



F.U.S.S.

Families Unite for Services & Support

The Autism Protocol

FUSS Ireland have carefully reflected on the recently launched, final iteration of the “Autism Protocol.” We wanted to ensure we gave it a fair re-consideration as we have made our feelings known about it in the past, based on concerns we had with drafts at the various stages since we first saw it in 2023. Representative bodies had voiced significant concerns that it failed to align with international best practice¹ and that it had not evidenced the reduced timeframes it claimed to deliver.² It claims to provide an expedited system of assessment designed to improve outcomes and free up teams to provide support. As an organisation we felt it was necessary to offer a constructive critique of its evidentiary foundations, something which children in Ireland have dealt with the ramifications of for many years now.³ The Irish protocol’s pivot toward "clarity of presentation" assumes that autism can be reliably separated from other neurodevelopmental differences in a streamlined setting. However, this binary approach is fundamentally flawed, and we feel that the protocol risks institutionalizing an inequitable system where the depth of assessment is determined by resource availability rather than the actual needs of the child. The protocol repeatedly refers to the success of the tiered model approach of Scotland and Australia, so we have provided a comparison.

Scotland

‘SIGN 145’ is the primary framework for the assessment of autism amongst adults and

¹ ‘Psychological Society of Ireland Response to Autism Protocol (2024)’

² ‘Association of Occupational Therapists of Ireland: Response to Autism Assessment Protocol (2025)’.

³ Noreen O’Leary and Geraldine Moran, ‘Applying Evidence to the Aspiration for Equity in Children’s Disability Services.’ (2025) 28 *Advances in Communication & Swallowing* 102

children in Scotland.⁴ As part of the ‘universal health review’, a healthcare professional may be alerted by parental concern or by their own clinical experience; that the child is potentially displaying indicators of non-typical developmental.⁵ In the context of this system,

“instruments may be used for information gathering, but they should not be used to make or rule out a referral for an assessment for autism.”⁶

In Ireland, a public health nurse will use the ‘ages and stages questionnaire’ to carry out a developmental checkup on a child to determine if there may be a need to refer that child onward for specialist input.⁷ Initial assessment within the Scottish system is for determining if the challenges experienced are indicative of the need for a diagnostic assessment. It is crucial to point out that there is no assessment of whether or not the person meets the criteria for autism at this early stage and the guideline clearly states “If on the basis of an initial assessment, it is suspected that the individual may be autistic, they should be referred for a specialist assessment”.⁸ The specialist assessment in the Scottish model is the only level at which autism is actually diagnosed, making it significantly different to the new Irish model. The Scottish model stresses the substantial professional experience needed to conduct an assessment accurately and places emphasis on how “assessment of individuals for autism cannot be rushed.”⁹ In 2021 Scotland introduced a new children’s developmental pathway framework (NAIT) with updates made in 2024¹⁰. This new pathway aimed to bring a neuro affirmative perspective to the process and broaden out its process by assuming co-occurrence of other neurodevelopmental conditions and aiming to get a more holistic

⁴ ‘Assessment, Diagnosis, and Interventions for Autism Spectrum Disorders: A National Clinical Guideline’ (Scottish Intercollegiate Guidelines Network 2016).

⁵ *ibid.* 4.1.3 para

⁶ *ibid.* 4.1.3 para 10

⁷ ‘National Guideline on the Use of the Ages & Stages Questionnaire for Developmental Screening of Children between 1 Month and 66 Months of Age’, HSE

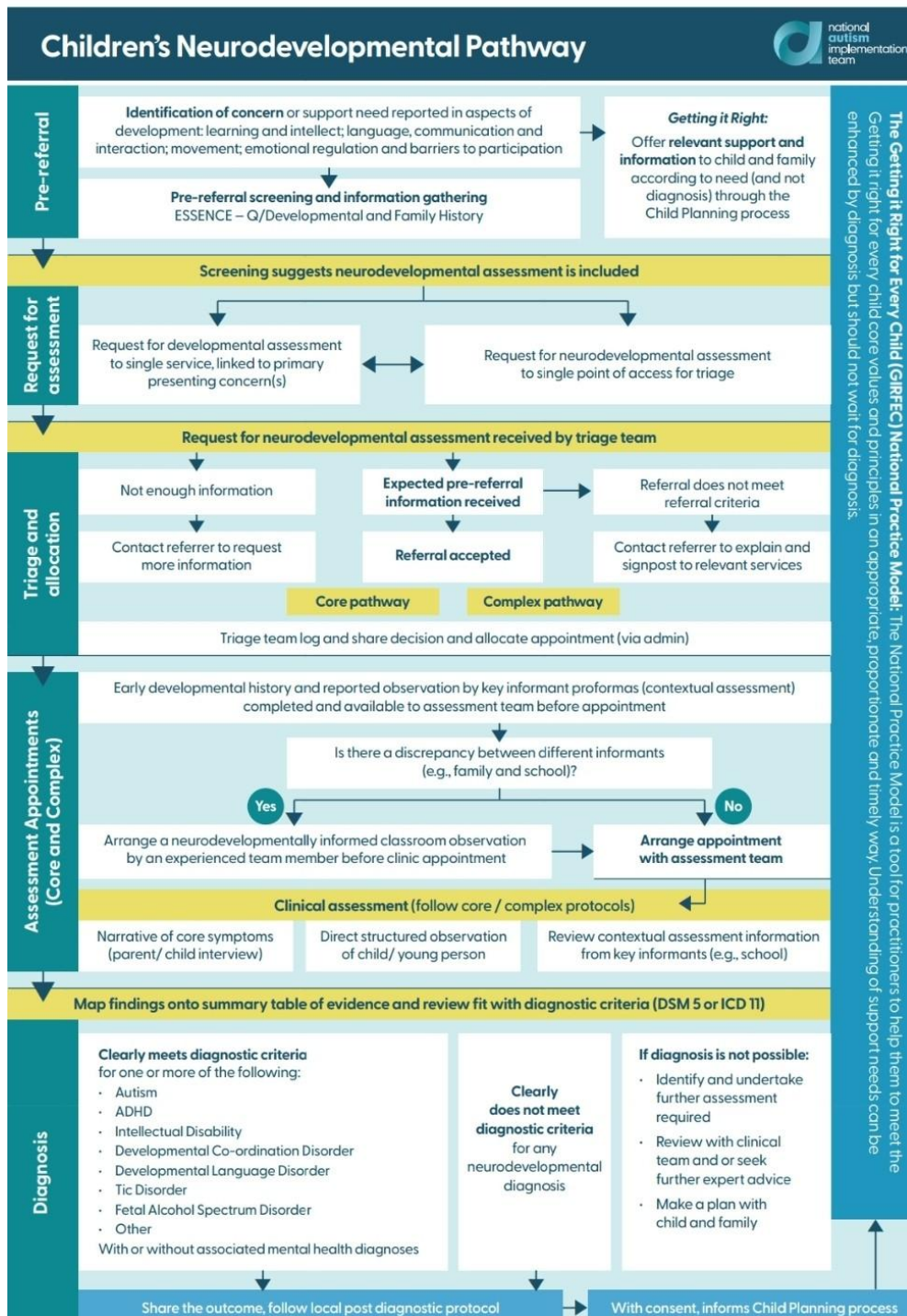
⁸ ‘Assessment, Diagnosis, and Interventions for Autism Spectrum Disorders: A National Clinical Guideline’ (n 4). 4.2.1

⁹ *ibid.* 4.2.3 para

¹⁰ ‘Children’s Neurodevelopmental Pathway Practice Framework : A workbook for assessment, diagnosis and planning’ (2024) National Autism Implementation Team

understanding of the child. A multi-disciplinary ‘expert’ team review a series of submitted screening documentation within the referral to determine the level of intensity of assessment needed. It also sets specific timeframes for how long assessments at each level are expected to be completed within.

Figure 5: NAIT Children’s Neurodevelopmental Pathway diagram



Australia

The other region cited as evidence of the success of tiered assessments in Australia. “The National Guideline for the assessment and diagnosis of autism in Australia” was created in 2018 and updated in 2023.¹¹ The foundational stage of the Australian model requires a “comprehensive needs assessment that comprises of an assessment of functioning and a medical evaluation”.¹² The comprehensive needs assessment (CNA) is a “core component of all assessments”(emphasis added) designed to ensure that if a diagnostic assessment is carried out then it is informed by a holistic understanding of the persons strengths and potential medical challenges.¹³ The tiered approach in the context of the Australian model is only introduced once the comprehensive needs assessment has been carried out.¹⁴ The tiered model will only then focus on the clarity of presentation and the level of diagnostic confidence.¹⁵ In addition to the comprehensive needs assessment required by the Australian model, its lead practitioner diagnostic level still requires input from at least one other practitioner.¹⁶ This again is in stark contrast to the protocol which not only bypasses entirely the comprehensive needs assessment, but also the need for input from another practitioner for tier one assessments.

¹¹ ‘National Guideline for the Assessment and Diagnosis of Autism.’

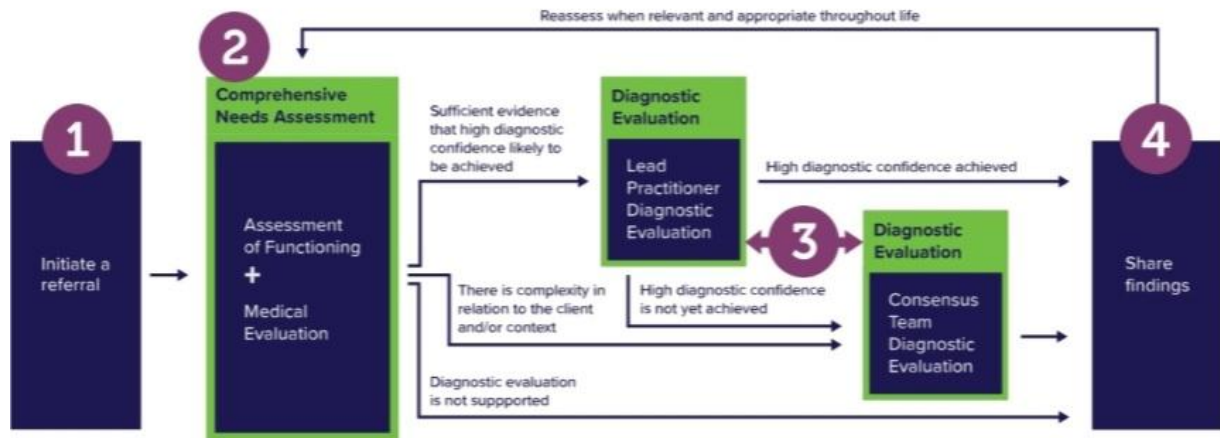
¹² *ibid.* 64 para 3

¹³ *ibid.* 64 para 3

¹⁴ *ibid.*

¹⁵ *ibid.*

¹⁶ *ibid.* 107 para 1 & recommendation 56



Ireland

The Scottish and Australian models are not only substantially different to the Irish model but they both provide a robust evidentiary basis. The HSE National framework for developing policies, procedures, protocols, and guidelines highlights the evidentiary disparity whereby the Australian and Scottish models are both compliant with the framework but our own fails to meet the standards, that we ourselves have set.

The HSE framework requires

“ Systematic methods used to search for evidence are documented (for PPPGs which are adapted/ adopted from international guidance, their methodology is appraised and documented).

- *Critical appraisal/analysis of evidence using validated tools is documented (the strengths, limitations, and methodological quality of the body of evidence are clearly described).*
- *The health benefits, side effects and risks have been considered and documented in formulating the PPPG.”*

Not one of these steps is included within the Irish document and where a summary of evidence is mentioned it is followed by ‘not applicable’.¹⁷ In order to provide informed consent to take part in an assessment under the protocol, parents and autistic adults deserve

¹⁷ ‘Autism Assessment and Intervention Pathways Protocol FINAL.’ 2.5

high quality, balanced information which offers clear pros and cons. The framework very clearly mandates the use of systematic search and appraisal of evidence, the Irish model explicitly states it ‘did not carry out or commission any additional research’ and instead relied entirely on historical HSE documents and a 2018 discussion paper.¹⁸

As an organisation, our stance is that the only thing that is ‘discriminatory and damaging’ is saying that some people do not need evidence-based assessment. ‘Extensive stakeholder engagement’ that doesn’t involve children is not good enough, children have a legal and ethical right to participate. International best practice develops for a reason and if we wish to claim superiority in Ireland then we quite simply must have the evidence to back that up. This new protocol is the latest in a protracted line of government attempts to use the language of rights and neuro affirmative practice to enact neo liberal policies. We will not accept this race to the bottom.

	Australian guideline (2023)	Scotland: SIGN 145 (2016) and NAIT (2023)	Ireland (2026)
Primary Method	GRADE framework ¹⁹	SIGN methodology ²⁰	Consensus ²¹
Evidence quality	Umbrella review (2018-2022)	Systematic review (2006-2014)	Review of prior own reports ²²
Validation	Approval of the National health and medical research council (NHMRC) ²³	NICE, accredited process ²⁴	Independent pilot ²⁵
Compliance with HSE own guidelines	High level of compliance	Compliant	Non-compliant

¹⁸ *ibid.* 1.4

¹⁹ Schünemann, H., Brożek, J., Guyatt, G., & Oxman, A. (Eds.). (2013). *GRADE handbook for grading quality of evidence and strength of recommendations*. The GRADE Working Group. guidelinedevelopment.org

²⁰ Scottish Intercollegiate Guidelines Network. (2019). *A guideline developer's handbook* (SIGN publication no. 50).

²¹ ‘Autism Assessment and Intervention Pathways Protocol FINAL’ (n 17). 2.4

²² *ibid.* 1.4

²³ Approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 8 December 2023 under section 14A of the National Health and Medical Research Council Act 1992.

²⁴ National Institute for health and Care Excellence no longer accredit individual guidelines, but the process used was to the highest standard at the time of its creation.

²⁵ Van 'T Hof and others, ‘Evaluation of the Implementation of the Autism Assessment & Pathways Protocol – Phase 2’ (2021) 25 *Autism* 862

