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# The right to participate in cultural life of persons with disabilities in Europe: Where is the paradigm shift?

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#### ABSTRACT

The UN Convention on the Rights of Persons with Disabilities (CRPD) is associated with a paradigm shift in how disability is approached, as it views persons with disabilities as holders of rights and as active members of society. It aims to ensure that people with disabilities are fully included in communal life, and, in Article 30, addresses participation in culture. This research article focuses on the implementation of Article 30, investigating whether there is evidence of the paradigm shift underpinning the CRPD in how cultural participation is approached by States Parties. Focusing on Europe and on the basis of a systematic qualitative document analysis of States' reports to the Committee on the Rights of Persons with Disabilities and recommendations made by the Committee in response to them, this article shows that the medical model of disability still underpins cultural participation. Signs of a paradigm shift are, however, evident in the way States address accessibility and identities of some groups. Physical access to buildings and heritage is a prominent issue, and awareness of the need to facilitate access to cultural content is emerging. This article concludes that full realisation of the paradigm shift in the cultural domain, while being essential to achieve full inclusion of persons with disabilities, is yet to come.

#### RÉSUMÉ

## Le droit de participer à la vie culturelle des personnes handicapées en Europe: où est le changement de paradigme?

La Convention des Nations Unies relative aux droits des personnes handicapées (CDPH) est associée à un changement de paradigme dans la manière d'aborder le handicap en considérant les personnes handicapées comme des titulaires de droits et des membres actifs de la société. Elle vise à garantir l'inclusion des personnes handicapées dans la vie de la communauté et traite de la participation culturelle des personnes handicapées dans son article 30. Ce texte de recherche porte sur la mise en œuvre de l'article 30 et s'attache à chercher des preuves de ce changement de paradigme dans la façon dont les États parties envisagent la participation culturelle. Focalisé sur l'Europe et basé sur une analyse documentaire qualitative systématique des rapports des États au Comité des droits des personnes handicapées et des recommandations formulées par ce dernier, cet article montre que le modèle médical du handicap demeure le fondement de la participation culturelle. Néanmoins, les signes d'un changement de paradigme se manifestent dans la manière dont les États abordent l'accessibilité et l'identité de certains groupes. L'accès physique des bâtiments et du patrimoine est un enjeu important et une prise de conscience sur la nécessité de faciliter l'accès au contenu culturel apparaît. Cet article conclut que le changement de paradigme dans le domaine culturel, tout en étant essentiel pour parvenir à l'inclusion des personnes handicapées, reste encore à réaliser.

### Keywords

- Convention on the Rights of Persons with Disabilities
- Paradigm Shift
- Culture
- Heritage
- Document Analysis

#### Mots-clés

- Convention relative aux droits des personnes handicapées
- Changement de paradigme
- Culture
- Patrimoine
- Analyse documentaire

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#### 1. Introduction

Until the '90s, the importance of participation in cultural life for people with disabilities was largely ignored by European policy makers, with disability policies focusing on areas such as welfare and employment (Kelemen & Vanhala, 2010; Waddington & Diller, 2002). Both the European Union's (EU) actions and those of its Member States primarily aimed at providing social services to persons with disabilities or at supporting vocational training (Waddington, 2005). The 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993), for the first time contextualised disability within the frame of human rights and included an explicit proviso on culture, 1 but did not result in an increased focus on cultural rights of persons with disabilities. It was only with the entry into force of the UN Convention on the Rights of Persons with Disabilities ("CRPD," or "the Convention"), the first binding human rights instrument on disability, that participation in culture started to be considered as a field of national disability policies, prompted by the need to implement Article 30 CRPD. This provision obliges States Parties to the Convention to ensure accessibility of cultural materials, services, activities, as well as cultural heritage, and to take appropriate measures "to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential." This obligation must be read in conjunction with Article 21 CRPD, which requires States Parties to the Convention to provide information in accessible formats, and to recognise and promote the use of sign languages, as well as to facilitate communication in Braille and other accessible formats. Moreover, Article 30 CRPD explicitly imposes on States Parties the duty to recognise and support the "cultural and linguistic identity" of people with disabilities, "including sign languages and Deaf culture."

Article 30 CRPD cannot be read in isolation. Rather, it must be interpreted in light of the general principles of the Convention embodying a "paradigm shift," away from a social welfare response to disability to a rights-based approach. The CRPD involves a groundbreaking "paradigm shift," from perceptions of persons with disabilities as

Rule 10 required States to ensure that "persons with disabilities are integrated into and can participate in cultural activities on an equal basis."

"objects" of charity, from the medical model, towards viewing persons with disabilities as holders of rights (Quinn, 2009: 216). The Convention 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 has been said to embrace the social model of disability (Kanter, 2015: 8), or the social-contextual model of disability, which may represent a more refined version of the social model (Broderick, 2015; Broderick & Ferri, 2019; Waddington, 2005).

In light of this paradigm shift, and, as recently suggested by Quinn (EASPD, 2020: 2), participation in culture must also be conceived of as an expression of personhood and dignity, which are cornerstones of the CRPD. Cultural 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 cultural participation of people with disabilities. Furthermore, as the UN Special Rapporteur in the field of Cultural Rights contends, culture has potential to promote fuller enjoyment of human rights, including by championing universality of human rights and dignity, embodying and embracing cultural diversity, challenging discrimination, and contributing to reconciliation (Bennoune, 2018).

Against this background, this article aims to answer the following research question: Is there evidence that the "paradigm shift" associated with the CRPD has occurred in relation to how cultural participation by people with disabilities is understood by States Parties to the CRPD? As will be further explained in Section 3, in order to answer this research question, we systematically reviewed States' reports to the UN Committee on the Rights of persons with Disabilities ("CRPD Committee") as well as queries raised and recommendations made by the CRPD Committee in response to them, and carried out a thematic analysis of them supported by a broader document analysis of shadow reports to the CRPD Committee made by organisations representing people with disabilities. While systematic reviews of the scientific literature are widespread, reviews of the kind conducted as part of this research are still scant, in spite of their potential for advancing knowledge and contextualising further studies (but see Byrne, 2019). The scope of our research is deliberately European, and we focus on Member States of the EU and the United Kingdom,<sup>2</sup> as well as the EU itself, which is a party to the CRPD since 2010 (Ferri & Broderick, 2020). This scope is not only dictated by the fact that this article is part of a larger project funded by the European Research Council, but is also adopted with a view to contributing to the (still limited) policy debate occurring in Europe. It is also informed by the understanding that culture is essential to end the marginalisation of persons with disabilities and to facilitate full participation in the life of communities (Council of Europe, 2017; Tatic, 2015).

The UK has now officially withdrawn from the EU, but it was a Member States during the timeframe considered. Furthermore, it remains "culturally" linked to the EU, which makes it interesting to consider issues emerging in the UK along with those emerging in other countries.

Council Decision 2010/48/EC of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities [2010] OJ L23/35.

In addressing this research question, we recognise that "culture" is a complex and multifaceted concept (Riddell & Watson, 2003). Its definition depends on the context and the disciplinary perspective of the writer (Johnson, 2020). For the purpose of this analysis, while valuing the broad understanding of culture put forward in literature (Williams, 1981: 13) and underpinned in Article 30 CRPD (Broderick & Ferri, 2019), we focus on arts practices and heritage. The term "arts practices" refers to different art forms, including literature, dance, music, theatre, and visual arts (Caust, 2019). We do so, not to conflate ideas of "culture" and "art," but because arts practices are visible and acknowledged forms of cultural expression and they should reflect a variety of voices and identities (Caust, 2019; European Union, 2019).

This article aims to fill a gap in current literature. Article 30 CRPD is one of the least studied human rights areas (Bantekas et al., 2018) and little scholarship has addressed arts participation. While there are various legal commentaries on Article 30 CRPD, little attention has been paid to its implementation. The CRPD Committee itself has provided limited recommendations on Article 30 (discussed below), which have tended to focus on ratifying or implementing the Marrakesh Treaty on copyright exceptions.<sup>4</sup>

In disability studies, cultural understandings of disability are increasingly important (Goodley, 2013: 631-2). Contributions from scholars and artists emphasise transformation of mainstream culture through involvement of people with disabilities in the arts. For example, Sandahl (2018: 84) argues that "the break-through" work of artists with disabilities is that which "tends to challenge, not replicate, mainstream traditions" and that without experiencing disabled artists' differences, the "mainstream status quo may not be able to imagine the ways it could be transformed." However, the focus on participation in the arts by people with disabilities remains limited, and understandings of the creative potential of people with disabilities to reshape the mainstream "remains largely untapped" (ibid.: 85). A scoping review of the literature on societal participation by people with disabilities in Europe showed that the most dominant area of focus is still labour-market participation (Hästbacka, Nygård & Nyqvist, 2016). Within the 37 articles reviewed in that study, seven focused on leisure activities of which only two focused on arts participation (in the form of dance, theatre and other cultural activities) (ibid.). This is notwithstanding how, as Scully (2012: 73) argues, the CRPD can act "as a tool for the transformation of how cultures think about disabled people."

The remainder of this article is divided into six sections. Section 2 briefly explores the paradigm shift instigated by the CRPD, as a conceptual frame of reference, outlining the evolution that the concept of disability has undergone by way of background. Section 3 outlines the methods used in this study. Section 4 presents our findings based on deductive identification of three key themes, and related sub-themes. Section 5

<sup>4.</sup> The Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or Otherwise Print Disabled (2013) was adopted under the auspices of the World Intellectual Properties Organization (WIPO) and requires "a standard set of limitations and exceptions to copyright rules in order to permit the reproduction, distribution and making available of published works in formats designed to be accessible" (to blind persons, visually impaired and otherwise print disabled persons). https://www.wipo.int/treaties/en/ip/marrakesh/summary\_marrakesh.html.

discusses those findings, engaging with the relevant academic literature. The final section concludes by highlighting that, while there is a rather mixed picture to be seen in States' reports, there are also some starting points on which to build towards realisation of the paradigm shift. That could be advanced by more detailed recommendations on Article 30 by the CRPD Committee.

### 2. The "paradigm shift" as conceptual frame of reference

As noted above, the CRPD involves a "paradigm shift," the idea of which we use here to frame and to structure our analysis. In that regard, we highlight in this Section the key features that characterise the "paradigm shift." We do not engage in a lengthy discussion of models of disability. Rather, we point to other works which do so (among others, Goodley, 2011, Ch. 1; Lawson & Beckett, 2020). We employ the concept of "paradigm shift" to embrace both a social-contextual understanding of disability (Broderick & Ferri, 2019) and a human-rights based approach in which people with disabilities take part in decisions affecting them. We also contend that the implementation of Article 30 must be embedded into the "paradigm shift" that the CRPD entails and must itself contribute this "paradigm shift."

It is well known that the social model challenged the medical model of disability. The latter is also known as the deficit model and was dominant until the 70s (but in many ways and subtly, as this article shows, continues to be influential). It approaches people with disabilities as "sick" and in need of medical intervention, locating the "problem" of disability within the person (Kanter, 2015: 8). Relying on medical definitions of disability is conducive to a "labelling" and stigmatising approach, segregated structures, alternative services and, frequently, lack of recognition of capacity to make decisions. Linked to the medical understanding of disability, there is also the charity model, where people with disabilities are conceived of as in need and objects of pity (Watson, 2003). As Kanter (2015) outlines, even civil society organisations perpetuated the segregation of people with disabilities through charity programmes based on the medical model.

The social model of disability has more recently been associated with attempts to shape disability politics, paving the way for, and complementing, a human rights approach to disability (as argued by Lawson & Beckett, 2020). The UK social model made a crucial distinction between impairment and disability - the latter being a socially constructed experience. It linked disability to the concept of oppression, responding to the medical model and to how, historically, people with disabilities have been treated as objects of pity and as burdens on families and societies. Thus, the social model, in its original formulation, politicises disability and explains disability as a social construct achieved through discrimination and oppression. Oliver (1990: 45) argued that "disablement has nothing to do with the body" which implies the need to dismantle social and physical barriers to participation. The social model has its critics within disability studies, often related to its exclusion of issues to do with impairment or bodies, but critics can also acknowledge its usefulness as a tool and political concept (see Thomas, 2004). While Waldschmidt (2018: 72) considers the social model an

"all-rounder," she also argues that over time many interpretations have "watered it down to reformist aspirations of social inclusion."

Disability scholars later emphasised cultural representations of disability, which result in prejudice experienced in everyday interactions (Riddell & Watson, 2003; Watson, 2003). From this perspective, disablement is experienced as the outcome of the witholding of social and cultural recognition (Watson, 2003). Within the field of critical or cultural disability studies, what has come to be central to understanding disability is not disability per se, but what dis/ability tells us about culture, with disability being understood as a social phenomenon that can illuminate culture (Titchkosky, 2003). For Titchkosky (2000) disability must be regarded as a place not only to be spoken about but from which to speak and learn about the human condition. For Waldschmidt (2018: 74) a cultural model of dis/ability differs from the mainstream approach in disability studies in its claim that one should no longer problematise only disability, but rather consider this category as just one side of a coin, whose reverse side also needs investigation, shifting the focus from the margins to the "centre" of society and culture. However, the cultural model remains rather implicit amidst an ongoing discussion of the implications of culture for disability constructions (see Goodley et al., 2019; Waldschmidt, 2018: 74).

An array of models of disability have emerged over recent decades, but in the context of human rights law and policy, by far the most influential is the human rights model (Lawson & Beckett, 2020), which is enshrined in the CRPD. As referred to in Section 1, the CRPD understands disability as resulting from interaction between persons with impairments and attitudinal and environmental barriers, and emphasises human dignity, inclusive equality and accessibility (Degener, 2016; Ferri & Broderick, 2019; United Nations, 2018). It has been argued that the human rights model is an improvement or historical progression on the social model (Degener, 2016), or, most recently, that the two should be understood as working together in ways that are complementary (Lawson & Beckett, 2020).

The concept of "paradigm shift" has been used by the CRPD Committee when it reviews each country's report and responds with detailed Concluding Observations. It sometimes refers to the need for a paradigm shift (under Article 8, awareness-raising). For example, the Concluding Observations on the Austrian initial report highlight how Austrian society has not seen "a complete understanding of the paradigm shift created by the human rights-centred approach in the Convention" and recommend awareness-raising "to effectively transform the old-fashioned charity model of disability" (CRPD/C/AUT/CO/1: paras 21-2; see also Concluding Observations for Belgium, CRPD/C/BEL/CO/1: para. 17). A range of scholarship engages with the idea of "paradigm shift," sometimes focusing on changes wrought by specific aspects of the CRPD within particular fields or areas of interest. In particular, there is attention to the "paradigm shift" in terms of disability rights (Harpur, 2012), with regard to representation of people with disabilities (Mittler, 2015), and in terms of legal capacity (Quinn, 2011). The "paradigm shift" involves moving from a social welfare response to disability, or to people with disabilities as objects of charity, medical treatment and social protection to a rights-based approach in which people with disabilities can be active members of society, and intrinsic to this is the need to remove barriers and to provide accommodations to facilitate participation (Kayess & French, 2008). In her

work focusing specifically on culture, Johnson (2020: 73-4) suggests that the "paradigm shift" involves constituting persons with disabilities as (1) persons with human rights, (2) stressing the right to be involved in decision-making about their lives and their nation's future through participation in, inter alia, cultural issues, and (3) requiring States to work to remove barriers which prevent the full participation of persons with disabilities in their communities. Johnson also links the emphasis in the CRPD on participation in decision-making to supporting the development of disability cultures, which provide a basis for positive self-identity by persons with disabilities.

On foot of this scholarly work and, in particular, consistent with the approaches of Kayess and French as well as Johnson, we employed the "paradigm shift" as a conceptual framework to structure the identification of themes in our analysis.

#### 3. Methodology

#### 3.1. Systematic document review and thematic analysis

This article, which represents the first step in a participatory research project applying a multi-method approach, is based on data gathered from an extensive systematic analysis of reports available on the CRPD Committee website. It relates to EU Member States plus the UK and the EU, and it encompassed reports of States Parties, Lists of Issues, and Concluding Observations made in respect of State reports by the CRPD Committee. This was by way of a systematic document review, adopting a thematic qualitative approach to document analysis. We focused on the approach of each document to participation in culture with, as we outlined in Section 1, specific reference to arts practices and heritage. Our reference period was between January 2008, when the CRPD came into force, and 15 January 2021.

Document analysis is a form of qualitative research that uses a systematic procedure to analyse documentary evidence and answer specific research questions (Gross, 2018), or as a method for reviewing or evaluating documents combining elements of content analysis and thematic analysis (Bowen, 2009: 27-32). Documents may be treated in a variety of ways, depending on the focus of the study, but a qualitative approach requires examination and interpretation to elicit meaning, gain understanding, and develop empirical knowledge (Bowen, 2009). Thus, qualitative document analysis seeks to make explicit the implications of various formulations and presentation strategies (Wolff, 2004: 289).

We collected reports on the CRPD website for 25 EU countries, the UK and the EU. <sup>5</sup> Two EU countries (Ireland <sup>6</sup> and Romania <sup>7</sup>) had not yet submitted initial reports. We reviewed 94 documents published on the CRPD website (up until 15 January

We retrieved reports mostly from the CRPD Committee website at https://www.ohchr.org/en/ hrbodies/crpd/pages/crpdindex.aspx. The search was complemented by additional searches on national government websites.

Ireland's initial State report was due in 2020. On 3 December 2020 a draft report was published initiating a consultation period after which the report will be finalised for submission in 2021.

Romania's first report was due in 2013 and has not yet been submitted, as the International Disability Alliance noted, 4.5.20: https://www.internationaldisabilityalliance.org/romania-covid19). The Disability Council International highlighted the delay in April 2015 (http://disabilitycouncilinternational.org/Resources.php).

2021), which are detailed in Table 1. They consisted of: 35 reports of States Parties (including initial reports for 26 countries plus the EU and subsequent reports for Austria, Belgium, Denmark, Germany, Hungary, Slovakia, Spain, and Sweden<sup>8</sup>); 35 Lists of Issues (which related to 24 countries<sup>9</sup> and the EU); and 24 Concluding Observations relating to the reports of States Parties.

Table 1. Reports reviewed: periodic reports of state parties, lists of issues and concluding observations published to 15 January 2021

Countries	Number of Reports of States Parties	Number of Lists of Issues	Number of Concluding Observations
EU countries: Austria, Belgium, Bulgaria, Croatia, Cyprus, Czechia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden	33	33	22
EU	1	1	1
UK	1	1	1
Total:	35	35	24

We conducted a thematic analysis, paying attention to language used in the documents to describe and interpret various meanings, ideas and social realities reflected in text. Thematic analysis involves examining the data collected, in written or other format, summarising it and drawing out key points by identifying recurrent themes (Tight, 2019) or, as Braun and Clarke (2006) put it, it involves searching across a data set (including a range of texts) to find repeated patterns of meaning. We examined the documents for references to culture, arts and heritage. We then indexed the data and searched for themes that identified patterns (Bowen, 2009; Braun & Clarke, 2006; Coffey, 2013) using a deductive approach, as explained in the subsection below. Our key focus was the approach to arts and heritage within the Article 30 response of States Parties and any related comments or recommendations made by the CRPD Committee in Lists of Issues or Concluding Observations. We also reviewed the content of reports of States Parties on Articles 9 (accessibility) and 21 (freedom of expression and communication) insofar as they related to art practices and heritage. With regard to the EU, in our analysis, we took note of the fact that it has "supporting competences in the area of participation in cultural life" (CRPD/C/EU/1: para. 171).

<sup>8.</sup> The second reports were a combined 2nd and 3rd report.

There were no Lists of Issues raised yet for two countries (Finland and the Netherlands). In the
case of ten countries, there were two Lists of Issues, some issued in advance of country reports
that had not been published within the review period.

In this article, when we refer to reports of States Parties, that is meant to refer to initial reports. Where a country has submitted a subsequent report, we clarify whether we mean the initial report or the combined 2nd/3rd report.

#### 3.2. A Deductive Approach to Thematic Analysis

In qualitative analysis of texts, a deductive approach can be derived from theories, hypotheses or existing systematic arrangements (Kuckartz, 2014), and there can be a combination of inductive and deductive approaches (Gross, 2018; Kuckartz, 2014). Braun and Clarke (2006: 84) characterise a deductive approach to thematic analysis as "top-down" and tending to be driven by the researcher's theoretical or analytic interest. We adopted a deductive approach, in that we analysed the data from the reports using the concept of "paradigm shift" (as outlined in Section 2) as a framework and as a lens through which we identified the themes that either supported or failed to support evidence of that "paradigm shift."

Coffey (2013) cautions that we cannot treat records – however "official" – as firm evidence of what they report but must approach them for what they are and for what they are used to accomplish. Rather, they should establish the meaning of the document and its contribution to the issues being explored (Bowen, 2009). We were aware of the purpose of the three types of reports reviewed. In the case of reports of States Parties, the purpose was to evidence compliance by governments with the provisions of the CRPD, and in the case of Lists of Issues and Concluding Observations, the purpose was to present queries, comments and recommendations of the CRPD Committee designed to improve that compliance informed by a broader set of inputs, including shadow reports from civil society organisations. Our discussion here engages most with States' reports and Concluding Observations, while also reinforcing points made by reference to Lists of Issues. We suggest that qualitative research can be enriched by a critical attention to the gathering and analysis of documents of various kinds (Coffey, 2013). In that connection, in order to further support our thematic analysis of States' Reports and Concluding Observations, which, in the course of the project, will be extended and enriched with empirical evidence, we have reviewed a selection of shadow reports submitted under the CRPD. In this regard, we attempt to reflect, what Wolff (2004: 289) characterises as the "conversation" between the document(s) being investigated and the subsequent or proceeding texts. Moreover, in order to contextualise the systematic document analysis, we refer to scientific literature to engage with the themes identified.

### 4. Trends in cultural participation of persons with disabilities: Findings of the thematic analysis

Our review reveals that States' reports varied in the degree of attention that they gave to Article 30, and to the aspects of cultural participation mentioned or emphasised (that is, arts, culture and also sport, tourism and broadcasting). Sometimes there can be a sense that participation in culture is less important than other areas of life. This, for example, was acknowledged in a shadow report from Croatia (Disability Ombudswoman of Croatia, 2014), which suggested that cultural activities are not considered "vital." However, using the concept of "paradigm shift" to deductively shape our analysis of the selected documents, we identified common trends and recurring themes in relation to the way people with disabilities are portrayed in the reports, with regard to the way cultural participation is conceived of, and with regard to how barriers to participation are understood and said to be addressed. Namely, we identified three overall themes. The first (within which there are three sub-themes) deals with whether disability is perceived as a social construct as evidenced by a focus on how barriers are perceived and on what accommodations are considered necessary. The second theme represents a throw-back to the medical model in how people with disabilities are constituted, and the third identifies where, by contrast, people with disabilities were constituted as holders of cultural rights or where there was recognition of disability culture(s) or identities. The thematic analysis also shows that there can be different, somewhat contradictory, understandings within the same report.

## 4.1. Disability as a social construct? A still blurred awareness of environmental and social barriers to cultural participation

The paradigm shift involves the idea of disability as stemming from the interaction between impairment and external barriers and should entail a strong awareness of what barriers exist in the area of culture and of what facilitates access. The CRPD adopts an all-embracing concept of accessibility in Article 9, and this informs Article 30. Under this main theme, we identified three sub-themes. The first, captured concern with physical inaccessibility, which was common across reports reviewed. This somewhat tallies with the wealth of scholarship highlighting the need for physically accessible environments for people with motor and sensory impairments (Mastrogiuseppe, Span & Bortolotti, 2020). The second sub-theme relates to broader awareness of barriers and accessibility of content of arts and heritage products intended to be inclusive of a diverse range of people with disabilities, and this awareness is, we suggest, more limited but developing. The third sub-theme concerns barriers related to other issues, social, attitudinal and financial, which was very limited in responses to Article 30.

#### 4.1.1. Emphasis on physical barriers

Physical barriers may be easier to recognise than attitudinal barriers (Bickenbach, 2011). In terms of identification of specific barriers, States' reports often focus on physical access to venues, and/or indicate steps taken or being planned to address this. Our review shows that this is frequently the first issue addressed in States' Article 30 CRPD responses. Such references (to physical accessibility/inaccessibility of venues like museums, galleries, theatres, libraries, or heritage sites) occur in the Article 30 responses in reports from 21 countries (out of a total of 26 States that had filled reports) although with different degrees of depth and areas of focus (see Table 2).

Interestingly, a few reports quantify the physical accessibility of certain types of venues. For example, according to the report from France, fully accessible cinemas account for 73 % of admissions (in 2014) (CRPD/C/FRA/1: para.300). The initial report from Germany suggests that 84 % of cinemas participating in a study were "accessible" but that only 6 % could provide aids for Deaf or hearing impaired people (in 2009) (CRPD/C/DEU/1: footnote 66 to para.263). The same report, however,

admits that "not all buildings which serve cultural purposes are barrier-free, and hence they are not accessible for all people equally," and that the lack of accessibility was highlighted by associations of persons with disabilities (para. 263). The Latvian report suggests that accessibility measures have taken place at 54 % of accredited museum visitor sites (or in 76 museums) and this includes accessibility mainly for people with "functional impairments" but also accessibility for people with other kinds of impairments (CRPD/C/LVA/1: para. 364). Sometimes States specifically refer to addressing the needs of wheelchair users in this context (see the Estonian report, CRPD/C/EST/1: para. 220).

Table 2. Reports of state parties: Physical access to arts/culture

Countries whose reports refer to physical accessibility of arts/cultural infrastructure (in initial reports and/or Combined 2<sup>nd</sup>/3<sup>rd</sup> reports)

Austria, Belgium, Bulgaria, Croatia, Czechia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Latvia, Luxembourg, Malta, Netherlands, Poland, Slovakia, Slovenia, Sweden

## 4.1.2. Moving towards a multidimensional approach to accessibility of cultural content

Accessibility of cultural knowledge depends on the complex interplay between a specific person interacting with particular environmental characteristics (Mastrogiuseppe, Span & Bortolotti, 2020). It can be made up of many complex factors, which significantly influence the possibility of benefiting from products, environments and services in a significant way (Aquario, Pais & Ghedin, 2017). States' reports show that alongside an emphasis on physical accessibility, there is an awareness of a broader approach to accessibility intended to be inclusive of a range of people with disabilities, and this awareness is, we suggest, more limited but developing. We identified it as the second sub-theme. In that connection, legislation, policies and various initiatives are cited designed to make cultural products like films, audiovisual products, theatres, exhibitions or content of libraries, museums sites accessible. There are examples of such initiatives given in States' reports of 18 countries (out of a total of 26 countries whose reports were reviewed – see Table 3) with variation both in their areas of focus and degree of engagement with these issues. The EU report also places an emphasis on accessibility of audiovisual media services for all EU citizens, which is regulated at the EU level (CRPD/C/EU/1: para. 172). 10 Other States' reports emphasise accessibility of the content of a particular type of cultural product or content such as films or libraries.

In the case of art galleries and other cultural venues, the report from Czechia states that museums progressively "make all expositions and exhibitions accessible" (CRPD/C/CZE/1: para. 449). That report also instances a venue with a tactile exposition, the digitalisation of content, and instances the Museum of Puppet Culture as

<sup>10.</sup> The report refers to Directive 2010/13/EU on the coordination of certain provisions laid down by law, regulation or administrative action in Member States concerning the provision of audiovisual media services (Audiovisual Media Services Directive- AVMSD), [2010] OJ L 95/1, 15.4.2010. Most recently the directive has been modified and recast (Directive (EU) 2018/1808 on the coordination of certain provisions laid down by law, regulation or administrative action in Member States concerning the provision of audiovisual media services (Audiovisual Media Services Directive) in view of changing market realities OJ L 303, 28.11.2018, p. 69-92).

enabling visitors to engage by touch; a festival of Pantomime and Motion Theatre is also referenced where Deaf or hearing-impaired people are said to constitute over half of participants (CRPD/C/CZE/1: paras 456-60). Other examples are seen in the Estonian report, which mentions theatres using text strips and sign language interpretation, loop systems, and also subtitling of films and inclusivity of cultural sites, museums and art galleries (CRPD/C/EST/1: paras 220-8). The report of Latvia outlines measures within Museums to make the content available to people with a broad range of impairments (CRPD/C/LVA/1: paras 365-70). The EU report refers to Europeana, as a portal that "brings together digitised content from Europe's museums, archives, libraries and audiovisual collections," and features content "designed to be universally accessible" (CRPD/C/EU/1: para. 175). In addition, a post-prototype version will be produced for blind people (para. 175). Furthermore, the European Commission is committed to ensuring that accessibility criteria are taken into account in the context of the European Capitals of Culture award (para. 175).

References under Article 30 CRPD to efforts to make library material more accessible for people with visual impairments were common. For example, the initial report from Denmark refers to a state-owned library producing audio books, e-books and Braille for visually impaired and dyslexic people (CRPD/C/DNK/1: para. 337). Much less common were references to Sign Language libraries, but the Finnish report refers to one (CRPD/C/FIN/1: para. 444). Also unusual were references to visual arts being made accessible for people with visual impairments. However, the Estonian report refers to improvements to the accessibility of the Art Museum of Estonia for "mobility, visual, hearing and intellectually impaired people" (CRPD/C/EST/1: para. 224).

Film is another area of focus in some reports. For example, the initial German report states that the "expansion of subtitling and audiodescription, can be considered in order to implement accessibility in film and on television" (CRPD/C/DEU/1: para. 174). It also highlights that the Film Promotion Act (*Filmförderungsgesetz*) supports audiodescription and subtitling, as well as providing for incentives 'for the creation of barrier-free versions of cinema films' (CRPD/C/DEU/1: para. 262). The second/third report from Denmark (CRPD/C/DNK/2-3: Annex 1: para. 17) mentions funding being made conditional on films having subtitles and an experimental scheme involving audio description. Other reports also highlight initiatives to support accessibility of film (e.g. reports from Slovakia, CRPD/C/SVK/1: paras 382-4; and France, CRPD/C/FRA/1: para. 300).

Table 3. Reports of state parties: accessibility of cultural content

Countries whose reports refer to accessibility of content of various types, including films and museums (in initial reports and/or Combined  $2^{nd}/3^{rd}$  reports)

Austria, Belgium, Croatia, Czechia, Denmark, Estonia, Finland, France, Germany, Italy, Latvia, Lithuania, Luxembourg, Poland, Slovakia, Slovenia, Spain, Sweden

Note: The above list includes reports that maintain a very limited focus on these issues, focusing, for example, on access only to one sector or one form of content.

Given that Article 30(3) CRPD explicitly obliges States Parties to "take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials," reports of most countries

(i.e. 16 countries) referenced copyright laws (typically in their responses to Article 30) (see Table 4). These tended to be references to exceptions to reproduction restrictions so that print works may be reproduced for people who are blind or visually impaired, in line with what is provided by the EU in relevant legislation. <sup>11</sup> Correspondingly, a focus on the Marrakesh Treaty and copyright is a feature of how the Lists of Issues <sup>12</sup> and Concluding Observations address Article 30. Thus, where a recommendation under Article 30 CRPD is made in the Concluding Observations, it is often related to copyright and has to do with signing, ratifying or implementing the Marrakesh Treaty. Most of those reports precede the decision of the Court of Justice of the European Union that established, in Opinion 3/15, that the EU is exclusively competent to conclude the Marrakesh Treaty on behalf of its Member States, and the adoption of EU legislation to implement that Treaty (Sganga, 2020).

Table 4. Reports of state parties: copyright exception

Countries whose reports refer to copyright exceptions (in initial reports and/or Combined 2<sup>nd</sup>/3<sup>rd</sup> reports)

Austria, Belgium, Bulgaria, Denmark, Finland, France, Germany, Greece, Hungary, Italy, Lithuania, Netherlands, Poland, Slovakia, Sweden, UK

Of the 24 Concluding Observations from the CRPD Committee reviewed (including those for the EU), there was an Article 30 recommendation in all but five of them. 13 Action in respect of copyright and the Marrakesh Treaty featured in all 19 recommendations made under Article 30, but, amongst them, only eight included additional comments or recommendations to address issues of cultural participation more broadly (as highlighted in Table 5). Amongst the latter, the Concluding Observations for Greece recommend actions to implement the Marrakesh Treaty and also include a wide-ranging statement of concern that people with disabilities face "barriers in their participation in cultural life, recreation, leisure and sport on an equal basis with others," which is said to be due, inter alia, to "limited access to cultural materials and activities in accessible formats, cultural performances and services [...]. and sites of national cultural importance" (CRPD/C/GRC/CO/1: paras 44-5). In the case of Slovakia, Concluding Observations (CRPD/C/SVK/CO/1: paras 81-2) express concern about lack of accessibility of libraries for persons with disabilities, including people with intellectual disabilities, and recommend increasing accessibility of Easy Read, digital, audio and Braille publications. Concluding Observations to the Maltese and Luxembourg reports specify that a budget is needed to promote and protect the

Currently the legislation in force is Directive (EU) 2019/790 of the European Parliament and
of the Council of 17 April 2019 on copyright and related rights in the Digital Single Market and
amending Directives 96/9/EC and 2001/29/EC OJ L 130, 17.5.2019, p. 92-125. On this see
Sganga (2020).

<sup>12.</sup> Of the 34 Lists of Issues reviewed that related to country reports there was an Article 30 query raised in 16 reports, with a query on the Marrakesh Treaty featuring in 10 of them and there were also some broader queries on other issues to do with culture, leisure or sport. In addition, the List of Issues raised for the EU also contained a query on accession to the Marrakesh Treaty (CRPD/C/EU/Q/1: para. 36).

Two of the Concluding Observations relate to one country (Spain), so there were Concluding Observations available in respect of 22 countries plus the EU.

right to participate in cultural life (CRPD/C/LUX/CO/1: para. 53; CRPD/C/MLT/CO/1: para. 44).

The need for enhancing the range of accessible formats – sign language interpretation, Braille, subtitles, Easy Read, augmentative and alternative modes of accessible communication for people with intellectual or psychosocial disabilities – is often raised by the CRPD Committee in Concluding Observations under Article 21 CRPD (dealing with freedom of expression and access to communication). A common recommendation is for more access to sign language interpretation or investment in training of sign language interpreters. Typically, these recommendations cross a range of areas of life such as access to justice, communication or public information. Only rarely are there specific Article 21 recommendations on the need for interpretation or other accessible formats in access to culture.

Table 5. Concluding observations from the CRPD committee: how they address article 30

How Article 30 is addressed	State Parties in respect of which Concluding Observations have been issued	
No recommendations made	Austria, Hungary, Latvia, Poland, Spain (CRPD/C/ESP/C0/1)	
Recommendations focus on copyright exceptions and/or ratification or implementation of the Marrakesh Treaty	Belgium, Cyprus, Czechia, Denmark, Germany, Italy, Portugal, Slovenia, Spain (CRPD/C/ESP/ CO/2-3), Sweden, the European Union	
Recommendations focus on copyright exceptions and/or ratification of the Marrakesh Treaty but also make recommendations that are broader in scope	Bulgaria, Croatia, Greece, Lithuania, Luxembourg, Malta, Slovakia, UK	

Note: Two sets of Concluding Observations had been issued for Spain.

#### 4.1.3. Social, attitudinal and financial barriers

The important role of arts practices as visible forms of cultural expression makes it an area of unique value in respect of disability with potential for challenging how the social order is communicated and reproduced. However, this potential remains untapped, not least because of social and attitudinal barriers and because of stigma, which are often the most difficult to counter (Bariffi, 2018). Our research suggests a limited and rather patchy approach to social, attitudinal and financial barriers to cultural participation across the reports reviewed, and we contend that there should be a more precise identification of these kinds of barriers and of systematic approaches to addressing them.

We did find these barriers acknowledged in States' reports. For example, the Estonian report refers to trainings and seminars for museum staff (CRPD/C/EST/1: para. 226; see also Latvian report, CRPD/C/LVA/1: para. 368), and the initial Slovakian report acknowledges efforts to educate people working in the cultural sector to "eliminate mental and physical barriers" (CRPD/C/SVK/1: paras 386-90; see also Greek report, CRPD/C/GRC/1: para. 274). The initial Belgian report mentions the need for measures to increase accessibility of infrastructure, and also to increase "receptiveness to sign language or subtitling at cultural events" (CRPD/C/BEL/1: para. 173).

States' reports often refer to grant schemes that are open to people with disabilities or that specifically target them. Less common was a commitment to an integrated approach across all areas of culture, including funding, such as that anticipated in the initial report from Sweden that a "disability perspective must be integrated in the regular granting of subsidies within the field(s) of culture..." (CRPD/C/SWE/1: para. 283). 14 It was also not common for States' reports to specify that schemes of social care/support covered participation in cultural events. Exceptions include the initial report from Germany, which referred to availability of assistance to attend events, and aids facilitating access to information on cultural events (CRPD/C/DEU/1: paras 264, 172; see also reports from Cyprus, CRPD/C/CYP/1: para. 235; and Latvia, CRPD/C/ LVA/1: para. 362). However, reports identify measures providing for free or discounted entry to museums or other venues and/or to companion passes. For example, the initial report from Belgium observes that "persons with disabilities are often obliged to be accompanied, increasing the cost of their participation" (CRPD/C/BEL/1: para. 169). To address this, some local authorities in Belgium are said to issue companion cards enabling companions to take part free of charge. There are references to companion cards or to free or discounted entry said to be operating or to be under consideration in reports from ten countries, as Table 6 shows. The Finnish report refers to free admission to many museums and to the EU Disability Card, enabling people with disabilities to verify their need of an assistant at cultural events (CRPD/C/FIN/1: paras 439-40). Sometimes these measures are said to be limited to specific venues, sectors, or by reference to degrees of impairment. For example, the Estonian report refers to free access to state museums, but only for children and people aged 16+ with "a profound disability" and their companions (CRPD/C/EST/1: para. 223).

Table 6. Reports of state parties: special arrangements for entry to venues

Countries whose reports refer to some form of free or discounted entry to museums or other venues for people with disabilities and/or for companions (in initial reports and/or Combined 2nd/3rd reports)

Belgium, Bulgaria, Czechia, Estonia, Finland, Greece, Italy, Lithuania, Slovakia, Spain

## 4.2. Throw-back to the medical model: cultural participation as therapy or education

The second theme from our deductive analysis deals with how people with disabilities are constituted in the cultural sphere. Article 30 responses suggest a patchwork in terms of how participation in arts and culture is understood, and in relation to what the motivation for this is – including motivations based on educating others, promoting health, compensating for health challenges, or fostering social inclusion. Thus, a medical, or therapeutic, or charitable understanding of disability is evident in reports of State Parties.

<sup>14.</sup> However, it is also notable that the subsequent List of Issues raised by the CRPD Committee for Sweden prior to the submission of its 2nd/3rd country report sought information "on the national strategy to protect the right to participate in leisure, sports and cultural activities in an inclusive manner" and on "the extent to which austerity measures affected this right" (CRPD/C/SWE/QPR/2-3: para. 23).

The Polish report refers to "library therapy and art therapy" for blind people (CRPD/C/POL/1: para.514) and the report from Czechia includes reference to "art-therapy" and to a programme of support to projects focused on exploiting the "therapeutic function of culture in order to compensate for disadvantages on account of health" (CRPD/C/CZE/1: para.452; emphasis added). Another report refers to public libraries organising home deliveries for people unable "to visit the library due to health reasons" (Estonian report, CRPD/C/EST/1: para.230). Sometimes a therapeutic approach was linked to ideas of tackling social exclusion. For example, the Lithuanian report refers to the "National Programme of Social Integration of the Disabled," listing a range of arts and cultural activities supported, including "social rehabilitation services" and to cultural events aimed at "improvement of the status of the people with disabilities in the society and reduction of their social exclusion" (CRPD/C/LTU/1: paras 304-6; emphasis added).

Sometimes, States' reports refer to cultural activities in terms of education about disability issues amongst the general public or people working in cultural sectors. There may, of course, be valuable aspects to such awareness-raising initiatives, but some of these references seem to suggest that disability is still constituted as an individual problem or an issue requiring a charitable response. For example, Hungary's initial report mentions support for people with disabilities "with regard to public education programmes" and public education conferences are described as opportunities for people with disabilities "to report their own *problems*" (CRPD/C/HUN/1: para.236; emphasis added). There can also be explicit links made between cultural events and charitable donations or fundraising efforts (e.g. Bulgarian report, CRPD/C/BGR/1: para.242).

Overall, this emphasis on therapy, education of others on "problems" of persons with disabilities, charitable aims and (to some extent) links to issues of social inclusion/exclusion reveal an understanding of disability within the responses to Article 30 of some State anchored to a medical understanding of disability, instead of the social-contextual and rights-based aims embodied in the CRPD's "paradigm shift." Furthermore, it clearly does not reflect the shift envisaged in cultural disability studies to problematising what is perceived as "normal" or "mainstream" culture.

## 4.3. People with disabilities as holders of cultural rights and supporting disability cultures

We identified, as the third theme, the recognition of people with disabilities as holders of cultural rights, for which there was some evidence. This implies the acknowledgement that persons with disabilities should not only have the right to access culture, but also the right to make decisions and to create culture, including, therefore, not only opportunities for amateur participation, but also possibilities to shape culture as professional artists and as workers in the cultural sphere. It also means developing supports for disability culture and for development of positive self-identities.

The need for cultural participation as self-expression or as an amateur activity was evident in the reports of many countries. For example, the Latvian report (CRPD/C/LVA/1: para. 370) refers to various opportunities for Deaf people, citing "a variety of creative self-expression measures: free time activities [...] educational and informative

measures [...] and amateur performances which is one of the most popular area of leisure for deaf people." The Lithuanian report mentions "artistic ability development classes" to provide "the opportunity to express their abilities in a variety of forms" (CRPD/C/LTU/1: para, 305), and the initial Slovakian report discusses the availability of "active and passive culture" (CRPD/C/SVK/1: para. 390).

There is a limited awareness shown in States' reports of people with disabilities as creators of culture in their own right, or as rights holders who make decisions in the cultural sphere, but there was some evidence of this. The reports of eight countries (or their Annexes) refer to disabled or Deaf artists or to artists or actors with disabilities (see Table 7). Sometimes these are cursory references, without any elaboration. For example, the Portuguese report addresses arts and culture briefly in one paragraph (CRPD/C/PRT/1: para, 273), mentioning services "for persons with disabilities, both as an audience and as artists." The UK report alludes to grants that promote the work of disabled artists (CRPD/C/GBR/1: para. 328).

TABLE 7. REPORTS OF STATE PARTIES: PEOPLE WITH DISABILITIES AS ARTISTS

Countries whose reports refer to professional engagement in the arts or to people with disabilities as artists (in initial reports and/or Combined 2nd/3rd reports)

Croatia, Czechia, Denmark, Portugal, Slovakia, Spain, Sweden, UK

Note: Reports from other countries instance initiatives that, while they do not explicitly refer to professional artists with disabilities, may involve them in practice.

Other reports, while making no explicit reference to professional artists, adopt somewhat ambiguous formulations. Examples include references to cultural or artistic "production(s)" (Italian report, CRPD/C/ITA/1: para. 168; second/third German report, CRPD/C/DEU/2-3: para. 62) or to artistic "practice" (Netherlands report, CRPD/C/NLD/1: para. 335; French report, CRPD/C/FRA/1: para. 301). In these cases, the use of words such as "production" or "practice/practising" seem to suggest a professional engagement, but this is not fully evident. Other reports refer generally to initiatives fostering cultural participation by people with disabilities. It is possible that those may in fact include professional artists with disabilities, but this remains unclear (see, for example, the Luxembourg report, CRPD/C/LUX/1: para. 393). There are also references to events or festivals organised by people with disabilities, an example being performances in sign language mentioned in the Latvian report (CRPD/C/ LVA/1: para. 370).

Several reports are, nonetheless, quite explicit about the need to develop both amateur and professional participation, and/or mention arts organisations that include disabled and non-disabled artists. For example, the initial report from Sweden recognises "personal creation" and opportunities to share in "professional artistic creation" (CRPD/C/SWE/1: para. 282). That report also states that it "is becoming increasingly common for professional theatre and dance groups to include actors and dancers both with and without disabilities" (para. 289). It instances the National Theatre, within which a Quiet Theatre produces drama in sign language (para. 287). The Croatian report refers to financial support for projects "that sensitise the public for artistic work of persons with disabilities and specific theatres of persons with disabilities" (CRPD/C/HRV/1: para. 217).

However, we found almost no explicit references within the CRPD reports reviewed to employment of people with disabilities within arts and cultural industries. The Slovenian report (CRPD/C/SVN/1: para. 236) was an exception, referring to "projects to improve the employability of vulnerable groups in the field of culture" characterised as a means to support social inclusion. The Estonian report also mentions "several" people with disabilities having qualified as data entry clerk in museums (CRPD/C/EST/1: para. 226).

As outlined above, Article 30(4) CRPD recognises the specific cultural and linguistic identity of people with disabilities, explicitly protecting sign language and Deaf culture. The formulation of this provision echoes Article 21(e), which requires States Parties to take measures "recognizing and promoting the use of sign languages." This is reflected in the reports from many countries in references to steps taken, or to be taken, towards the recognition of sign language users or of Deaf people as a linguistic or cultural minority (e.g. reports of Belgium, CRPD/C/BEL/1: para.97; Croatia, CRPD/C/HRV/1: para. 17; Finland, CRPD/C/FIN/1: para. 259; Hungary, CRPD/C/ HUN/1: para. 17; and Lithuania, CRPD/C/LVA/1: para. 158). 15 Interestingly, several reports deal with sign language most extensively under the implementation of Article 21 CRPD, rather than under Article 30. However, several reports highlight the promotion of Deaf culture, and research exploring the history or culture of Deaf people within education. In some reports, the term "minority" is not used, but sign language is referenced as a "separate" or "independent" language (e.g. initial German report, CRPD/C/DEU/1: paras 167, 259). The Finnish report represents an interesting case in its level of detail. It refers to sign language users as a "language and cultural minority" (CRPD/C/FIN/1: para. 259). A consciousness of different linguistic groups amongst Deaf people is shown in references to Sámi and sign language users, who are said to represent minorities among persons with disabilities (para. 257). It also refers to measures needed to protect the endangered Finnish-Swedish sign language (para, 266). It recognises also that sign language can be considered a native language if a parent or older sibling is a sign language user and if sign language has been used with a child since birth (para. 261).

Still other reports refer to lack of legislative instruments recognising and protecting sign language or they emphasise measures providing for the use of sign language. For example, the report from Luxembourg mentions that sign language enjoys "*de facto* recognition" (CRPD/C/LUX/1: para. 237), but the related Concluding Observations recommend expediting "enactment of legislation to recognize German sign language" and "promoting other sign languages to respect the multilingual character of the State party" (CRPD/C/LUX/CO/1: para. 39).

References to Braille and to other alternative forms of communication were common in reports from States, often in responses to Article 21 CRPD and in relation

<sup>15.</sup> A complex picture emerges from reports of State parties on this issue. Sometimes it is not clear if a State report is claiming that it recognizes sign language in an official way or if it is only providing for its use (and the latter can be the case even if it is possible to otherwise ascertain that a country does in fact officially recognise sign language in law). Sometimes a State report does not mention sign language recognition but a subsequent set of Concluding Observations commends that country for having introduced measures to do so. An updated status of the legal recognition of sign languages has been recently provided by the World Federation of the Deaf at The Legal Recognition of National Sign Languages - WFD (wfdeaf.org).

to access to information and communications and were not framed in terms of cultural or linguistic identity. There is no recognition of users of Braille or other forms of communication as cultural or linguistic minorities. This is perhaps unsurprising given that Deaf people and sign language users are the sole group specified in Article 30 CRPD in the context of linguistic identity, and the only group that has advocated for recognition as a minority. Thus, outside of Deaf culture or sign language, ideas about disability identities, or disability culture more generally, were very rare in the reports reviewed. However, there were a small number of references to events that seem designed to highlight or celebrate the lives or achievements of people with visual impairment. For example, the Lithuanian report refers to events organised by the Lithuanian Library to mark "important dates in the lives of public figures who were blind" (CRPD/C/ LTU/1: para. 294). The initial Slovakian report had some references to the "culture of persons with sight disabilities" and, in the context of museums and galleries, to the development of "the culture of the disabled" (CRPD/C/SVK/1: paras 379, 385).

On the whole, it is possible to detect an understanding of Deaf people as having a distinct cultural or linguistic identity (even if that is not always fully supported in practice) and a limited, if developing, sense of people with disabilities as contributors and shapers of culture. However, there is much yet to be done to realise the provisions of Article 30(2) CRPD, which involve ensuring that measures are taken that enable people with disabilities to "develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society."

#### 5. Evidence of paradigm shift?

As indicated above, the approach to Article 30 CRPD of the States Parties under consideration varies. However, on a general note and before further discussing the findings of the thematic analysis, our review makes evident that a lengthy response relating to arts and heritage under Article 30 is not necessarily representative of a thoroughgoing approach to addressing cultural participation. For example, there are many initiatives referred to under Article 30 in the report from Bulgaria (CRPD/C/ BGR/1) and to a lesser extent in the report of Croatia (CRPD/C/HRV/1). However, the degree to which this might represent a comprehensive approach at a national level to meet the objectives of Article 30 CRPD remains unclear. In fact, in the case of those two countries, subsequent Concluding Observations express concern about levels of participation of persons with disabilities in cultural life and contain recommendations aimed at increasing participation (CRPD/C/BGR/CO/1: paras 65-6; CRPD/C/HRV/ CO/1: paras 47-8).

It is also interesting that States' reports present few details on levels of cultural participation by people with disabilities. The reports of two countries cite surveys suggesting that cultural participation by people with disabilities is relatively low (Estonia, CRPD/C/EST/1: para. 227; UK, CRPD/C/GBR/1: para. 327; see also Denmark's reference to under-representation in "general association life," CRPD/C/DNK/1: para. 346). The Estonian report cites a series of statistics about cultural participation, stating that 54.1 % of people with disabilities do not participate in any cultural activities (compared to 35.5 % of non-disabled people) and that only 5.6 % participate regularly (CRPD/C/EST/1: para. 227).

We contend that a systematic, mainstreamed approach to culture informed by the potential for cultural transformation that the CRPD represents (Scully, 2012) is yet to be realised. This need for mainstreaming was articulated comprehensively in a document accompanying a shadow report from the National Confederation of Disabled People of Greece (NCDP) (2019: 20), which made the following recommendation:

"To mainstream the disability dimension in every cultural policy, process, action, measure and program to ensure the human right of persons with disabilities and chronic diseases to full and equal participation as public, employees and/or creators-artists in the cultural heritage, sites, material, services as well as in the modern culture..."

Delving more into our deductive thematic analysis shows that States' reports present a mixed picture, or patchwork, in terms of how they reflect and realise the "paradigm shift" embedded in the CRPD in relation to cultural participation. The analysis shows that medical or charity models of disability are still influential, and engagement with culture is sometimes linked to the mere desire to promote health, enhance rehabilitation or to foster social inclusion. In that connection, we contend that State Parties still problematise disability, rather than locating it within mainstream culture (Waldschmidt, 2018: 74).

A "throw back" to the medical model tallies with a still somewhat limited understanding of barriers faced by people with disabilities. It has recently been argued that the current focus on the rights of people with disabilities to participate in social and cultural life suggests the need to rethink the concept of accessibility (Mastrogiuseppe, Span & Bortolotti, 2020). Our analysis of States Parties' reports nonetheless suggests that there is a developing sense of the need for a broader approach to accessibility, such as access to the content of cultural products for people with a broad range of disability-types. We found, however, that there continues to be an emphasis on barriers as mostly constituted by physical inaccessibility of cultural buildings. Clearly, the latter is an important aspect of cultural participation, especially for people with physical impairments, but this falls short of the conceptualisation of disability advanced by the CRPD. Furthermore, such a developing awareness is somewhat counterbalanced by a far more bittersweet picture emerging from shadow reports submitted to the CRPD Committee by civil society groups, which, where they deal with culture, detail inadequate accessibility of cultural offerings. For example, in their shadow report, the Belgian Disability Forum (2014) suggests that while accessibility of cultural activities is guaranteed under regional regulations, implementation is lacking. A report coordinated by the Disabled People's Organisations Denmark (DPOD) (2019: para. 48) suggests that many cultural institutions – such as theatres, museums and cinemas – are not accessible either in terms of physical accessibility of buildings or digital accessibility of apps, websites or content. Similarly, the shadow report from the German CRPD Alliance (BRK-Allianz, 2013: 90-1) suggests that both physical accessibility and accessibility of content is inadequate across a range of cultural and heritage venues and for people with different kinds of impairments.

Our analysis also ascertained limited explicit recognition that each person with a disability is unique and may require specific and diverse supports to access culture, that can include tactile and sound signage elements (e.g. Braille, Easy Read, pictograms or audio description), cognitive accessibility in the environment and in information, and social accessibility (e.g. training of personnel, facilitating access for interpreters personal assistants and adapting times and rhythms to the needs of each participant) (Universidad de Deusto, 2019). In that regard, there seem also to be a limited acknowledgement of the value of reasonable accommodation when it comes to cultural rights.

References to social, attitudinal or financial barriers to participation in arts or heritage were quite limited, as was recognition of a potential role for people with disabilities to transform arts practices and hence for challenging how the social order is communicated and reproduced. States Parties often recognise the linguistic identity of sign language users, or suggest that measures are planned towards that recognition, but there is little evidence that recognition of cultural identity is apprehended more broadly as applying to other groups of people with disabilities. Also, shadow reports frequently contend that, in practice, support for Deaf culture is inadequate. For example, the German BRK-Allianz (2013) report refers to inadequate support for the cultural identity of people who use Plain Language or German Sign Language, and a report from France suggests that sign language is not as broadly recognised as the government report suggests (Fédération Nationale des Sourds de France, 2019; see also report from the PanCyprian Alliance for Disability, 2017). But, even within disability studies, the issue of the existence of a "disability identity" (other than as relates to Deaf people) is a contested issue (Davis, 2013: Siebers, 2008: 11) as is the conceptualisation of disability culture(s) (Johnson, 2020). However, there are arguments for recognition of various cultural perspectives of people with disabilities and of the role of a range of art-forms in articulating those shared cultures (Johnston, 2020). For Jakubowicz and Meekosha (2003: 190) disability culture seeks to revalorise disability experiences and turn upside down the devaluation that society accords people with disabilities, arguing that disability culture affirms "different embodiments through literature, drama, sport and music." Our review shows that these issues have yet to be reflected to any extent in how reports of States Parties from EU countries address Article 30 CRPD and in how the CRPD Committee responds to them.

In our analysis of States Parties' reports, we also detected a rather limited understanding of people with disabilities as makers and shapers of culture in their own right. References to employment within cultural organisations were also almost non-existent.

On the whole, we contend that the still narrow approach to accessibility, the limited awareness shown in the States' responses on Article 30 CRPD about disability identities, the evident focus on people with disabilities as consumers of culture or participants at an amateur level fall short of the obligations of Article 30 CRPD. Most significantly the perspective adopted by States Parties to cultural participation still fails to realise the overall "paradigm shift" brought about by the CRPD. In our analysis, however, we noted that the CRPD Committee has, thus far, provided limited guidance in the field. The Lists of Issues and Concluding Observations from the Committee often show a rather narrow focus on copyright issues in their comments and recommendations on Article 30 CRPD, which does not support a more comprehensive approach to cultural participation. In short, while there is evidence of some change, there is untapped potential for arts practices to challenge the cultural order, and to

realise the role that the CRPD could play as a transformative instrument for our cultural-moral understanding of disability (Scully, 2012: 73).

#### 6. Concluding remarks

In this article we argued that the implementation of Article 30 CRPD must be embedded within the "paradigm shift" that the Convention entails and must itself contribute this "paradigm shift." The CRPD has potential to effect a cultural transformation in how disability is understood and is consistent with the emphasis within critical or cultural disability studies on the need to analyse and transform what is perceived as mainstream culture from the perspective of disability. As the former Special Rapporteur on the Rights of Persons with Disabilities argues, neither awareness-raising programmes nor the generalisation of anti-discrimination measures will alone suffice for disability to be embraced as part of human diversity and a cultural transformation is needed in how society relates to the difference of disability (Devandas-Aguilar, 2019).

Our review suggests that data collection on participation in culture of persons with disabilities is scant. In order to effect change, a systematic approach to gathering information on persons with disabilities working in the cultural sectors, and accessing cultural activities, is vital. Data collection could be informed by outcome indicators elaborated by the Office of the High Commissioner for Human Rights (OHCHR) in support of a disability inclusive 2030 Agenda for Sustainable Development. Outcome indicators (which complement structural and process indicators) measure the results of efforts to further human rights. Among those indicators, it would be important to gather information on the number and proportion of persons with disabilities accessing museums, galleries, libraries and cultural venues and sites, as compared to other persons, on the time spent by persons with disabilities in cultural activities, as compared to other persons, and on the number and proportion of persons with disabilities who receive public financial support for cultural programmes and for higher education and professional development related to the area of cultural life. All data should be disaggregated by sex, age and type of disability to enhance an intersectional approach.

Our review also shows that some aspects of the "paradigm shift" may be developing. We base this on changes we identify in how disability is understood in reports of some countries, to a broadening out of how accessibility is conceived of in some reports, to a widespread recognition of cultural identity of Deaf people or sign-language users, and of a limited, but developing, recognition of the need to support professional artists. Even if we see elements of a medical or charitable model still in evidence in relation to Article 30 CRPD, there is some evidence of a developing understanding of people with disabilities as rights-holders, as autonomous beings and of participation in culture as an expression of personhood and dignity. This provides a basis for more in-depth queries and recommendations on culture by the CRPD Committee, which, as yet, have tended to focus largely on issues of copyright and the Marrakesh treaty. Those recommendation should direct attention of States Parties to all the aspects of cultural participation envisaged in the CRPD and support them in realising the "paradigm shift" associated with the CRPD.

The adoption of a comprehensive approach to cultural participation of persons with disabilities would be vital to challenge negative views of people with disabilities, assumptions that disability art is merely a hobby or form of therapy rather than a professional endeavour, and could ultimately transform how society understands and relates to disability.

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