

Colm Gildernew MLA Chair Committee for Health Room 419, Parliament Buildings Ballymiscaw, Stormont Belfast, BT4 3XX

By email to: Committee.health autismbill@niassembly.gov.uk

6 October 2021

Dear Chair,

Re: Call for Evidence on the Autism (Amendment) Bill

The Northern Ireland Human Rights Commission (the Commission) welcomes the Committee for Health Call to Evidence on the Autism (Amendment) Bill and the opportunity to submit evidence for consideration.

The Commission, pursuant to Section 69(4) of the Northern Ireland Act 1998, shall advise the Assembly whether a Bill is compatible with human rights—(a) as soon as reasonably practicable after receipt of a request for advice; and (b) on such other occasions as the Commission thinks appropriate. In addition, the Commission, pursuant to section 78A(6) of the Northern Ireland Act 1998, must advise the Assembly whether a Bill is compatible with Article 2(1) of the Ireland/Northern Ireland Protocol. In accordance with these functions, the following advice is submitted to the Committee for Health to assist the Committee's scrutiny of the Autism (Amendment) Bill.

The Commission bases its advice on the full range of internationally accepted human rights standards, including the European Convention on Human Rights (ECHR), as incorporated by the Human Rights Act 1998, and the treaty obligations of the Council of Europe (CoE) and United Nations (UN) systems. In addition to these treaty standards, there exists a body of 'soft law' developed by the human rights bodies of the CoE and UN. These declarations and principles are non-binding but provide further guidance in respect of specific areas.

Article 2 of the Ireland/Northern Ireland Protocol to the UK-EU Withdrawal Agreement (the Protocol) requires the UK Government to ensure there is no diminution of rights, safeguards and equality of opportunity, as set out in the relevant part of Belfast (Good Friday) Agreement 1998, resulting from the UK's withdrawal from the EU. The relevant part of the Belfast (Good) Friday Agreement includes the right to equality of opportunity in all social and economic activity regardless of disability. Article 2 also commits the UK Government to keep pace with certain provisions of EU equality law listed in Annex 1 of the Protocol. The UK Government has also affirmed that there are additional EU obligations falling within the scope of Article 2 which protect the rights of disabled people.¹

Overall, the Commission welcomes the Autism (Amendment) Bill and its intention to strengthen the impact of the autism strategy, enhance training and information services in line with international best practice, and improve scrutiny of the Department's functions. As examined below, many of the elements of the Bill relate to obligations deriving from the UN Convention on the Rights of Persons with Disabilities (UN CRPD).² It provides a rounded framework which the Department can rely upon to develop a human rights-based approach to issues affecting persons with disabilities, including autism spectrum disorders, in Northern Ireland (NI).

The Commission highlights relevant human rights standards and principles in respect of points for consideration, to assist the development of legislation and support policy in this area. If enacted, the Commission looks forward to working with the Department pursuant to its role under Article 33(2) of the UN CRPD as 'Independent Mechanism' in Northern Ireland (IMNI). IMNI is performed jointly with the Equality Commission for Northern Ireland to promote, protect and monitor the implementation of the UN CRPD.

Autism Strategy

The Commission welcomes clause 1 which broadens the field of persons who may be consulted on the strategy. Article 4(3) of the UN CRPD requires State parties to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations" in the development and implementation of policies relevant to the implementation of the UN CRPD. Article 12 of the UN Convention on the Rights of the Child (UN CRC)³ similarly requires the views of the child to be sought, either directly or through a representative. Clause 1 is in line with these requirements but to provide additional assurance, the Commission recommends that the Autism Strategy compels expressly the Department to involve and consult people

¹ NI Office, 'UK Government Commitment to "No Diminution of Rights, Safeguards and Equality of Opportunity" in Northern Ireland: What does it Mean and How will it be Implemented?' (NIO, 2020), at para 13

² Ratified by the UK in 2009.

³ Ratified by the UK in 1991.

with autism, parents/carers of children and adults with autism, and representative organisations working within the autism sector in its development, monitoring, and implementation of the Strategy.

The Commission is aware that the needs of persons with autism spectrum disorder have not been fully met to date. It recognises that there is a need for cross-departmental co-ordination to ensure that needs are assessed and addressed effectively, particularly at key transition points in the lives of persons with autism.

The collation of robust data and evidence, which enhances learning, is integral to effective cross-departmental work. Therefore, the Commission welcomes the proposed inclusion of a specific duty upon the Department to request Health and Social Care Trusts to provide data on the prevalence of autism both in adults and in children. This is consistent with Article 31 UN CRPD, which requires State parties to collect appropriate data to enable them to formulate and implement policies which give effect to the Convention. The availability of robust data is similarly imperative to an effective monitoring process under Article 33.

The UN CRC contains specific reference to children with disabilities, in recognition of their vulnerability to segregation and discrimination. Article 3 requires that, in all actions concerning children, the best interests of the child shall be a primary consideration. In addition, as part of their obligations under Article 23, State parties are required to "set up and develop mechanisms for collecting data which are accurate, standardised and allow disaggregation, and which reflect the actual situation of children with disabilities".⁴

In 2017, the UN CRPD Committee was concerned at the lack of UK Government and NI Executive-led initiatives "aimed at assessing and sufficiently addressing the inclusion of and living conditions for persons with disabilities, particularly in NI and the overseas territories". The Commission therefore welcomes the proposed addition of new components to the Autism Strategy, as set out in clause 2. In particular, the Commission welcomes the inclusion of training initiatives for NI departments and other public bodies. The commission believes such training initiatives assist in raising public awareness and understanding of autism. This also ensures early intervention and information services are tailored to the needs of persons with autism and provided when needed by that person.

The UN CRPD Committee recommended that the UK Government and NI Executive "collect information and adopt a strategic and measurable plan

⁴ CRC/C/GC/9, Committee on the Rights of the Child 'General Comment No.9: The rights of children with disabilities' 27 February 2007, at 19.

⁵ CRPD/C/GBR/CO/1, 'UN CRPD Committee Concluding Observations on the Initial Report of the UK of Great Britain and NI', 29 August 2017, at paras 8 and 9.

of action for improving the living conditions of all persons with disabilities, including in close cooperation with authorities in NI".⁶ The Commission welcomes the strategic approach in clause 3, requiring proper account be taken of best international practice, adoption of a multidisciplinary approach and, crucially, the setting of measurable targets, developed in consultation with those promoting the rights of persons with autism.

Article 2 of the Ireland/Northern Ireland Protocol (enacted by the Withdrawal Agreement Act), includes a requirement for the UK Government to keep pace with any amendments to the Employment Equality Directive, which prohibits discrimination on grounds of disability in employment and vocational education.⁷ The Commission recommends that the Committee reminds the Department to consider the Employment Equality Directive and continue to monitor relevant current and future CJEU jurisprudence insofar as it is relevant to those parts of the Autism Strategy relating to employment and vocational education.

As the EU has acceded to the UN CRPD,8 there is an overriding obligation to promote, protect and implement the UN CRPD through EU law and policy. The UN CRPD is relevant to the interpretation of Withdrawal Agreement, including Article 2 of the Protocol, and to all EU measures referenced in that Agreement. 10 The UN CRPD is similarly relevant to the interpretation of any additional underpinning EU obligations for the rights, safeguards and equality of opportunity listed in the relevant part of the Belfast (Good) Friday Agreement. 11 The UK Government has accepted that the Withdrawal Agreement, and those parts of EU law made applicable by it, will have the same legal effect in the UK as in the EU and that individuals will be able to bring legal challenges to vindicate their Article 2 rights. 12 The Commission recommends that the Committee reminds the Department that, in the development of the Autism Strategy, it has a duty to ensure there is no diminution of the rights, safeguards or equality of opportunity in the relevant part of the Belfast (Good Friday) Agreement as a result of the UK's withdrawal from the EU, in line with Article 2 of the Protocol.

Autism funding reports

Article 4 of the UN CRPD is explicit that, with regard to full enjoyment of economic, social and cultural rights, each State party must take measures

 $^{^6}$ CRPD/C/GBR/CO/1, 'UN CRPD Committee Concluding Observations on the Initial Report of the UK of Great Britain and NI', 29 August 2017, at paras 8 and 9.

⁷ Directive 2000/78/EC, `EU Council Directive on Establishing a General Framework for Equal Treatment in Employment and Occupation', 27 November 2000.

⁸ EU Commission Press Release, 'EU Ratifies UN Convention on Disability Rights' (5 January 2011).

HK Danmark (Jette Ring and Lone Skouboe Werge), Case 335/11 and Case 337/11, 11 April 2013, at paras 28-32; Z v A Government Department, Case C-363/12, 14 March 2014, at para 85.
Article 2(a)(iv) and Article 4 UK-EU Withdrawal Agreement 2020.

¹¹ Belfast (Good Friday) Agreement, 10 April 1998, Part 6 on Rights, Safeguards and Equality of Opportunity – Human Rights.

¹² NI Office, 'UK Government Commitment to "No Diminution of Rights, Safeguards and Equality of Opportunity" in Northern Ireland: What does it Mean and How will it be Implemented?' (NIO, 2020), at para 28; Section 7A, EU Withdrawal) Act 2018.

to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to progressive realisation¹³. The Commission welcomes the new requirement in clause 4 that the Minister must prepare autism specific annual funding reports which must be laid before the Assembly. The Commission reiterates the importance of allocating sufficient financial and human resources for this specifically and continuing for general obligations under the UN CRPD.

The Commission reminds the Committee that the overall purpose of the UN CRPD is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities". The UNCRPD makes repeated reference to the realisation of human rights "on an equal basis with others", referring to equality between, and among, persons with or without disabilities. Therefore, the Commission highlights the importance of comprehensive, consistent, and co-ordinated approaches to implementing all obligations under the UN CRPD.

The Commission recommends that the Autism Strategy and its associated action plans and funding reports, are developed, implemented, and monitored in tandem with the anticipated Disability Strategy from the Department for Communities. While the Commission has not yet had sight of the draft Disability Strategy, it is likely that there will be areas of overlap and the Department may wish to consider this to ensure complementarity.

It is notable that the report of the Disability Strategy Expert Advisory Panel identified resourcing as a key barrier to equal opportunity and made six recommendations for action, advising that "if no additional resources are allocated to the Disability Strategy this will make achievement of its objectives hugely challenging and restrict the extent to which this can be meaningful".¹⁵

The Commission recommends that the NI Executive ensures sufficient and proportionate financial and human resources are dedicated to developing, implementing, and monitoring the Autism Strategy to ensure full compliance with the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

Autism Reviewer

The Commission welcomes clause 5 of the Bill, which proposes the appointment of an autism reviewer who will provide additional scrutiny on matters relating to autism. If established, the Commission will be interested to learn and give further consideration to how this role will feed

¹³ Article 4, UN CRPD

¹⁴ Article 1, UN CRPD

¹⁵ Department for Communities, 'Report from the Disability Strategy Expert Advisory Panel' (DfC, March 2021) at 2.5

into the overall monitoring and implementation of the UN CRPD through the IMNI.

I hope these comments are helpful. Should any further human rights issues arise within the context of the Committee's consideration of the Bill, the Commission would be happy to advise. We remain at the disposal of the Committee for further advice or engagement as necessary.

Yours sincerely,

Alyson Kilpatrick BL Chief Commissioner

A. Thysatel