

THE COURT OF APPEAL (CIVIL)

Record No. 2021/277

Between:-

AND (SUING BY HIS FATHER AND NEXT FRIEND)

Applicants

-and-

HEALTH SERVICE EXECUTIVE

Respondent

-and-

IRISH HUMAN RIGHTS AND EQUALITY COMMISSION

Notice Party

OUTLINE LEGAL SUBMISSIONS ON BEHALF OF THE IRISH HUMAN RIGHTS AND EQUALITY COMMISSION

I. Introduction

On 26 November 2021, this Court granted the Commission liberty to appear as amicus
curiae in these proceedings. By way of consultative case stated, the Circuit Court has
asked this Court for guidance on the following question:

Where it has been determined by an assessment officer that an applicant has a disability, can the assessment of need be regarded as complete for the purposes of the Disability Act 2005 if it does not incorporate any diagnostic assessment of the child's disability, whether in determining the existence of a disability or in setting out the nature and extent of the disability?

While this question may be regarded as raising a net issue of statutory interpretation, it has significant implications in practice for the rights of persons with disabilities. For this reason, in the Commission's submission, it is important that the legislation is interpreted – and the case stated answered – in a manner consistent with the individual's fundamental rights, including those rights protected under the State's obligations under international law and, in particular, the United Nations Convention on the Rights of Persons with Disabilities.

II. The Position of the Amicus Curiae

- 3. The definition of disability in the 2005 Act is such that it is a person's impairment that gives rise to a substantial restriction in the person's capacity to carry on a profession or occupation or to participate in social or cultural life in the State. This is not a social model of disability as has been contended for by the Respondent in its submissions. This is because the definition attributes responsibility to the impairment for the restriction in the person's capacity.
- 4. The social model of disability recognises that it is the interaction between an impairment and various barriers that may hinder a person's participation in society on an equal basis with others.
- 5. Under the 2005 Act, an assessment officer cannot determine that a person has a disability, unless they are satisfied, that the person has an "enduring physical, sensory, mental health or intellectual impairment", which gives rise to a substantial restriction in the person's capacity to carry on a profession or occupation in the State or to participate in social or cultural life in the State.
- Where the identification of such an impairment requires a diagnostic assessment, this
 does not in itself constitute a medical model of disability, nor is it inconsistent with
 the social model of disability as provided for in the CRPD.
- 7. The Respondent's interpretation of disability, under the 2005 Act, has the effect of potentially depriving the applicant of his fundamental rights contrary to the provisions of the CRPD and Article 42A of the Constitution.

III. The Applicants' Case

- 8. As is clear from its long title, one of the central purposes of the 2005 Act is to enable provision to be made for "the assessment of the health and education needs occasioned to persons with disabilities by their disabilities". To this end, Part 2 of the 2005 Act makes provision for Assessments of Need, Service Statements and Redress. At the heart of Part 2 of the 2005 Act is the independent assessment of need. Under section 8, an independent assessment officer carries out an assessment of an applicant and prepares an assessment report setting out the findings together with a determination as to whether the applicant has a disability and, if so, a statement of inter alia the nature and extent of that disability, the health and education needs of the applicant, and the services appropriate to meet those needs.
- 9. In circumstances set out in the case stated, an assessment report issued to the Applicants on 13 January 2021: Grounding Affidavit, Exhibit 33. In section 4 of the report, the assessment officer determined that the applicant, had a disability as defined by the 2005 Act. In section 5, the assessment officer provides a description of the nature and extent of solding speech and language therapy, psychology, physiotherapy and occupational therapy provided by an interdisciplinary team. In addition, based on observation and his parents' reports, the assessment officer stated that required "further diagnostic assessment". No specific education needs are identified in the assessment report. Thus, while determining that has a disability, the assessment report does not identify or diagnose any "enduring physical, sensory, mental health or intellectual impairment" which gives rise to the determination of disability.
- 10. Against this backdrop, the Applicants claim that, by failing to provide any diagnosis in respect of "'s disability, the Respondent has failed to complete the assessment of need under the 2005 Act.
- 11. In particular, as set out in the Case Stated (§10), sparents are concerned that has Autism Spectrum Disorder ('ASD'). While none of the clinical or

multidisciplinary reporting raised the question of ASD in his case, sparents arranged for an educational psychologist to swear an affidavit to the effect that an ASD assessment was warranted.

- 12. The Applicants further claim that the lack of formal diagnosis causes a significant prejudice to insofar as he cannot access vital services, with a knock-on effect on his education and social life and creating a detriment in respect of delayed treatment and early intervention: Grounding Affidavit, §14.
- 13. For its part, the Respondent takes the view that the assessment of need is complete for the purposes of the 2005 Act and that the question as to "whether or not spresenting behaviours also meet the criteria for one or other diagnosis" is separate to the question as to whether has a disability as defined in the 2005 Act and the nature and extent of that disability: Case Stated, §15.
- 14. It is against this backdrop that the Circuit Court has asked this Court whether the assessment of need for the purposes of the 2005 Act can be regarded as complete where it has been determined that has a disability, but the assessment does not incorporate any diagnostic assessment of the child's disability whether in determining the existence of a disability or in setting out the nature and extent of the disability.

IV. The Legal Framework

- 15. The proper interpretation of the 2005 Act lies at the heart of this case stated. As the relevant provisions of the 2005 Act have been set out in detail in the parties' submissions, the Commission will not set out the legislative framework in detail in these submissions but will instead refer to the relevant provisions where appropriate.
- 16. It is important to reiterate, however, that the very first stated purpose of the 2005 Act, as set out in its long title, is "to enable provision to be made for the assessment of health and education needs occasioned to persons with disabilities by reason of their disabilities".

- 17. In the Commission's submission, the assessment of the health and education needs of persons with disabilities under the 2005 Act engages a range of fundamental rights of applicants for assessment, including the constitutional right to bodily integrity (*Ryan v. Attorney General* [1965] IR 294; *MX v. HSE* [2012] 3 IR 254) and the right to education (*O'Donoghue v. Minister for Health* [1996] 2 IR 20; *Sinnott v. Minister for Education* [2001] 2 IR 545). In the case of children, such as the assessment of need also engages Article 42A of the Constitution under which the State "recognises and affirms the natural and imprescriptible rights of all children and shall, as far as practicable, by its laws protect and vindicate those rights".
- 18. It follows that, in carrying out its functions under the 2005 Act, the Respondent must do so in a manner that is consistent with the Constitution and the fundamental rights guaranteed thereunder: *McDonald v Bord na gCon* [1965] IR 217; *East Donegal Cooperative v. Attorney General* [1970] IR 317; *The State (Lynch) v. Cooney* [1982] IR 337.
- 19. In addition, in accordance with long established principle, Irish law must, so far as possible, be interpreted in a manner consistent with the State's obligations under international law: The State (D.P.P.) v Walsh [1981] IR 412, 440; Domhnaill v Merrick [1984] IR 151, 159; N.S. v Anderson [2008] 3 IR 417, 427.
- 20. Of particular relevance in this context is the United Nations Convention on the Rights of Persons with Disabilities ('Convention' or 'CRPD'), which is referenced in the parties' submissions. Having signed the Convention on 30 March 2007, Ireland ratified the CRPD on 20 March 2018. Since that time, the CRPD has been binding on the State as a matter of international law. While, by reason of Article 29.6 of the Constitution, the Convention which has not been directly incorporated into Irish law does not directly have the force of law in the State, the Irish courts have regard to the Convention in ensuring that that Irish law is interpreted, so far as possible, in line with the State's obligations thereunder: see e.g. Nano Nagle School v. Daly [2019] 3 IR 369. This is particularly important in the context of legislation, such as the 2005 Act, which directly engages the State's obligations under the Convention.

V. The Definition of Disability under the 2005 Act in light of the CRPD

The Definition of Disability under the 2005 Act

- 21. Under section 8(7) of the 2005 Act, in order for an assessment to be complete, it must include a determination as to whether the applicant has a disability and, if so, it must contain a statement inter alia of "the nature and extent of the disability". An assessment is defined in section 7(1) as meaning an assessment to determine "the health and education needs (if any) occasioned by the disability and the health services or education services (if any) required to meet those needs".
- 22. Disability is defined in section 2 of the 2005 Act as meaning, in relation to a person, "a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment".
- 23. For the purposes of Part 2 of the 2005 Act, section 7(2) provides that the concept of "substantial restriction" in the definition of disability in section 2 shall be construed as meaning a restriction which:
 - (a) is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and
 - (b) gives rise to the need for services to be provided continually to the person whether or not a child or, if the person is a child, to the need for services to be provided early in life to ameliorate the disability.
- 24. According to the Applicants, an assessment of need under section 8 of the 2005 Act requires an assessment of all necessary matters, including diagnosis of the applicant's disability where one has not already been attached: Applicant's Submissions, §9. This is necessary to determine whether an applicant has a disability and to include "a meaningful statement of what the nature and extent of the disability is". In making this submission, the Applicants state that they are not endorsing a medical model of disability or arguing for an approach to disability that is diagnosis-led, but that they

need to know the nature of the impairments from which their son suffers in order to meet his complex health and educational needs and to direct their limited resources to address them: Applicant's Submissions, §10.

25. According to the Respondent, the interpretation of the 2005 Act contended for by the Applicants is not supported by the definition of disability under the Act "which, consistent with a developing understanding of what disability entails (and reflected in the UN Convention on the Rights of Persons with Disabilities), conceives of disability not by reference to the underlying medical condition, but rather to the restriction on participation in life experienced by persons with disabilities": Respondent's Submissions, §3. In making this submission, the Respondent draws a sharp contrast between a 'social' conception of disability, which it says the 2005 Act provides for, and a 'medicalised' definition, which it says the Act eschews: Respondent's Submissions, §\$34-44. On this basis, the Respondent submits that "not only is it unnecessary to attach a diagnosis in order to make that determination, but that to do so would fly in the face of the language of the Act and the conception of disability that underpins it": Respondent's Submissions, §46.

The Conception of Disability under the CRPD

- 26. It is true that the CRPD involves a shift from a conception of disability focused on disability as a medical condition to a broader conception, which focuses on persons with disabilities as rights holders. While this conception is sometimes described as espousing a social model, the Committee on the Rights of Persons with Disabilities describes the approach under the Convention as a "human rights model". This human rights model recognises "that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights": Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018) on equality and non-discrimination, §9.
- 27. The CRPD does not provide a definition of disability for all purposes. As expressed in the Preamble (§5), the CRPD recognises "that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal

and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

- 28. According to Article 1(1) CRPD, the purpose of the Convention is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". Article 1(2) CRPD provides that persons with disabilities "include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". As is clear from its terms, this definition is inclusive and non-exhaustive: see e.g. Committee on the Rights of Persons with Disabilities, Communication No. 10/2013, §6.3.
- 29. While it is undoubtedly the case that the conception of disability under the CRPD cannot be limited to a medical conception, it is also clear that this conception does not exclude a medical element where appropriate. This is reflected in the express reference in Article 1(2) CRPD to persons with "long-term physical, mental, intellectual or sensory impairments" which, in interaction with various barriers, may hinder the effective participation of persons with disabilities in society on an equal basis.

Interpretation and Application of the 2005 Act in light of the CRPD

30. While the definition of disability in section 2 of the 2005 Act focuses on "a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State", this restriction is specifically expressed to be "by reason of an enduring physical, sensory, mental health or intellectual impairment". Thus, while the definition makes reference to restriction on participation in society, the definition includes a medical element: see e.g Flynn, "Ireland's Compliance with the Convention on the Rights of Persons with Disabilities: Towards a Rights-Based Approach for Legal Reform" (2009) 31(1) DULJ 357. This element of the definition is arguably reinforced when interpreted alongside section 7(2) of the 2005 Act which – while specifically referable to the restriction – emphasises the permanent nature of the restriction and the continual need for the provision of services.

- 31. In the Commission's submission, the definition of disability under the 2005 Act, which includes this medical element, is capable of being, and ought to be, interpreted in accordance with the State's obligations under the CRPD. As noted above, the definition in Article 1(2) CRPD also includes a medical element insofar as it refers to persons who have "long-term physical, mental, intellectual or sensory impairments".
- 32. What is important for the purposes of the CRPD is that the conception of disability under the 2005 Act is not confined to this medical conception alone and that it is interpreted and applied in a manner that promotes and protects the rights of persons with disabilities. As discussed further below, this includes the right to health protected under Article 25 CRPD.
- 33. In this regard, a determination that a person has a disability within Part 2 of the 2005 Act, is concerned with the assessment of *inter alia* the health needs of applicants. In this context, the medical element of a disability is likely to be of particular importance.
- 34. This being so, the Commission does not consider that a definition of disability which includes a medical element that may in turn require diagnosis in appropriate cases runs contrary either to the language of the 2005 Act, the conception of disability which underlies that Act, and/or the State's obligations under the CRPD.
- 35. The approach adopted by the Respondent both in practice in its Standard Operating Procedure and in principle in its submissions appears to side-line the medical element of the definition of disability under the 2005 Act, which may be particularly important in the assessment of health needs under section 8: see, in particular, Respondent's Submissions, §§ 49 and 62.
- 36. Indeed, the Respondent goes so far as to argue that reference to a person's underlying condition requires departure from the clear language of the 2005 Act because disability is defined by reference to restriction on a person's capacity to participate: Respondent's Submissions, §62. The reference to impairment in section 2 is simply understood as providing "examples of the nature of the disability": Respondent's Submissions, §68.

- 37. However, in the Commission's submission, this argument does not take full account of the fact that the restriction under the Act is expressly stated to be "by reason of an enduring physical, sensory, mental health or intellectual impairment". This constitutes a core element of the definition of disability under the 2005 Act. The assessment officer must, under section 8(7), make a determination as to whether a person has a disability and, if so, provide a statement inter alia of the nature and extent of the disability and the applicant's health and education needs. Accordingly, it is difficult to understand how an assessment of need can be effectively carried out without appropriate identification and/or diagnosis of an applicant's impairment, which gives rise to their disability in appropriate cases. Indeed, while the issue may not have been definitively determined to date, the case-law under the 2005 Act to date appears to support the view that diagnosis is a relevant part of the assessment of need process: Applicant's Submissions, §§28-32; Respondent's Submissions, §§56-57.
- 38. In this regard, it is of concern to the Commission that the Respondent's Standard Operating Procedure not only fails to provide for diagnosis in appropriate cases, but in fact appears to exclude diagnosis as part of the assessment process as a matter of course: see Section 2, HSE Guidance for Assessors. The approach of the Respondent appears to be to exclude diagnosis even where this might be necessary and/or appropriate for the determination as to whether a person has an impairment that could give rise to a disability and, if so, the nature and extent of the disability and the person's education and health needs.
- 39. Further, the Respondent's Standard Operating Procedure includes in its Glossary of Terms and Definitions §5.0, a definition of disability (purportedly under the legislation) which completely excludes reference to an enduring physical, sensory, mental health or intellectual impairment in respect of the person.
- 40. The Applicants' case illustrates the problems to which this approach may give rise in practice:
 - (i) Notwithstanding that the Respondent has determined that has a disability, the Respondent has not identified the nature of that disability save by way of general description of the manner in which he presented at assessment;

- (ii) While the assessment report recognises that "further diagnostic assessment" is required as part of shealth needs, the assessment report does not include any diagnosis, even of an initial character. Nor does the assessment report make any reference to any education needs of
- (iii) Despite the recognition of the need for further diagnostic assessment, the service statement furnished to the applicant does not make any reference to further diagnostic assessment. Insofar as it makes provision for the services of an interdisciplinary team, it is clear that there will be a substantial delay before is able to avail of those services; and
- (iv) In the meantime, parents say that their son's access to vital services is prejudiced by the lack of any diagnostic assessment as part of the assessment.
- 41. In this way, the failure to identify or diagnose a person's impairment, which might give rise to a finding of disability in the context of the assessment of health and education needs in appropriate cases, is likely to hinder that person's "full and effective participation in society on an equal basis with others" (Article 1(2) CRPD). If a person's impairment is not properly identified or diagnosed, and a finding of disability not made in appropriate cases, there is a real risk that the nature and extent of disability and the health and education needs of that person will not be meaningfully or accurately stated in the assessment under section 8 of the 2005 Act.
- 42. For these reasons, in the Commission's submission, the Respondent's interpretation and application of the 2005 Act cannot be reconciled with the terms of sections 2, 7, 8 and 9 of the 2005 Act, interpreted in light of the State's obligations under the CRPD and 's rights under Article 42A of the Constitution. While the conception of disability under the CRPD cannot and must not be reduced to a medical conception alone, this does not mean that the appropriate assessment of disability, particularly in the context of a person's health needs, excludes diagnosis in appropriate cases.

VI. The Substantive Rights of Persons with Disabilities

43. In the Commission's submission, an approach to the interpretation and application of the 2005 Act that excludes diagnosis from an assessment of need as a matter of course is also likely to run contrary to the substantive rights and obligations under the CRPD.

- 44. Article 3 CRPD identifies the general principles that underpin the Convention, including the principles of full and effective participation and inclusion in society and of respect for the evolving capacities and rights of children with disabilities are all of particular relevance.
- 45. Under Article 4 CRPD, State Parties, such as Ireland undertake to ensure and promote "the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability". To this end, States undertake inter alia to "adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention", to "take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes" and to "refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention".
- 46. Article 7 CRPD expressly recognises the position of children with disabilities. States must take "all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children" and, in all actions concerning children with disabilities, "the best interests of the child shall be a primary consideration".
- 47. Of special importance in the present context is the right to health enshrined in Article 25 CRPD. Under Article 25, States Parties recognise that persons with disabilities have "the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" and are required to "take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation". In particular, under Article 25(b) States Parties are obliged to provide "those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons" (emphasis added).

- 48. In the Commission's submission, an assessment of need under the 2005 Act, which excludes the identification and diagnosis of a person's disability in appropriate cases, cannot be reconciled with the State's obligation under Article 25(b) CRPD.
- 49. This is not simply an abstract concern. Its real and practical importance for persons with disabilities is illustrated by the facts of the Applicants' case. If there is no diagnosis as part of the assessment of health needs, notwithstanding a recognition that this is required in a particular case, early identification and intervention, and the design of services to minimise and prevent further disabilities, is likely to be significantly prejudiced.
- 50. In its Initial Report on the Rights of Persons with Disabilities to the UN Committee on the Rights of Persons with Disabilities (December 2020) the State, in examining compliance with Article 25, reports under Early Identification and Intervention at §342, that the Disability Act 2005 provides for the assessment of needs of persons with disabilities and the drawing up of Service Statements for individuals. It is difficult to reconcile the reliance on the part of the State on the assessment of needs process under the 2005 Act in demonstrating its compliance with its obligations under Article 25, with the position now adopted by the Respondent in the within case stated.
- 51. While the Respondent does not disagree with the importance of early diagnosis, it submits that the 2005 Act "does not provide a mechanismfor providing that diagnosis" and that no entitlement to diagnosis arises under the 2005 Act because the language and spirit of the Act is framed in terms of a restriction on participation rather than the underlying cause of the restriction: Respondent's Submissions, §§ 53(b) and 90.
- 52. For the reasons set out above, the Commission submits that the definition of disability under the 2005 Act, for the purpose of the assessment of need process, cannot be understood by reference to the restriction on participation alone without regard to its medical element. Properly understood and applied, the assessment of need process under the 2005 Act therefore can, and should, provide a suitable mechanism for early diagnosis, identification and intervention, as appropriate, in line with the State's obligations under Article 25(b) CRPD.

- 53. Such an approach is consistent not only with the right to health under Article 25 CRPD but also with the other rights guaranteed under the Convention, including the right to education in Article 24 CRPD, the right to habilitation and rehabilitation in Article 26 CRPD, and the right to participation in cultural life, recreation, leisure and sport in Article 30 CRPD.
- 54. In particular, in recognising the right to education without discrimination and on the basis of equality of opportunity, at paragraphs (c) to (e) of Article 24(2) CRPD, specifically require that States ensure that: reasonable accommodation of the individual's requirements is provided; that persons with disabilities receive the support required within the general education system to facilitate their effective education; and that effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion.
- 55. Finally, it is important to note that the Convention underlines the importance of persons with disabilities being actively involved in decision-making processes about policies and programmes, including those directly concerning them (Preamble, §15; Article 4(3) CRPD) and the importance of family members receiving the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities (Preamble, §24; Article 23(3) CRPD). This is relevant in the present case in circumstances where the Applicants have specifically requested a diagnosis in order to ensure that the assessment of need under section 8 of the 2005 Act is meaningful and effective.

VII. Conclusion

56. For these reasons, the Commission submits that – interpreted in a manner consistent with the rights of persons with disabilities – an assessment of need cannot be regarded as complete for the purposes of the Disability Act 2005 where it determines that the applicant has a disability but does not incorporate any diagnostic assessment of the child's impairment giving rise to that disability notwithstanding that such assessment is necessary and appropriate in the particular case in order to identify the disability, its nature and extent, and *inter alia* the health and education needs of the applicant. If the

2005 Act is interpreted and applied as excluding diagnosis of a child's impairment giving rise to a disability as a matter of course, this is liable to undermine, rather than uphold, the rights of persons with disabilities under the Constitution and the CRPD.

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12 January 2022