part of a care organization’ and, therefore, have difficulty accessing cultural funding, and an Austrian Deaf organization said that we ‘[are] usually only

patronized' (AT, D). A Portuguese participant felt that, when people with intellectual disabilities try to participate in culture, they tend to be treated 'as if they were children and that is not who they are' (PT, A&D). Likewise, a shadow report in respect of Portugal suggests that there is still a charitable model operating ([Autistic Minority International 2016](#)). A Swedish organization noted that the object should be:

not to create a lot of theatre groups with only disabled people, it is to include people into all the-
atre groups. And to change that mindset of people to understand that inclusion should happen
everywhere. (SE, A&D)

On the whole, the already tenuous narrative of limited progress in ensuring active participation of persons with disabilities in culture is deeply challenged by a counternarrative of existing barriers, stigma and stereotypes. Furthermore, the lack of a comprehensive approach, already discussed in respect of the first individual dimension of cultural participation (i.e. access to culture as audience), was echoed in relation to the second individual dimension (i.e. the right to be a creator of cultural goods and to be involved in culture as a professional artist).

6. Concluding remarks

Article 30 CRPD recast the right to participate in cultural life, already envisaged in general human rights instruments such as the UDHR and the ICESCR, through the lens of disability. In doing so, it imposes a range of far-reaching obligations on States Parties in order to ensure that persons with disabilities can enjoy cultural goods, services and heritage as audiences on an equal basis with others, and can create art as well as contribute, as amateurs or professionals, to cultural life. In that connection, it requires States Parties to adopt positive measures that support people with disabilities in developing their creative, artistic and intellectual potential.

The analysis conducted shows that, in all the countries considered, official narratives emerging from States reports and national disability strategies showcase the adoption of an array of legislative and policy actions, list good practices and contend that numerous steps have been taken to improve access to cultural goods service and heritage. These narratives seek to convey a sense of mainstreaming of accessibility measures across the cultural sector. They try to portray the embedding of a broad conception of accessibility, in compliance with the approach adopted by the CRPD Committee (2014), in the implementation of Article 30 CRPD. They also attempt to show awareness of access to culture as an essential tool to participate in society. The narrative of active participation is far less bold and shows that all the countries considered have not yet fully promoted agency and empowerment of individuals with disabilities, as would be required by Article 30 CRPD read in light of the general principle of participation.

Shadow reports and data gathered through our empirical research challenge those narratives. They reveal a fragmentary approach to cultural participation of persons with disabilities in all respects. Although the existence of good practices was highlighted by several participants, counternarratives suggest that full accessibility of cultural goods, services and heritage has not been achieved. Participants in our study highlight a range of existing barriers for audiences with disabilities. Most fundamentally, however, counternarratives show that all the countries considered fail to fully recognize the role of people with disabilities as producers of culture, revealing the existence of under-acknowledged stereotypes rooted in

the medical model of disability. Charitable approaches, which are at odds with the human rights model of disability embedded in the CRPD, are still widespread. In particular, participants' accounts reveal an absence of mainstreaming of creation by people with disabilities associated with reductionist medicalized notions about what it is to experience disability and limited appreciation that people with disabilities could be professional artists/performers and workers within cultural organizations.

This article shows that the rather fragmentary, project-based approaches that are observed by the participants in our study fall short of the obligations set out in the Convention and do not fulfil the human rights model of disability. This article also evidences the need for continued emphasis on physical access to cultural buildings for audiences and performers, but also the necessity of greater access to a broad range of content of cultural goods for people with different types of disabilities. Furthermore, it highlights the need for recognition of and more robust support for activities involving people with disabilities as artists and arts workers.

On the whole, the counternarratives presented make evident that the full implementation of Article 30 CRPD may only occur when a comprehensive approach and mainstreaming of opportunities both for access to culture and for active participation in culture is adopted.

Acknowledgments

We would like to acknowledge the contribution of interview participants. We are also grateful for the insightful comments of peer reviewers.

Funding

This research article has been written within the remit of the project '*Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths—DANCING*'. This work was supported by the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme [Grant Agreement No 864182]. This review article reflects only the authors' views and does not necessarily reflect those of the European Union or the ERC.

Conflict of interest statement. None declared.

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