Submission

to the National Disability Authority (NDA) on future strategic focus for NDA over the 3 years 2022 to 2024

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1. Introduction

1.1. This Submission

In line with the legislative requirements set out in the National Disability Authority Act 1999, the National Disability Authority (NDA) is developing its strategic plan for the period 2022 to 2024. In order to draw up a comprehensive and informed new strategy, the NDA is consulting with both internal and external stakeholders. The objective of the consultation is to ensure that the views and concerns of stakeholders are taken into account in the new strategy. The new strategy will guide the NDA over the next three years. With this in mind, the present research-informed submission aims to contribute to the elaboration process of the new strategy by answering the four questions included within the consultation document.

The present submission is a research-led contribution to policy development and is aimed to support the enhancement of disability rights in Ireland. It has been prepared by Prof. Delia Ferri, supported by Dr. Ann Leahy and Ms. Neža Šubic, in response to the invitation to share views on future strategic focus for NDA over the 3 years 2022 to 2024, issued on 22 December 2020. Prof. Ferri, Dr. Leahy and Ms. Šubic have distinguished expertise on disability rights (and, more broadly, on human rights), as well as on equality, intersectionality, and inclusion. This submission has been developed within the remit of a large-scale project entitled *Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths* (DANCING). The project is funded by the European Research Council (ERC) Consolidator, under the Grant No. 864182, with Delia Ferri as the Principal Investigator. More Information on the Project is available at the Cordis Site: here.

The submission is made by the authors (Prof. Ferri, Dr. Leahy, and Ms. Šubic) in a personal capacity and not on behalf of the Department of Law of Maynooth University (MU), or the MU Assisting Living & Learning (ALL) Institute. The views and opinions expressed in this submission are those of the authors and do not necessarily reflect the official policy of MU.

1.2. The Authors

Delia Ferri is a Professor of Law at Maynooth University and co-Director of the ALL Institute. She is affiliated researcher at the DIRPOLIS Institute (Institute of Law, Politics and Development) of Scuola Superiore Sant'Anna (Italy) within the research cluster on social rights, social inclusion and disability, and a fellow at the Burton Blatt Institute of Syracuse University (USA). Since 2018, she has been a member of the Royal Irish Academy (RIA) Standing Committee in International Affairs (SCIA). Recently, she has been Visiting Professor at the Academia Interamericana de Derechos Humanos of the Autonomous University of Coahuila (Mexico). Delia is Principal Investigator (PI) of the project Protecting the Right to Culture of Persons with Disabilities and Enhancing Cultural Diversity through European Union Law: Exploring New Paths (DANCING), for which she was awarded a European Research Council (ERC) Consolidator grant of € 2 million. She is also co-investigator in the project SHAPES, funded by the EU Horizon 2020 programme and led by the ALL Institute. Her research in this project focuses on regulatory frameworks to support independence and enhanced quality of life for older people, in particular older people with disabilities. She also holds a position of co-investigator in the project Rethinking Digital Copyright Law for a Culturally Diverse, Accessible, Creative Europe (ReCreating Europe), led by Scuola Superiore Sant'Anna Pisa, and funded by the EU Horizon 2020 programme. Within this project, Delia investigates access to digital cultural goods for people with disabilities, from an intersectional perspective. Moreover, since 2004, Delia has taken part in policy-oriented studies on the rights of persons with disabilities, participatory processes and cultural diversity. Among many others, in 2016, she co-authored (with Anna Lawson) the report on *'Reasonable accommodation for disabled people in employment'* for the European Commission. She has also acted as consultant for several NGOs and worked as expert in capacity-building projects such as 'Laws and policies concerning accessibility in employment contexts for persons with disabilities' for the *Deutsche Gesetzliche Unfallversicherung e.V.* funded by the German Ministry for Labour and Social affairs (2018-19), and 'Promoting the social rights of persons with disabilities by building the capacity of Armenian civil society organisations to engage with the Council of Europe monitoring mechanisms' (2017). Delia has published extensively in the fields of International and Comparative Disability Law and European Union Law.

Ann Leahy is a Postdoctoral Researcher with the DANCING project. Her PhD, completed at the Department of Sociology of Maynooth University, was an interdisciplinary study of the intersection between disability and ageing. She is the author of a book on that subject (forthcoming from Policy Press), the writing of which was supported by a prestigious Irish Research Council Postdoc Fellowship. She worked for many years in the voluntary sector in Ireland including at Age & Opportunity (where she was Assistant CEO) and at Social Justice Ireland (where she was an Irish Research Council Scholar). In those roles she contributed to many policy and research processes in a range of areas of social policy including ageing, disability, poverty and health. She has served on many inter-agency committees and consultative fora. She has a background in law and worked as a solicitor early in her career.

Neža Šubic is a Postdoctoral Researcher with the DANCING project. Her doctoral project at UCD, funded by the UCD Sutherland School of Law, explored social rights in the context of the European Arrest Warrant. Neža is specialized in EU law and in human rights law. She has taught in the area of EU law both at UCD and at Maynooth University, and has published in the fields of EU law and human rights law in both Irish and international journals. Prior to commencing her PhD studies, Neža worked as an assistant lawyer at the European Court of Human Rights (ECtHR) in Strasbourg, and completed traineeships at various Slovene national courts, and at the Legal Service of the European Commission in Brussels. Neža holds an LL.B. from the University of Ljubljana, and an LL.M. from the University of Edinburgh. In 2017, she passed the Slovene State Examination in Law.

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1.3. Focus of this Submission

In line with the aims of this consultation, this **research-led contribution** is structured in response to the questions that were included in the consultation document. It is informed by the human rights model of disability envisaged by the UN Convention on the Rights of Persons with Disabilities (CRPD). It takes into account relevant international law, as well as

European Union law, and relies on well-established disability law scholarship and disability studies literature.

In the National Disability Authority Strategic Plan 2019 – 2021,¹ the strategic priorities were articulated as follows: 1. To provide research-informed advice to government to guide the development and implementation of national policies, programmes and strategies relevant to the lives of persons with disabilities; 2. To understand and advise on societal changes, challenges and opportunities that impact on the lives of persons with disabilities; 3. To promote and monitor the implementation of Codes of Practice, standards and guidelines in services, and to evaluate policy and practice; 4. To continue to build awareness and adoption of Universal Design across society in Ireland; 5.To continue to be an effective and pro-active organisation, committed to delivering on our strategic priorities and communicating our work. This submission takes into account those priorities and provides a forward-looking approach on how those might be advanced and improved. It critically discusses challenging issues that have emerged in these strategic priority areas and provides recommendations on how these might be enhanced.

As required, the submission is articulated around the four questions set by the NDA: 1) What are your views on the NDA's strategic approach and impact to date? 2) In your opinion, what are the critical challenges and questions the NDA needs to address in its new strategy and programme of work? 3) What areas of activity, in your view, should the NDA prioritise across the next three to five years? 4) What other issues or considerations will be particularly relevant to the strategic focus of the NDA across the next three to five years?

In line with the questions articulated by the NDA, section 2 discusses the impact of the NDA's activities thus far, highlighting strengths and weaknesses, and taking into account current scholarly debates. Section 3 identifies in a succinct manner three main issues that the NDA should address in the next three years. Section 4 identifies two areas of action for further development, while section 5 suggests a major focus on cultural participation as essential for full inclusion of persons with disabilities in society. This submission endeavours to respect, as far as feasible, the word limit indicated by the NDA, which is set to be of 400 words for each of the questions. However, some sections are longer than this limit as they refer to various primary and secondary sources in support of the analysis provided.

This submission uses people-first language ('persons/people with disabilities'), in line with the language used in the CRPD and with the CRPD's understanding of disability.

2. The NDA's Strategic Approach and Impact to Date

The NDA is an independent statutory body with a duty to provide evidence-informed advice and information to the Irish Government and to the public sector on disability matters. Undoubtedly, to date, the NDA has provided notable advice on a wide range of matters, supporting the development and implementation of disability policies and the current National Disability Inclusion Strategy 2017-2021 (NDIS). Fleming, McGilloway and Barry, for example, note that the NDA 'commissioned and supported a number of key evidence-based policy documents, which have seen the disability sector in Ireland align itself more closely

¹ NDA, *National Disability Authority Strategic Plan 2019 – 2021*, available at: http://nda.ie/About-Us/Corporate-Publications/Strategic-Plans/Strategic-Plan-2019-2021/.

with international best practice'.² The NDA completed a mid-term review of the NDIS in January 2020. Under Strategic Priority 1 of the NDA action plan 2019-2021, the NDA also supported the adoption and roll-out of sectoral instruments, which address specific policy fields. The NDA has also supported the continued implementation of the Comprehensive Employment Strategy for Persons with Disabilities (CES) 2015-2024, which is a key area of focus given that the second 3-year action plan under the CES will coincide with the NDA's strategic plan. Furthermore, in the last few years, the NDA has referred consistently to the CRPD (ratified by Ireland in 2018), has acknowledged the role of the Convention as 'global normative standard',³ and has sought to support its implementation.

On the whole, the NDA's policy work is noteworthy for its breadth and scope. However, as yet, its impact has not achieved fundamental change, and has not yet embedded a human rights approach in Irish disability policies, nor fully addressed structural inequalities. In 2015, a leading disability scholar, Professor Gerard Quinn, now UN Special Rapporteur on the Rights of Persons with Disabilities, highlighted a very slow change in Irish disability policies and little progress made in regard to mainstreaming services. 4 Most recently, in November 2020, Dr. Rosaleen McDonagh (Chair of the Disability Advisory Committee of the Irish Human Rights and Equality Commission) has stated that 'Ireland has had a stagnant history in relation to disabled people' and that disability rights 'have been slow to be fulfilled'. 5 This observation is still current, and tallies with the remark put forward by different organizations that the NDIS is quite vague and aspirational.⁶ Independent Living Movement Ireland's (ILMI) Submission to the Mid Term Review of the NDIS, which was conducted by the NDA, suggests that 'In providing a complete overview of disability policy development and service delivery comprising 114 actions by its very nature the NDIS becomes too big, with too broad a focus and not enough tangible actions to be clearly implemented, monitored and evaluated for impact and success'. It also tallies with the criticism raised by several scholars on the sectoral policy instruments adopted by the Government in the last few years. This criticism extends from the content and process of adoption of those instruments (in particular for the lack of involvement of Disabled People Organizations - DPOs)8 to their implementation.9 Harsh

² P. Fleming, S. McGilloway and S. Barry, 'The Successes and Challenges of Implementing Individualised Funding and Supports for Disabled People: an Irish Perspective' (2016) 31(10) *Disability & Society* 1369 at 1372.

³ A. Broderick and D. Ferri, *International and European Disability Law. Text, Cases and Materials* (Cambridge University Press 2019). In this sense also (among many others) D. McCausland, P. McCallion, D. Brennan, et al. 'The Exercise of Human Rights and Citizenship by Older Adults with an Intellectual Disability in Ireland' (2018) 62 *Journal of Intellectual Disability Research* 875.

⁴ G. Quinn, 'All Power to the People – Why Change on Disability Policy is so Slow in Ireland: Lessons for the Next Generation of Researchers' (Disability Studies Association of Ireland conference, Dublin, 2015), cited in C. May-Simera, 'Is the Irish (Republic of) Comprehensive Employment Strategy Fit for Purpose in Promoting the Employment of People with Intellectual Disabilities in the Open Labor Market? A Discussion Using Evidence from the National Intellectual Disability Database' (2018) 15(4) *Journal of Policy and Practice in Intellectual Disabilities* 284 at 293.

⁵ R. McDonagh, Statement at the Joint Committee on Disability Matters debate (Dublin, 11 Nov 2020), available at: https://www.oireachtas.ie/en/debates/debate/joint committee on disability matters/2020-11-11/2/.

⁶ For example, the Disability Federation of Ireland's (DFI) review of the NDIS 'addressed issues such as its lack of ambition, concrete targets and deadlines.' DFI, *Annual Report 2019* (2020), at 8, available at: https://www.disability-federation.ie/assets/files/pdf/final annual review 2019 - interactive version.pdf.

⁷ ILMI, Independent Living Movement Ireland submission to the Mid Term Review of the National Disability Inclusion Strategy (NDIS) (2019), at 3, available at: https://ilmi.ie/wp-content/uploads/2019/12/ILMI-Submission-to-NDIS-November-2019.pdf/.

⁸ See on this point the observations of Moloney (Member of the Academic Network of Disability Experts for Ireland) in C. Moloney, *Living Independently and Being Included in the Community* (2019) ANED, at 14, available at: https://www.disability-europe.net/country/ireland.

⁹ K. Cullen and D. McDaid, *Evidence Review to Inform the Parameters for a Refresh of A Vision for Change* (2017), available at: https://health.gov.ie/blog/publications/evidence-review-to-inform-the-parameters-for-a-refresh-

criticism was, for example, raised on the CES,¹⁰ for its conservative approach. Van Aswegen highlights that a paternalistic and charitable discourse in the Irish government's understanding of disability is still present.¹¹ Furthermore, the work of the NDA has not yet fully addressed a key issue in Irish policy, namely the implementation of policy commitments and of the rights of persons with disabilities. This has been highlighted since the 2005 National Disability Strategy, in respect of which, as Jenkins notes, key aims have not been realised.¹²

The NDA also undertakes and commissions research in relation to disability. This research, in our opinion, is extremely important as it is key to support evidence-based policies. The advancement in data collection that has been achieved by the NDA in the last 10 years is significant. Among the various strands of research, as recently highlighted by McConkey, the NDA's research on public attitudes to disability is noteworthy.¹³ McConkey indicates that 'to date, there have been few recent studies that have explicitly investigated public attitudes to the rights of people with disabilities and furthermore to have done so with nationally representative samples', and that the Republic of Ireland is an exception to this trend.¹⁴ Since 2001, the NDA has commissioned 'national surveys of public attitudes to disability at around five yearly intervals'.¹⁵ According to McConkey, these surveys 'provide an opportunity to examine the views of the Irish public on certain rights of persons with disabilities and possible changes over time',¹⁶ while '[m]onitoring the public's perceptions of rights and of the participation in society of people with disabilities, is [also] a fruitful means of assessing the impact of the Convention'.¹⁷

3. Critical Challenges and Questions to Be Addressed in the New NDA's Strategy and Programme of Work

In this section, we limit ourselves to highlighting three critical challenges that the NDA should address in the new strategic plan.

a) Participation of People with Disabilities in the NDA's Work

A first challenge that NDA should address is that of participation of DPOs in its own work. The recent policy advice released to the Department of Justice and Equality should support the

<u>of-a-vision-for-change/.</u> Another example is the area of housing, in relation to which, with reference to the National Housing Strategy for People with Disabilities 2011 – 2016, Salmon, Garcia Iriarte, Donohoe, et al, argue that 'although the policy commitment to community living in Ireland is clear, implementation is protracted.' N. Salmon, E. Garcia Iriarte, B. Donohoe, et al, 'Our Homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland' (2018) 47(1) *British Journal of Learning Disabilities* 19 at 20.

¹⁰ J. Van Aswegen, 'Disabling discourses and charitable model of disability: labour market activation for people with disabilities, Ireland – a critical policy analysis' (2017) 35(3) *Disability & Society* 435.

¹¹ Ibid. See also J. Van Aswegen, D. Hyatt and D. Goodley, 'A critical discourse problematization framework for (disability) policy analysis' (2019) 19(2) *Qualitative Research Journal* 185. However, for a more positive assessment of the CES, see G. Scanlon, A. Kamp and A. Cochrane, 'Transition(s) to work: the experience of people with disabilities in Ireland' (2020) 35(1) *Disability & Society* 1556.

¹² M. Jenkins, 'Equal Recognition before the Law: A Call for a Statutory Social Care Advocate for Vulnerable Adults in Integrating Health and Social Care' in T. O'Connor (ed), Integrated Care for Ireland in an International Context: Challenges for Policy, Institutions & Specific Service User Needs (Oak Tree Press 2013).

¹³ R. McConkey, 'Public perceptions of the rights of persons with disability: National surveys in the Republic of Ireland' (2020) 14(2) *ALTER* 128.

¹⁴ Ibid 129.

 $^{^{15}}$ Ibidem.

¹⁶ Ibid 130.

¹⁷ Ibid 137.

NDA's adoption of a structured approach to DPOs participation. This was already somewhat highlighted by the NDA Director in November 2020.¹⁸ The forthcoming Participation and Consultation Network, but also the DPO Coalition that was formed from the ground up to write a shadow report to be submitted to the CRPD Committee, might provide new input to the NDA's work. A major participation of DPOs across the span of NDA's action could also be facilitated by creating synergies with other existing participatory mechanism. For example, in December 2018, the Irish Human Rights and Equality Commission (IHREC) established a Disability Advisory Committee (DAC). The role of the DAC is that of assisting the IHREC. However, this Committee could also provide *ad hoc* support and advice to the NDA.

b) Synergies with IHREC (within the limits of their different mandates and roles)

As recalled in the Report *Twenty Years of Disability Policy Development in Ireland*, ¹⁹ the NDA has been assigned a new function to provide information and advice to IHREC, which will perform the role of monitoring body in compliance with Article 33 CRPD. This role includes the development and provision of statistical information if required, in order to assist IHREC in carrying out its function. This would be extremely important given the obligations undertaken by Ireland under Article 31 CRPD in relation to statistical data. Particular attention should also be paid to the future collaboration between the NDA and the IHREC. The latter body has also undergone some criticism in recent years. Flynn for example suggests that the IHREC's 'role of *amicus* briefs in drawing the Court's attention to the CRPD is still underdeveloped'. ²⁰ In this light, while keeping the role of the two bodies distinct, a fruitful synergy and dynamic interaction between the NDA and the IHREC might be a driver not only for policy change, but also for a more effective protection of the rights of persons with disabilities. A synergy between NDA and IHREC could also support a cross-cutting human rights approach to disability.

c) Enhancement of Ex-Ante and Ex-Post Impact Assessment Activities

In order to effect change, the NDA could enhance their *ex-ante* and *ex-post* impact assessment activities through a more comprehensive use of human rights based indicators elaborated by the Office of the High Commissioner for Human Rights (OHCHR) in support of a disability inclusive 2030 Agenda for Sustainable Development.²¹ The OHCHR indicators are intended to guide States on actions and measures to be taken in implementing the CRPD and facilitating assessment of progress. These indicators encompass structural, process and outcome indicators. Structural indicators measure the acceptance, intent and commitment to human rights and enactment of legal instruments and the adoption of policies for the implementation of human rights. Process indicators measure efforts to transform commitments into desired results and assess policies and measures taken to implement commitments on the ground. Outcome indicators measure the results of efforts to further human rights. Structural indicators are key for *ex-ante* impact assessment, while process and outcome indicators should be key in *ex-post* assessment.

¹⁸ A. Hartney, Statement at the Joint Committee on Disability Matters debate (Dublin, 11 Nov 2020), available at: https://www.oireachtas.ie/en/debates/debate/joint committee on disability matters/2020-11-11/2/.

¹⁹ NDA, *Twenty Years of Disability Policy Development in Ireland*, at 33, available at: http://nda.ie/about-us/20-years-of-disability-policy.pdf.

²⁰ E. Flynn, 'Ireland', in L. Waddington and A. Lawson (eds), *The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts* (OUP 2018) 220 at 243.

²¹ The OHRCH human rights based indicators are available here: https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPDindicators.aspx#Project.

4. Areas of Activity that the NDA Could Prioritise

As noted above, alongside data collection, policy advice and research have been particularly important parts of the NDA's work. These areas of activity should be strengthened by including a more solid approach to EU disability law and policy. As noted above, the work of the NDA, thus far, has placed a strong emphasis on the CRPD, which is a ground-breaking document and represents decades of work to change attitudes and approaches to persons with disabilities. This should be further combined with reference to relevant EU law.

The European Disability Strategy 2010–2020 (EDS)²² is rarely mentioned and, in the past *National Disability Authority Strategic Plan 2019 – 2021*, there is scant attention to EU law with the exception of the Web Accessibility Directive.²³ The EU Charter of Fundamental Rights (the Charter) is also dramatically underused by the NDA, in spite of it being the EU constitutional catalogue of fundamental rights. Besides the principle of equality and non-discrimination (Article 21 of the Charter), Article 26 of the Charter affirms 'the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community'.²⁴ This principle should be considered a point of reference for Irish policies. In reviewing policy advice and studies, as well as NDA's webpage, it is noticeable that there are scant references to EU law. In recent years, the NDA has engaged with research done by EU bodies and agencies such as the European Union Agency for Fundamental Rights (FRA).²⁵ However, a more extensive use of the work done by EU institutions and bodies could effectively support national research and comparative approaches.

In the new NDA strategy, alongside a renewed focus on the CRPD, more attention and a better focus should be given to the EU Charter of Fundamental Rights and to EU disability law as part of the NDA's work. In fact, EU disability law is not only a new and increasingly prominent field of law and academic research, ²⁶ it is also extremely relevant to Irish people with disabilities, given that the implementation of the CRPD is also happening at the EU level. The EU in fact ratified the CRPD by virtue of the Council Decision 2010/48/EC of 26 November 2009.²⁷

The year 2020 was the concluding year of the EDS which should be soon replaced by a new Strategy for the period 2021-2030. The NDA should pay great attention to the new EDS and foster awareness raising on this new policy instrument at the government level and also among the general public. The EDS has not had any major influence on Irish policy in the past

²² Commission, 'European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe' COM(2010) 636 final.

²³ Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies [2016] OJ L327/1.

²⁴ See also C. O'Brien, 'Article 26' in S. Peers, T. Hervey, J. Kenner and A. Ward, *The EU Charter of Fundamental Rights: A Commentary* (Hart Publishing 2014) 709; and N. Šubic, 'The Rights of Persons with Disabilities in the EU Charter of Fundamental Rights: Some Reflections on the 20th Anniversary of the Charter' (2019) Ideas in ALL Blog, available at: https://www.ideasinall.com/the-rights-of-persons-with-disabilities-in-the-eu-charter-of-fundamental-rights-some-reflections-on-the-20th-anniversary-of-the-charter/.

²⁵ For example, for references to FRA's research on DPO involvement, see NDA, *Advice Paper on Engagement with Disabled Persons' Organisations* (2020), at 14, available at: http://nda.ie/publications/others/uncrpd/.

²⁶ D. Ferri and A. Broderick, 'Introduction' in D. Ferri and A. Broderick (eds), *Research Handbook on EU Disability Law* (Edward Elgar 2020), 1.

²⁷ 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.

decade.²⁸ The new European Strategy should be used by the NDA to support national policy change.

The NDA should also refer in a more comprehensive manner to other EU soft law instruments which include references to disability when relevant and appropriate. Disability is currently being mainstreamed in EU policies. For example, the EU Gender Equality Strategy includes a reference to women with disabilities.²⁹ The Strategy on the Rights of the Child (2021-24), currently in the making, and subject to a consultation,³⁰ will also likely include specific references to children with disabilities. The European Pillar of Social Rights (the Pillar), proclaimed in 2017,³¹ and whose status is admittedly unclear, could also be included as a reference when appropriate. The Pillar – a soft law document laying down twenty principles "essential for fair and well-functioning labour markets and welfare systems in 21st century Europe"-32 is not a disability-specific instrument but its three overarching themes equal opportunities and access to the labour market, fair working conditions, and social protection and inclusion – are very relevant to people with disabilities. 33 Moreover, the Pillar includes a few explicit references to disability. In particular, Chapter I of the Pillar, on equal opportunities and access to the labour market, reaffirms the right to equal treatment and non-discrimination, inter alia, on the ground of disability in the labour market and access to services (Principle 3). Chapter III, on social protection and inclusion, encompasses a provision (Principle 17) on the inclusion of people with disabilities, stating that '[p]eople with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs'. This principle tallies with the more general Principle 10, which states the right of all workers to a high level of protection of their health and safety at work, and provides that workers have a 'right to a working environment adapted to their professional needs and which enables them to prolong their participation in the labour market'.

5. Other Issues for NDA's Consideration

In the latest NDA plan, and more broadly in NDA activities thus far, there has been little attention to participation in cultural life. There is only a cursory mention of the Irish Sign Language Act and its implementation. We suggest that the NDA includes a **focus on cultural life**, as this is essential to end the marginalisation of persons with disabilities in society³⁴ and to facilitate full participation in the life of the community.³⁵

²⁸ Commission, 'Evaluation of the European Disability Strategy 2010-2020' SWD(2020) 289 final, at 20.

²⁹ Commission, 'A Union of Equality: Gender Equality Strategy 2020-2025' COM(2020) 152 final.

³⁰ Information on the initiative for the EU Strategy on the rights of the child is available at: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12454-Delivering-for-children-an-EU-strategy-on-the-rights-of-the-child.

³¹ Commission, 'Establishing a European Pillar of Social Rights' COM (2017) 250 final.

³² Commission, 'Commission Recommendation of 26 April 2017 on the European Pillar of Social Rights' C(2017) 2600 final.

³³ More information on the Pillar is available at: https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights en.

³⁴ D. Tatic, Access for People with Disabilities to Culture, Tourism, Sports and Leisure Activities: Towards Meaningful and Enriching Participation (Council of Europe 2015), available at: https://rm.coe.int/16805a2a23%20(2017.

³⁵ Council of Europe, *Strategy on the Rights of Persons with Disabilities 2017-2023* (2017), available at: https://www.coe.int/en/web/disability/strategy-2017-2023.

The importance of culture in approaches to disability is reflected in the statement of the then Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, that '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 that 'what is needed is a cultural transformation of the way society relates to the difference of disability'³⁶. This is consistent with the focus within the field of disability studies in recent decades on culture, on the potential of people with disabilities to influence it, and on disability as a lens with potential for reinterpretation and transformation of mainstream culture³⁷. Furthermore, the loss of opportunities to participate in cultural life for people with disabilities entails also a loss for the society as a whole because of the lack of cultural diversity resulting from such an inaccessible and exclusionary cultural realm.

The implementation of the Irish Sign Language Act 2017 is key and the NDA's informed policy advice and data collection would be important to support that implementation. More attention should also be given to the implementation of the European Union (Marrakesh Treaty) Regulations 2018 S.I. No. 412 of 2018. These Regulations, which came into force in October 2018, transpose into Irish law EU Directive 2017/15641 which facilitates the use of certain copyright protected works, without the authorisation of the rightsholder, for the benefit of persons who are blind, visually impaired or otherwise print disabled.

The NDA should also include as an issue research on the possibility of Ireland opting in to the **EU Disability Card**. In post-Covid times, this card might enhance the number of EU citizens with disabilities visiting Ireland. The EU disability card is a pilot project involving eight EU countries (Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania and Slovenia) to ensure equal access to benefits for people with disabilities mainly in the areas of culture, leisure, sport and transport. The card is mutually recognised between EU countries participating in the system, on a voluntary basis. In 2019 the European Commission started an assessment process on the initiative. The assessment study will provide a basis for the NDA to provide informed policy advice and to assess the feasibility of the Irish Government deciding to eventually opt in.³⁸

Overall, in our research we have ascertained that there is limited quantitative and qualitative data on access to cultural activities, goods and services for people with disabilities or on persons with disabilities as artists or cultural producers. In some countries, such as the UK, some national statistics suggest that figures for disabled workers in the arts remain very low.³⁹ Only a few festivals include disabled artists alongside non-disabled ones,⁴⁰ and it is not clear whether accessibility of performances is ensured. We suggest that the NDA's work should promote a comprehensive approach to the right to participate in cultural life within its future work.

³⁶ UN Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities* (2019) A/HRC/43/41, para 75, available at: https://undocs.org/en/A/HRC/43/41.

³⁷ See for example T. Titchkosky, *Disability, self, and society* (University of Toronto Press 2003); D. Goodley, *Disability studies: An interdisciplinary introduction* (SAGE 2011); and A. Waldschmidt, 'Disability–Culture–Society: Strengths and weaknesses of a cultural model of dis/ability' (2018) 12(2) *ALTER* 65.

³⁸ On the EU Disability Card, see also: https://ec.europa.eu/social/main.jsp?catId=1139.

³⁹ Arts Council England (ACE), *Grant-in-Aid and Lottery Distribution Annual Report and Accounts 2015/16* (2016), available at: http://www.artscouncil.org.uk/sites/default/files/download-file/ACE166 Annual Report 201516.pdf.

⁴⁰ British Council, 'European Disability Arts Festivals' (undated), available at: https://www.disabilityartsinternational.org/resources/european-disability-arts-festivals/.

Karima Bennoune, the UN Special Rapporteur in the field of cultural rights, has stated⁴¹:

Even in these trying times, when more than half a million people have died from the virus, *cultural rights are not a luxury*. They are key to the overall implementation of universal human rights and a crucial part of the responses to many current challenges, from discrimination and poverty to COVID-19 itself. Moreover, the safeguarding and promotion of culture contributes directly to many of the Sustainable Development Goals — safe and sustainable cities, the promotion of gender equality, and peaceful and inclusive societies.

Given the disproportionate effect of COVID-19 on people with disabilities, it is very important that, in post-Covid era, the arts and culture develop in a way that fosters their inclusion.

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⁴¹ K. Bennoune, 'Culture is at the Heart of Our Response to Covid-19' (Local and Regional Governments Day on Accelerating transformation from the ground-up in a post-Covid era, UN High Level Forum on Sustainable Development, July 2020), at 1, available at: https://www.ohchr.org/Documents/Issues/CulturalRights/K.Bennoune-speechHLPF2020.docx. Emphasis added.

Selected Bibliography

- Arts Council England (ACE), *Grant-in-Aid and Lottery Distribution Annual Report and Accounts*2015/16 (2016), available at:

 http://www.artscouncil.org.uk/sites/default/files/download-file/ACE166 Annual Report 201516.pdf
- Bennoune, K 'Culture is at the Heart of Our Response to Covid-19' (Local and Regional Governments Day on Accelerating transformation from the ground-up in a post-Covid era, UN High Level Forum on Sustainable Development, July 2020), available at: https://www.ohchr.org/Documents/Issues/CulturalRights/K.Bennoune-speechHLPF2020.docx
- British Council, 'European Disability Arts Festivals' (undated), available at: https://www.disabilityartsinternational.org/resources/european-disability-arts-festivals/
- Broderick A and Ferri D, *International and European Disability Law. Text, Cases and Materials* (Cambridge University Press 2019)
- Commission, 'European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe' COM(2010) 636 final
- Commission, 'Commission Recommendation of 26 April 2017 on the European Pillar of Social Rights' C(2017) 2600 final
- Commission, 'Establishing a European Pillar of Social Rights' COM (2017) 250 final
- Commission, 'A Union of Equality: Gender Equality Strategy 2020-2025' COM(2020) 152 final
- Commission, 'Evaluation of the European Disability Strategy 2010-2020' SWD(2020) 289 final
- Council of Europe, *Strategy on the Rights of Persons with Disabilities 2017-2023* (2017), available at: https://www.coe.int/en/web/disability/strategy-2017-2023
- Cullen K and McDaid D, Evidence Review to Inform the Parameters for a Refresh of A Vision for Change (2017), available at: https://health.gov.ie/blog/publications/evidence-review-to-inform-the-parameters-for-a-refresh-of-a-vision-for-change/
- DFI, Annual Report 2019 (2020), available at: https://www.disability-federation.ie/assets/files/pdf/final_annual_review_2019_-interactive_version.pdf
- Ferri D and Broderick A, 'Introduction' in Ferri D and Broderick A (eds), Research Handbook on EU Disability Law (Edward Elgar 2020)
- Fleming P, McGilloway S and Barry S, 'The Successes and Challenges of Implementing Individualised Funding and Supports for Disabled People: an Irish Perspective' (2016) 31(10) Disability & Society 1369
- Flynn E, 'Ireland', in Waddington L and Lawson A (eds), The UN Convention on the Rights of Persons with Disabilities in Practice: A Comparative Analysis of the Role of Courts (OUP 2018) 220
- Goodley D, Disability studies: An interdisciplinary introduction (SAGE 2011)

- Hartney A, Statement at the Joint Committee on Disability Matters debate (Dublin, 11 Nov 2020), available at: https://www.oireachtas.ie/en/debates/debate/joint committee on disability matters/2020-11-11/2/
- Jenkins M, 'Equal Recognition before the Law: A Call for a Statutory Social Care Advocate for Vulnerable Adults in Integrating Health and Social Care' in O'Connor T (ed), Integrated Care for Ireland in an International Context: Challenges for Policy, Institutions & Specific Service User Needs (Oak Tree Press 2013)
- ILMI, Independent Living Movement Ireland submission to the Mid Term Review of the National Disability Inclusion Strategy (NDIS) (2019), available at: https://ilmi.ie/wp-content/uploads/2019/12/ILMI-Submission-to-NDIS-November-2019.pdf
- May-Simera C, 'Is the Irish (Republic of) Comprehensive Employment Strategy Fit for Purpose in Promoting the Employment of People with Intellectual Disabilities in the Open Labor Market? A Discussion Using Evidence from the National Intellectual Disability Database' (2018) 15(4) Journal of Policy and Practice in Intellectual Disabilities 284
- McCausland D, McCallion P, Brennan D and McCarron M, 'The Exercise of Human Rights and Citizenship by Older Adults with an Intellectual Disability in Ireland' (2018) 62(10)

 Journal of Intellectual Disability Research 875
- McConkey R, 'Public perceptions of the rights of persons with disability: National surveys in the Republic of Ireland' (2020) 14(2) ALTER 128
- McDonagh R, Statement at the Joint Committee on Disability Matters debate (Dublin, 11 Nov 2020), available at: https://www.oireachtas.ie/en/debates/debate/joint committee on disability mat ters/2020-11-11/2/
- Moloney C, Living independently and being included in the community (2019) ANED, available at: https://www.disability-europe.net/country/ireland
- NDA, Advice Paper on Engagement with Disabled Persons' Organisations (2020), available at: http://nda.ie/publications/others/uncrpd/
- NDA, *National Disability Authority Strategic Plan 2019 2021*, available at: http://nda.ie/About-Us/Corporate-Publications/Strategic-Plans/Strategic-Plans-2019-2021/
- NDA, *Twenty Years of Disability Policy Development in Ireland*, available at: http://nda.ie/about-us/20-years-of-disability-policy.pdf
- O'Brien C, 'Article 26' in Peers S, Hervey T, Kenner J and Ward A, *The EU Charter of Fundamental Rights: A Commentary* (Hart Publishing 2014) 709
- Quinn G, 'All Power to the People Why Change on Disability Policy is so Slow in Ireland: Lessons for the Next Generation of Researchers' (Disability Studies Association of Ireland conference, Dublin, 2015)

- Salmon N, Garcia Iriarte E, Donohoe B, Murray L, Singleton G, Barrett M and Dillon M, 'Our Homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland' (2018) 47(1) *British Journal of Learning Disabilities* 19
- Scanlon G, Kamp A and Cochrane A, 'Transition(s) to work: the experience of people with disabilities in Ireland' (2020) 35(1) *Disability & Society* 1556
- Šubic N, 'The Rights of Persons with Disabilities in the EU Charter of Fundamental Rights: Some Reflections on the 20th Anniversary of the Charter' (2019) Ideas in ALL Blog, available at: https://www.ideasinall.com/the-rights-of-persons-with-disabilities-in-the-eu-charter-of-fundamental-rights-some-reflections-on-the-20th-anniversary-of-the-charter/
- Tatic D, Access for People with Disabilities to Culture, Tourism, Sports and Leisure Activities:

 Towards Meaningful and Enriching Participation (Council of Europe 2015), available at: https://rm.coe.int/16805a2a23%20(2017
- Titchkosky T, Disability, self, and society (University of Toronto Press 2003)
- UN Human Rights Council, Report of the Special Rapporteur on the rights of persons with disabilities (2019) A/HRC/43/41, available at: https://undocs.org/en/A/HRC/43/41
- Van Aswegen J, 'Disabling discourses and charitable model of disability: labour market activation for people with disabilities, Ireland a critical policy analysis' (2017) 35(3) Disability & Society 435
- ——, Hyatt D and Goodley D, 'A critical discourse problematization framework for (disability) policy analysis' (2019) 19(2) *Qualitative Research Journal* 185
- Waldschmidt A, 'Disability–Culture–Society: Strengths and weaknesses of a cultural model of dis/ability' (2018) 12(2) ALTER 65