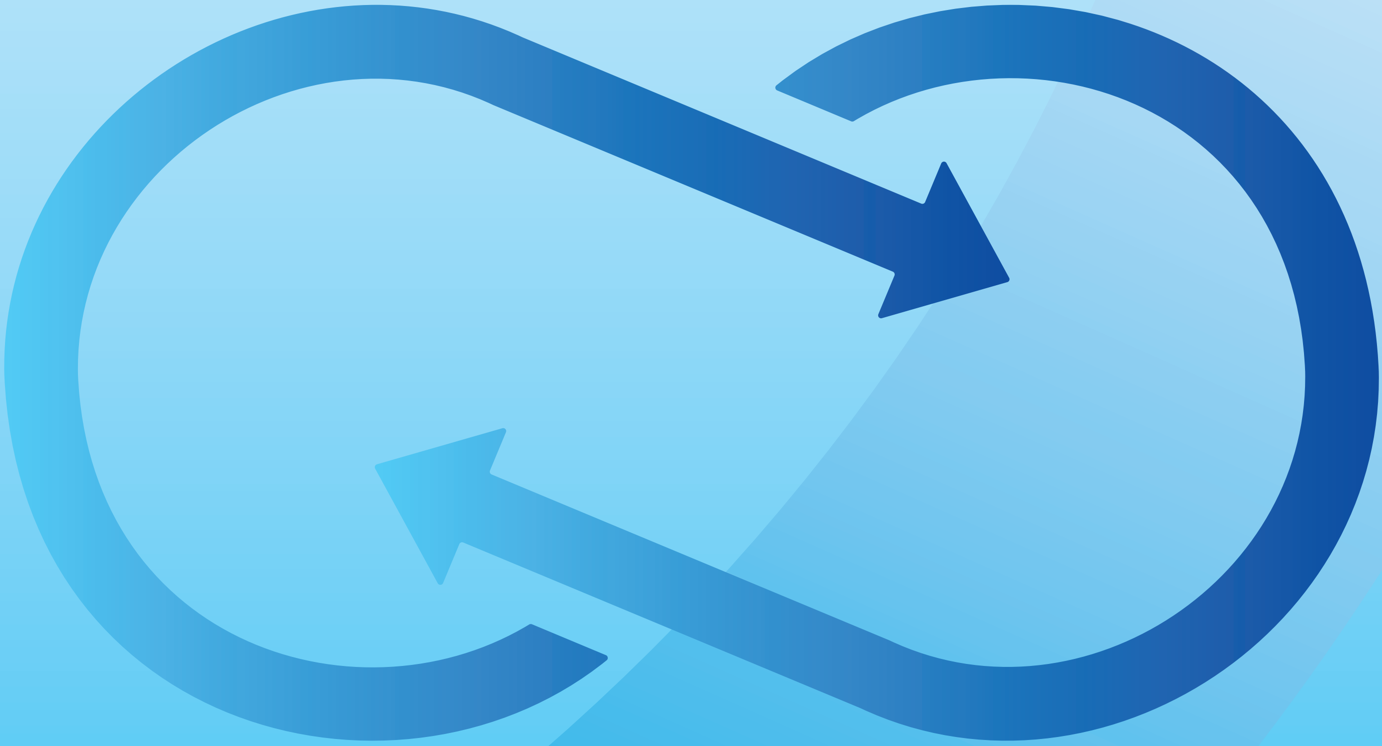
# Autism Assessment and Intervention Pathways Protocol



National Policy ☐ National Procedure ☐ National Protocol ☑

National Guideline ☐ National Clinical Guideline ☐

# HSE National Protocol for Autism Assessment and Intervention Pathways

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| The protocol is designed to assist clinicians in assessing for Autism in the Irish Health Services, including those provided by the HSE, Section 38 and 39 organisations funded by the HSE and private providers, where appropriate. |
| **Description:** |
| The protocol matches the intensity of assessment to the complexity of the presentation, as decided by the assessing clinicians. It is a pathway specifically for autism assessment, and this includes differential assessment and diagnosis, as required; as well as the development of a formulation to provide clearer understanding of the person's lived experience, and the services and supports they require. |

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# Foreword

## Chief Executive Officer

I am delighted to publish the Autism Assessment and Intervention Pathways Protocol which has been developed following a 2017 review of Irish health services for Autistic people.

The Autism Protocol will operate across disability, primary care and mental health services. It will support integrated ways of working across these services and is part of the evolution of policies linked to increased integrated working as exemplified by the Integrated Healthcare Areas (IHAs) and the Single Point of Access (SPoA).

The development of this protocol involved comprehensive consultation with a broad range of stakeholders, which reaffirms the collective ambition of all to have a protocol which will support service delivery and improve the quality and equity of services to people with autism. Arising from the consultation that included substantial input from the public, a tiered approach to autism assessment was mandated, a key characteristic of the protocol. It has been developed by a sub-committee of the Service Improvement Programme Board for the Autistic Community. The Committee, drawing from its multidisciplinary and lived experience inputs, developed a very welcome neuroaffirmative approach to assessment that seeks to identify a person's strengths, along with their differences and difficulties, and any associated service and support needs. The protocol recognises that assessment should be an ongoing part of their service user experience and not something that should happen only once in a person's life. Another welcome feature of the Autism Protocol is the emphasis placed on the value of a clinical formulation which will help people with autism understand better how different aspects of their lived experience and circumstances may interact and change over time.

The Protocol defines procedures that are considered necessary to provide an efficient, safe and accurate assessment of autism, which also requires clinicians to confirm that they have the necessary training and competencies to undertake autism assessment.

The Protocol applies to all assessments of Autism and this extends to privately-funded assessments where there is an intent to present the assessment to support access to HSE or HSE-funded services.

Finally, I would like to take this opportunity to acknowledge and thank the commitment of the Service Improvement Programme Board for the Autistic Community in supporting the development of this work which I know will add enormously to strengthening our processes and services for Autistic people.

**Anne O'Connor**
CEO
Health Service Executive (HSE)

# Foreword

The Autism Assessment and Intervention Pathways Protocol represents a significant milestone in the development of services for Autistic people. For the first time, we will have a standardised assessment process across disability, primary care and mental health services. The Autism Protocol adopts a tiered approach to assessment, aligning the intensity of assessment to the clarity of presentation. It will contribute to promoting more timely, coherent, and effective assessments for autistic people.

The process of developing the framework has taken 5 years, strengthen by a rigorous, inclusive and participative process. This has included multiple meetings of the Autism Assessment and Intervention Pathways Protocol Working Group, benefiting from multidisciplinary, managerial and lived experience expertise. Earlier drafts of the Autism Protocol were piloted across different sites, with more than 240 assessments being completed. The evaluation of pilot sites was designed and independently evaluated by the Centre for Effective Services, which was itself advised by an independent Expert Advisory Group, also comprised of lived experience, clinical and academic expertise.

The experience of piloting and the independent evaluation presented important learning incorporated into subsequent drafts, which were presented through workshops and webinars to civil society organisations, to the nominees of professional bodies and to HSE and HSE-funded service planners and managers. The Service Improvement Programme Board for the Autistic Community – which also has lived experience, multidisciplinary and senior management expertise – provided further comment, insight and support throughout the process. Following detailed review by the HSE Clinical Forum the Autism Protocol has been approved as being clinically appropriate and it will now become the required approach to undertaking Autism assessments throughout HSE and HSE-funded services.

As the Autism Protocol becomes widely used there will of course be more learnings and we have committed to an annual review conference to which all relevant stakeholders will be invited. We have also established an Autism Assessment and Intervention Pathways Protocol Implementation Consultation Group, which again has lived experience expertise as well as nominees from each of the professional bodies involved in autism assessment. Additionally, we will be undertaking implementation planning workshops in each Regional Health Area.

I would like to thank the hundreds of people who have participated in developing this Protocol - the members of the above committees, those who attended workshops and webinars, and those service users and service providers who have taken part in piloting of the Autism Protocol. I would particularly like to thank Prof Mac MacLachlan (Maynooth University), the independent chair of the above working groups; Sharon Barry, Project Manager; and Anne Tighe, Business Manager; for their enduring commitment to this important work.

The Autism Assessment and Intervention Pathways Protocol will make an important contribution to strengthening integration across our services. It will enhance person-centred, neuroaffrimative, and rights-based practice. Along with new resources to support In-Reach teams for autism assessment the Autism Protocol can provide safer and better informed access to the services and supports that Autistic people may require.

It has been a privilege to be a part of this journey, and I am very proud of the work we have collectively done. Complimentary to this work has also been the development of Autism Awareness Training, available on the HSeLanD, which I would encourage all staff to complete.

**John Fitzmaurice**

Chair, Service Improvement Programme Board for the Autistic Community

# Contents

# Outline of Autism Assessment & Intervention Pathways Protocol

# Outline of Autism Assessment & Intervention Pathways Protocol

## Background

Minister for Health Simon Harris commissioned a review of Irish health services for individuals with Autism. Informed by nearly 400 submissions, over 200 of which came from parents and carers, the resultant (cross-divisional) HSE report made thirty-six recommendations (2017). These included timely access to assessment by shifting away from highly intensive Autism assessments towards a tiered approach to assessing Autism (see also McNally et al, 2020). It also recommended that assessments can take place in primary care, with the facility to access more specialist services dependent on presentation. More specifically, the assessment-related recommendations were:

1. Introduce an assessment pathway where all referrals to primary care services with query Autism are assessed using the protocol or onward referral to secondary care services.
2. Introduce a tiered approach to assessment in secondary care services (such as Children's Disability Network Teams (CDNTs) and Child and Adolescent Mental Health Services (CAMHS) or Primary Care Autism Assessment Teams (PCAATs) in primary care, whereby the required intensity of an assessment process is determined by the complexity of presenting experiences and the clinicians' judgement of these.
3. For co-occurring presentations (e.g. query Autism with moderate-to-severe mental health issues) different secondary care services (for example CDNT's, CAMHS) will undertake assessments in consultation with each other and, if possible, in unison.
4. Formulate evidence-based guidelines for how privately sourced Autism assessments are conducted, evaluate whether these are adhered to and whether such outsourcing provides value for money.

## Scope

The scope of this document outlines good practices for Autism assessment across the lifespan as informed by practice guidelines, and proposes a spectrum of service for those individuals who may require an assessment for Autism.

### *In scope*

- Agreement on a standardised assessment and intervention approach for those with suspected Autism, based on the research carried out:
- (i) Review of assessment instruments and models in use

  (ii) HSE Autism Spectrum Disorder Diagnostic Protocol – see discussion paper and related literature
- Design and development of training programme for tools/resources included in the standardised assessment approach.
- Agreement on a tiered approach to assessment
- The design of a summary process map with service user outcomes, outline of core service offerings and most relevant good practice options for consideration by the programme board.
- Piloting of the proposed approach in select services

### *Out of scope*

- It does not provide an overview of the potential role of each service professional in the assessment process.
- Communication and awareness-raising will be carried out as part of the Autism awareness project
- Additional research is not part of this project.

### Target audience

This protocol is designed to assist clinicians in assessing for Autism in the Irish health services, including those provided by the HSE, Section 38 and 39 organisations funded by the HSE and private providers, where appropriate. The Assessment and Pathways Working Group has consulted widely with stakeholders in the design and formulation stage of this project. This is particularly important in the context of the implementation of a tiered approach to assessment. Membership included three lived experience/parent representatives, representatives of the disciplines most commonly involved in the assessment of Autism working in primary care, disability and mental health services. It also included senior operational managers and heads of service from those care groups, as well as children's teams and representation which included roles such as occupational therapy, psychology, public health nursing, social work and speech and language therapy.

Additional input was sought and provided for review of the protocol through the NCAGL Mental Health, executive clinical directors, and clinical lead for paediatrics – with specific input also provided by psychiatry, community medical doctors and educational psychologists sourced through the National Educational Psychology Service (NEPS) office.

Appendix 2 outlines the membership of the working group.

## Objectives

1. To develop an operational model for a progressive approach to Autism assessment and intervention.
2. To identify clear and functioning pathways to services with a consistent core service offering.
3. To develop specific training materials to support the agreed standardised assessment approach.
4. To develop processes, procedures or guidelines where required to underpin implementation.
5. To pilot the proposed approach.
6. To design and develop an implementation plan.

## Outcomes

- There will be a standardised assessment approach agreed for all services involved in the assessment and identification of Autism.
- Training will be available for all staff involved in the assessment and identification of those with suspected Autism.
- Pathways will be available to guide individuals with suspected Autism to early intervention/services with reference to the *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (2019)* – hereafter referred to as the 'National Access Policy' or NAP.
- All those with suspected Autism will be assessed using a standardised approach.
- All staff dealing with the assessment of those with suspected Autism will be familiar with or trained in the methods/tools/ resources included in the standardised assessment approach.
- Waiting times for those awaiting assessment will be similar in different areas and therefore reduced in many cases.
- Assessment and intervention will be clear.
- Equitable access to assessment for all will be achieved regardless of location.

# The purpose of the protocol

As part of the implementation process, the Service Improvement Programme Board for the Autistic Community sponsored the establishment of an operational framework working group with responsibility for making specific recommendations relating to Autism assessment and intervention pathways, piloting and capacity-building for frontline professionals. The purpose of this document is concerned primarily with pathways to assessment and assessment procedures and subsequent pathways to interventions. It does not detail interventions as this is the topic of a separate piece of work to be conducted.

## The use of identity-first language

In developing this protocol we recognise that terminology in the context of disability is frequently contested, reflecting different historical conventions, disciplinary perspectives and socio-political systems. In the first instance, we emphasise the importance of clinicians respecting the terminology preferences of individuals, and their families, when undergoing assessment. This document uses ‘identity-first’ language. This is in order to honour the preference shift which has been well documented across Autism self-advocacy globally in recent years. We also recognise that many people associate ‘identity-first’ language with Autism as a form of neurodiversity and a positive identity. However, in using ‘identity-first’ language we are not suggesting that people should only, or primarily, identify as, or be identified by others through, their experience of disability. We also recognise that many disabled people/people with disability prefer to primarily identify themselves in ways that do not refer to disability at all. We also recognise that internationally, person-first language is preferred in many countries and by many international organisations. However, some other English-speaking countries also use identity-first language.

# Glossary of terms

***AMHS*** – Adult Mental Health Service (AMHS) is a multidisciplinary service that provides assessment and interventions for people who are 18 years or older who are experiencing moderate to severe mental health difficulties.

***Assessment*** – An assessment is used to determine if someone is Autistic, while establishing their needs and the services and supports that may benefit them. It should therefore allow the clinician to formulate an understanding of the presenting needs, with an option to include a formal diagnosis (DSM or ICD). Where this is done, the assessment should still be needs-led rather than diagnostically-focussed.

***Assessment intensity*** – Refers to the depth and breadth of assessment components required to understand a person's presentation, and to make recommendations for services and supports, where appropriate. Where there is reason to believe that the likely required intensity of assessment is low, or unknown, an Autism Assessment (Tier 1) may be undertaken in the service where Autistic traits are first identified. More complex assessments (Tier 2 or 3) need to be conducted in services where those assessment skills exist, most commonly, in Disability or Primary Care Services.

***Autistic Traits/sub clinical traits*** – Difficulties or differences that may be on the Autism Spectrum and may commonly occur in the general population but which are not necessarily associated with difficulties or distress.

***CAMHS*** – The Child and Adolescent Mental Health Service (CAMHS) is a multidisciplinary service that provides assessment and interventions for young people and their families who are experiencing moderate to severe mental health difficulties.

***CDNT*** – Children's Disability Network Team are competency-led teams usually comprising15-40 practitioners, from a range of different profession, providing interdisciplinary supports and services to children aged 0–18 years who present with needs arising from a disability and identified as complex according to the National Access Policy.

***Clarity of presentation*** – The relative ease or difficulty in understanding a person's presentation of their strengths and difficulties

***Complex needs*** – Complex needs refer to one or more difficulties which contribute to a range of significant functional difficulties that usually require the services and support of a specialist interdisciplinary disability team.

***Complexity of needs*** – The types of services and supports required to address needs and build on strengths and/or differences.

***Diagnosis*** – The ICD 11 (or DSM 5) category to which the person's presentation can be ascribed (where possible). In the case of Autism this is descriptive rather than explanatory.

***Formulation*** – A narrative indicating the understanding of the relationship between presenting differences or difficulties and predisposing, protective, precipitating and perpetuating factors (5 Ps).

***Formulation/re-formulation*** – Formulation is a joint effort between the person and the clinician to summarise the information obtained from a clinical assessment, based on the causes and nature of presenting problems and their maintaining factors, along with the person's history, resulting in a framework for developing the most suitable services and supports for that person at that time.

***Frank presentation*** – Presentations that are obvious/clear/classic, and are essentially relatively easy to recognise.

***Individual Family Service Plan*** – is an individualised plan for how the child and family can best be supported. It is developed by collaborative goal settings between family members and practitioners, and it primarily used in CDNTs.

***Interdisciplinary*** – Refers to people from different disciplines working together to integrate and synthesise their different disciplinary knowledge, skills and perspectives, to focus on the service needs of the person and their family (where appropriate).

***Intradisciplinary*** – Refers to working within only one disciplinary perspective.

***In reach model*** – Where services and supports are delivered quicker and aligned to their usual service pathway – clinicians work together to look after a person's health and wellbeing in one place, or primarily through one team rather than the person travelling to various health centres or different health or social services teams. An example would be where a mental health practitioner provided services to a person who is primarily receiving services from a disability team, and in doing so the mental health practitioner brings their service to the team and the person in the usual context in which they receive a disability service.

***Intervention*** – An intervention is defined by the World Health Organisation as an act performed for, with or on behalf of a person or population, whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions. In this protocol, while assessment is recognised as one type of intervention, the term intervention is used to describe services and supports delivered following a period of assessment. It is also used to describe services or supports for persons with disabilities, whose disabilities may not be considered to be health conditions per se.

***Layered services*** – Services which may be provided alongside, in parallel on ‘on top’ of each other, rather than separately , or in a ‘stepped-care’ way, where a person must step up or step down to one type of service or another.

***Masking*** – The use of specific behavioural and cognitive strategies by Autistic people to adapt to or cope within the predominately non-Autistic social world, and in doing so to make their Autistic experience less obvious or identifiable to others.

***MHID*** – Mental Health Services for People with Intellectual Disability

***MHID team*** – An MHID team is a specialist adult mental health service specifically for adults with an intellectual disability. It is a multi-disciplinary team, with clinicians who have the appropriate training and experience to assess and help this population, taking into account their specific needs. An MHID service is a distinct and separate service but aims to complement and be closely linked to, the services provided by primary care, disability and community mental health teams.

***Moderate to severe mental health difficulty*** – A moderate to severe mental health difficulty has a significant impact on your daily life. It stops you from doing things you want to do and need to do. For example, seeing friends and going to school, in the case of younger people (CAMHS), or seeing friends and going to work in the case of older people (AMHS).

***Multidisciplinary*** – Refers to people from different disciplines working together in parallel, applying their different disciplinary skills and perspectives.

***Neuroaffirmative*** – Considering different presentations of neurodiversity as positive and valued variations of human diversity in general. Avoiding deficit, disease or disorder related terminology which diminishes the value of human differences.

***Neurodiversity*** – The range of differences in individual brain function and behavioural traits regarded as part of normal variation in the human population

***Neurodivergent*** – A term to describe people whose brains develop or work differently from what is considered typical.

***Neuro-typical*** – A term used to describe individuals of typical developmental, intellectual and cognitive abilities. In other words, it is not used to describe individuals who have Autism or another developmental difference or delay. However, this terminology is also contested, as every person’s brain is structurally and functionally distinct, and therefore it is problematic to suggest that some people are typical, while others are not.

***Pathway*** – The service providing some form of assessment through a range of options within primary care, disability or mental health services.

***Primary Care*** – Primary Care is all of the health or social care services that you can find in your community, outside of hospital. It includes GPs, public health nurses, primary care psychology and a range of other services within community health networks, including physiotherapy, occupational therapy, speech and language therapy, social work, dietetics and other disciplines.

***Specific services and supports*** – Meaning very intensive and individualised services and supports to address very specific needs. These will be required by and of benefit to relatively few people.

***Strength-based approach*** – A strengths-based approach to care, support, services and inclusion, which identifies and builds on the positive skills and abilities that people have, on what they can do, rather than focusing on (deficits) what they cannot do.

***Targeted services and supports*** – These resources address specific needs shared among some people with disability. They will be required by and of benefit to only some people.

***Tier*** – The level of intensity of assessment

***Universal services and supports*** – These services and supports may benefit many people, are not necessarily specific to types of disability or need and may be preventative, reducing the likelihood of complex needs developing. These resources should be of benefit to many people.

# Overview of approach

The protocol is focused on Autism as mandated in a 2017 Irish Government report that arose from extensive consultation with multiple stakeholders, including over 200 submissions from people with lived experience and family members. This protocol is designed to guide practitioners through options for the assessment of persons presenting with possible Autism. It adopts a **tiered approach to assessment** as required by the 2017 report, where the intensity of assessment is aligned with the clarity of presentation – less clear presentations generally requiring more intensive assessment. The choice of which tier or tiers to use and any instruments they may wish to use is made by the practitioner, this protocol therefore reinforces the absolute autonomy of practitioners to use their clinical judgment regarding the most appropriate means of assessment.

A tiered approach to assessment also occurs in other jurisdictions (for instance, Scotland and Australia) and aligns with research evidence that some presentations of autism are easier to identify than are others. For all tiers the outcome of the assessment process should be to establish an understanding of the person's presentation. This should include a **formulation** and the **identification** of interventions, services and supports required by the individual; and where possible **determination** of the presentation in terms of a **diagnostic label**, preferably referring to ICD 11 (World Health Organisation's International Classification of Diseases 11th Revision) criteria (but DSM 5 – the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition criteria are also acceptable). ICD and DSM are the only internationally recognised standards for establishing a diagnosis. Any activities undertaken to inform this decision do so through the application of clinical judgement to interpret the information gained from the review of previous documentation, observations, interviews or use of assessment tools. This protocol also aligns with Kavanagh et al's, (2025) handbook and review of the literature and specifically their assertion that no existing guidelines state that standardised assessment tools must be used "they all state that tools may be considered as aids in gathering information but they do not state that they must be used". The use of assessment tools is entirely a decision for the practitioner given the context of the assessment and the characteristics of the person being assessed.

It is incumbent upon practitioners to ensure that those receiving a **diagnosis** do so fully informed that such a label is a description rather than an explanation of the person's experience, and that such a label is not directly related to establishing their current service needs, which require to be identified on a personal basis. Furthermore, such a label does not necessarily predict future needs or have prognostic value. However, it is also very important to acknowledge that receiving a diagnosis can be a difficult but also a very meaningful event for many people, as it may help them interpret their experiences in a new way. A diagnosis may also provide a sense of authentication, and facilitate identification with others who may share some of their experiences. For some people the provision of a diagnosis can be a powerful and empowering experience.

The protocol also recognises that tangible actions to support a person or their family should occur **as soon as possible**, including alongside and sometimes prior to assessment, and that the person's experience and outcomes from receiving services or supports may in itself help to provide a better understanding of the presentation and the sorts of things that may be helpful to the person or their family. As such, assessment is not a one-off event but a recursive and sometimes life-long process.

This protocol accords with understandings of Autism as an element of **neurodiversity** which may be experienced along a continuum, across a spectrum and which is dynamic. This means that Autism may be associated with different experiences, both daily and across the life-course. The protocol also promotes a **neuroaffrimative** approach to Autism, meaning that differences and difficulties associated with Autism often are also associated with strengths that should be valued, supported and built on, rather than described or understood as impairments, deficits, a disorder or a disease.

The protocol applies to all practitioners undertaking an assessment for autism. The protocol is to be used across the range of **pathways for assessment** that exist in primary care, disability and mental health services, whether they are services provided directly by the HSE, HSE-funded services or other services geared towards undertaking assessments to subsequently be considered by HSE provided or HSE-funded services.

This protocol does not replace a broader **developmental assessment** which may be undertaken at the discretion of practitioners, particularly in the context of likely co-occurring conditions that require additional assessment.

Safe and appropriate application of this protocol requires clinical supervision within the context of an **appropriate clinical governance structure**, as for all clinical activities (see here for more information on clinical governance).

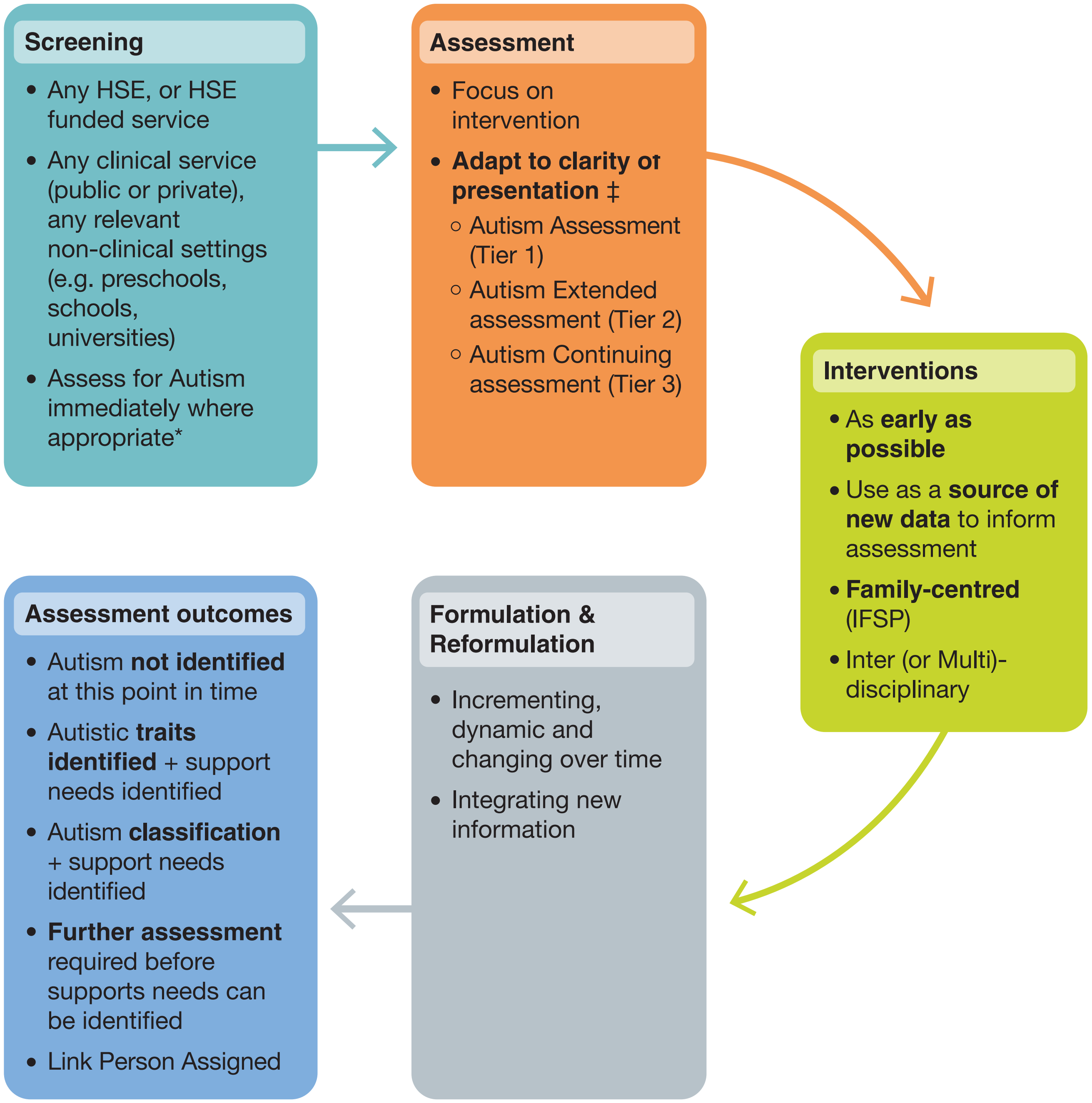
Practitioners working in Mental Health, Primary Care and Disability Services should also refer to their service specific clinical governance documents.

There are a number of **important matters not yet addressed** in this protocol document but which are the subject of on-going or work to be undertaken with professional bodies, civil society and other stakeholders. Further work is ongoing regarding supporting effective triage and development of a more detailed competency framework to compliment this protocol document. As part of a Protocol Implementation Consultation Group the professional bodies have already identified key components of a competency framework for all staff interacting with autistic people and for staff undertaking formal assessment for autism; as well as making a number of helpful suggestions to improve the Protocol itself. This document focuses on Autism assessment and the associated pathways to assessment and intervention. It does not suggest particular intervention strategies, modalities or techniques. **Autism interventions**, services and supports will be the focus of a future complementary and companion piece of work. Other important issues to be addressed relate to the use of the protocol in private practice settings, the use of digital technologies for assessment and to support clinical decision-making, services to support adults and particularly people moving from child to adult services, along with the need for ongoing training and support for the use and development of the protocol. The Service Improvement Programme for the Autistic Community has also recently completed three Autism Awareness Training modules which are now hosted on HSeLanD and are appropriate for all types (clinical and non-clinical) and levels of staff to use. This is a first step in supporting staff awareness and competence in their interactions with Autistic people.

**Implementation workshops** will be held in each of the six Regional Health Areas with a view to the integrated nature of the protocol contributing to stronger service integration across each of the regions, while also taking into account their distinct context, service strengths and configurations. This protocol also commits to an **annual review conference** (Annual Review of the Autism Assessment and Interventions Pathways Protocol) which will consider the above and other issues in consultation with the full range of stakeholders. The conference will be informed by on-going evidence collection regarding the performance of the protocol and other matters related to increasing and targeting resources in the most effective ways to enhance the full inclusion and participation of Autistic children and adults in all spheres of life.

Figure 1 presents a high-level overview of the approach to assessment and intervention taken within this protocol. Subsequent sections of this document explain the approach in more detail.

Figure 1: Assessment Process



**Screening**

- Any HSE, or HSE funded service
- Any clinical service (public or private), any relevant non-clinical settings (e.g. preschools, schools, universities)
- Assess for Autism immediately where appropriate*

**Assessment**

- Focus on intervention
- **Adapt to clarity of presentation ‡**
  - ○ Autism Assessment (Tier 1)
  - ○ Autism Extended assessment (Tier 2)
  - ○ Autism Continuing assessment (Tier 3)

**Interventions**

- As **early as possible**
- Use as a **source of new data** to inform assessment
- **Family-centred** (IFSP)
- Inter (or Multi)-disciplinary

**Formulation & Reformulation**

- Incrementing, dynamic and changing over time
- Integrating new information

**Assessment outcomes**

- Autism **not identified** at this point in time
- Autistic **traits identified** + support needs identified
- Autism **classification** + support needs identified
- **Further assessment** required before supports needs can be identified
- Link Person Assigned

*This protocol seeks to promote

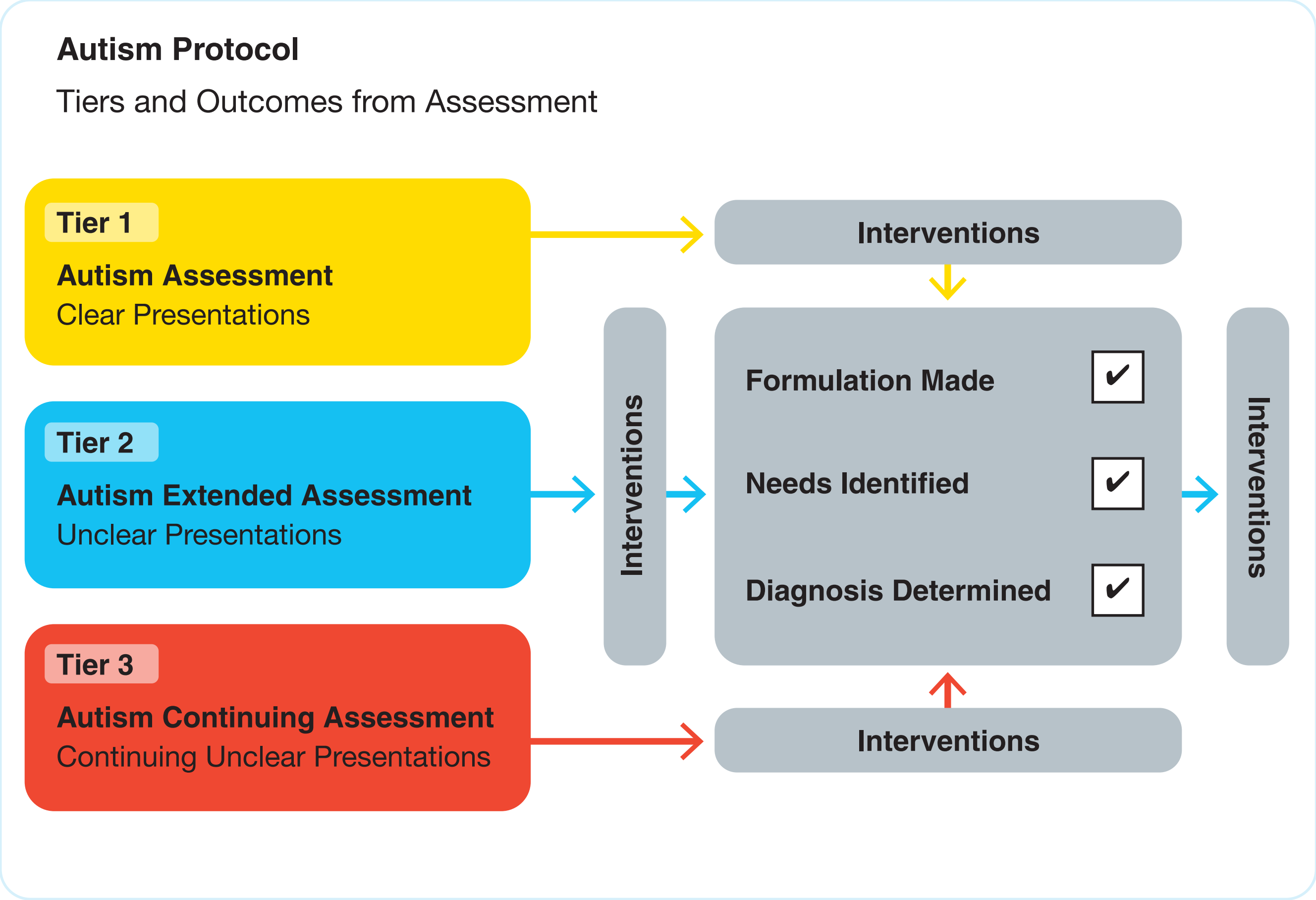
1) A Single Point of Access approach means that services are accessed where they are first encountered (either directly or following a referral from a general medical practitioner, public health nurse, school principal, educational psychologist or other persons). This may involve integrated working with teams across disability, primary care and mental health services.

2) A ‘each contact counts’ approach is where each contract results in meaningful progress in a person’s service journey, rather than being shunted from one service to another before any meaningful progress can be achieved.

## Expected outcomes from using the protocol

Formulation of presentation; identification of strengths, differences, and difficulties; diagnosis and specification of required services and supports; may all result from assessments conducted through Tier 1, 2, or 3 (see Figure 2).

Figure 2: Tiers and Outcomes from Assessment

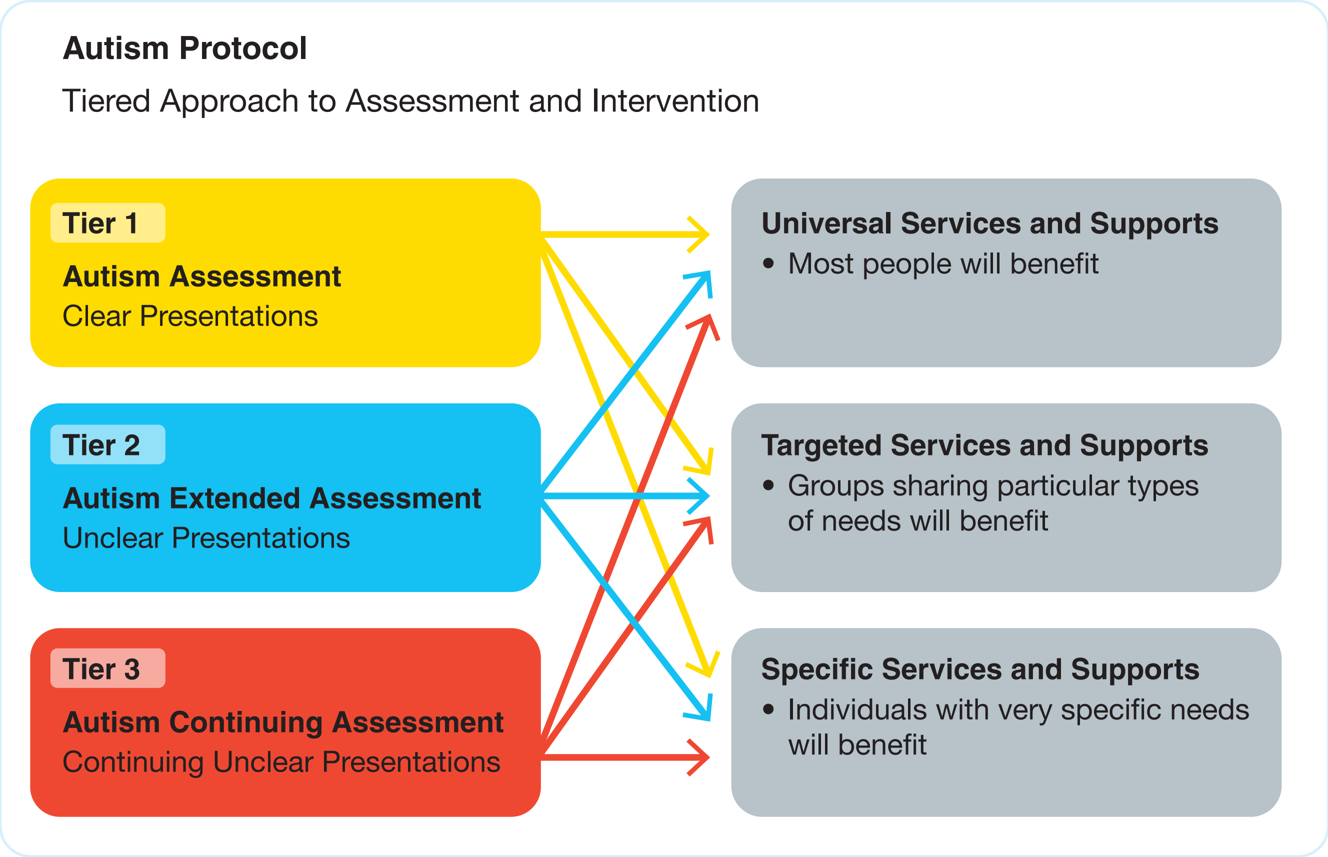


**Autism Protocol**

Tiers and Outcomes from Assessment

Each level of assessment within the protocol can result in the same range of outcomes for the person being assessed – each can recommend interventions that are universal, targeted or specific (See Figure 3)

Figure 3: Tiered Approach to Assessment and Intervention



In the event that a clear decision cannot be made following assessment at a specific tier, then the assessor can move to the next level of assessment. This should not require a new referral where the next level of assessment is taking place in the same service, but rather augmenting existing information with the additional information that will be provided at the next level of assessment. The continuum of assessment therefore matches clarity of presentation with intensity of assessment. Table 1 (Autism protocol terminology related to assessment and intervention) summarises the conceptual differences between key terms related to assessment and intervention. Of course, assessment may in itself provide a useful intervention for some people, and for others it may be more of a means to access the necessary services.

The practitioner decides if a person is suitable for a Tier 1 or a Tier 2 assessment. These may be done sequentially or the practitioner may decide that someone is most suitable to go directly to a Tier 2 assessment. Tier 3 assessments will constitute continuing assessments with a previous tier having been completed prior to this, with the Tier 3 building on – rather than repeating – the previous assessment. The person receiving a Tier 3 assessment will hopefully experience assessment as a continuing process rather than one assessment ending and another starting. Assessments across all levels should be contiguous, without breaks or delays between them.

### Table 1: Specific terminology used in this protocol (see also glossary)

| | |
|---|---|
| **1. Clarity of presentation** | The relative ease or difficulty in understanding a person's presentation of their strengths and difficulties. |
| **2. Intensity of assessment** | The depth and breadth of assessment required to understand a person's presentation. |
| **3. Tier** | The level of intensity of assessment. |
| **4. Formulation** | A narrative indicating the understanding of the relationship between presenting differences or difficulties and predisposing, protective, precipitating and perpetuating factors (5 Ps), or an alternative structured approach. |
| **5. Complexity of needs** | The types of services and supports required to address needs and build on strengths and/or differences. |
| **6. Interventions** | Practical actions to reduce difficulties, support strengths or enhance wellbeing, delivered though a range of services and supports including digital, group and individual work. |
| **7. Diagnosis** | The ICD 11 (or DSM 5) category to which the person's presentation can be ascribed (where possible). In the case of Autism this is descriptive rather than explanatory. |
| **8. Pathway** | The service providing some form of assessment through a range of options within primary care, disability or mental health services. |

# Tiered assessment for Autism

The tiered approach to assessment for autism adopted in this protocol accords with tiered approaches to assessment for autism recently adopted in other jurisdictions (such as Scotland and Australia). The intensity of assessment should be matched to the clarity of presentation, with less clear presentations requiring more information to be gathered from deeper and/or broader assessments. For each tier the procedures to be used by practitioners to fulfil assessment requirements are determined by their own clinical judgement. While the protocol provides a structure for assessment, decisions regarding any documentation to be reviewed, instruments to be used, or procedures to be followed, are clinically determined.

All assessments for Autism require the synthesis of a range of information and a determination if the pattern of that information accords with a formulation and/or diagnosis of Autism, or not. This pattern of information includes:

1) review of any existing referral or case notes to establish case history,
2) interview/discussion with the child/parent, and possibly others, or with the adult if it is an adult assessment,
3) interpretation of any results from assessment tools used,
4) observation of the person's behaviour,
5) clinical judgement to synthesis these different sources of information.

The intensity of assessment required to gather this information should be aligned with the clarity of presentation. Complex presentations may be less obvious and thus less clear and require more intensive assessment.

Tier 1 is primarily intended for the assessment of relatively clear presentations where less intensive assessment can achieve the same threshold of clinical confidence, as is the case for more intensive assessments of less clear presentations (Tiers 2 or 3). There are also two other contexts where Tier 1 assessments may be considered.

One is where the level of engagement required for meaningful use of psychometric instruments is not possible. This may, for instance, be the case for someone who is non-speaking, socially very anxious or has experienced significant trauma, is withdrawn and not trusting of the clinician. Or it could be where a child has come from a very different country, culture and/or context, has little English, and there may be no known norms for the instruments in their country of origin. In such cases the routine use of such instruments can be discriminatory, and departs from the protocol's guidelines.

For the assessment of adult autism the same types of information are required as for younger people.  However, with the status of adult-normed assessment instruments for autism being unclear, this information may have to be gained through clinical judgment, even with more complex presentations.

There is not necessarily any relationship between the clarity of presentation and the level or range of subsequent interventions, services or supports required by someone. The National Access Policy (NAP) relates to the complexity of case management, which may well be different to the clarity of presentation.

All tiers of assessment can avail of some types of intervention (such as universal supports) in parallel to the assessment process, and at times these interventions can be more targeted to presenting needs.

### What is an Autism assessment tool?

It is a standardised assessment tool that has been designed and carefully tested to provide clinical professionals with information that can inform their decision about whether somebody is autistic. While these tools provide useful information, they are not diagnostic on their own and must be interpreted by clinical professionals in the context of other relevant clinical information.

Tables 2-5 describe components involved in screening and in assessment at Tier 1, Tier 2 and Tier 3.

### Table 2: Screening

#### Screening

**Who?**

- Any child or adult suspected of having a pattern of differences or difficulties in terms of social functioning/communication/sensory experience

and

these difficulties have an undesired impact on the person.

**By Whom?**

Any service provider/referral agent (including general practitioner, public health nurse, principal teacher, educational psychologist, social worker, or others)

**Where?**

- Concerns can be identified in:
    - Any clinical service (public or private)
    - Relevant non-clinical settings (e.g. preschools, schools, universities)
- Concerns may be self-identified by an adult (or by a family member in the case of a child)

**How?**

- Concerns should be discussed with the person/family
    - Where the concern relates to a minor, a referral may be made with the consent of the family to the appropriate service in line with the National Access Policy/CAMHS Operational Guideline
    - Where the concern occurs in a clinical setting, the use of additional screening measures & team consultation may add further clarity to this discussion

**What outcomes?**

- Agreement that further assessment is not required (e.g. screening measures negative)
- Period of monitoring of concerns (with or without accompanying intervention/referrals)
- In service Autism Assessment – Tier 1 (see below box), where the service has sufficient competencies to complete this immediately
- Referral to appropriate services for Autism Assessment

## Table 3: Autism Assessment Tier 1

### Autism Assessment – Tier 1

**Who?**

- A child/adult already known to services.
- Child/Adult with clear presentation, existing SLT/OT/Paediatric assessments and/or reports.
- Those individuals who have been identified as requiring further assessment of autism.
- Those individuals for whom available psychometric procedures or norms may be inappropriate.

**Where?**

- Should be conducted in primary care or disability services.
- In Mental Health Services assessments may be conducted in the context of differential diagnosis.

**How?**

Low intensity assessment of autistic traits may include

1. **Review:** referral letter and case file notes (including previous assessments if they exist).
2. **Interview:** developmental and personal history/clinical interview with the use of assessment measures and processes that provide clear documentary evidence of personal characteristics that support formulation, diagnosis (ICD-11/DSM-5-TR) and service recommendations.
3. **Assessments:** which may include assessment tools, adapted as clinically indicated, pro-formas, other professional reports.
4. **Informal observation:** clinic, home, school, or other naturalistic setting.
5. **Clinical judgement:** specific behaviours and support needs related to social communication differences(SC), stimming, special interests or circumscribed interests, preference for routine or predictability and sensory experience across environments; consider if intellectual, communication, health difficulties, or any mental health difficulties may play a role. This should be clearly evidenced in the report.

**Timescale Recommendation for Tier 1 Assessment:** Many assessments will be completed in less than 10 hours, but some may take longer.

**What outcomes?**

- Autism out-ruled (with support pathway for any concerns identified).
- Identification of autistic traits and:
    - referral to or provision of appropriate *intervention/supports* for 3-9 months or until such time as adequate evidence/observation can inform a classification decision, if required
    - recommendation for a period of *monitoring, development, or further intervention* at which time assessment need can be reviewed
    - referral for *more detailed assessment* (immediately or following an inconclusive period of intervention). Continues to receive support from the current service provider until they are picked up by the new service provider.
- Autism confirmed: formulation made, needs identified and diagnosis determined; with recommended interventions specified.

## Table 4: Autism Extended Assessment Tier 2

### Autism Extended Assessment – Tier 2

**Who?**

- Child/Adult whose presentation is not clear and may be difficult to categorise or assess (e.g. due to differential classification questions, marginal traits, lack of clear evidence).

  Child/Adult who has undergone a period of monitoring or intervention which has not resulted in clear relevant evidence.

**Where?**

- Should be conducted in primary care or disability services.
- In Mental Health Services assessments may be conducted in the context of differential diagnosis.

**How?**†

1. **Prior Autism Assessment – Tier 1** (or similar activities undertaken if directly entered into a Tier 2 assessment).

AND:

2. **Formal observation:** e.g. ADOS, or similar standardised observation schedule.
3. **Formal clinical interview:** e.g. ADI-R, or similar standardised interview schedule.
4. **Clinical Judgement.**

**Timescale Recommendation for Tier 2 Assessment:** Many assessments will be completed in an additional 10 hours (where a Tier 1 assessment has already been done). If Tier 2 is directly accessed then assessments are expected to take longer than 10 hours.

**What outcomes?**

- Autism out-ruled (with support pathway for any concerns identified).
- Recommendation for further review following a period of intervention, development, or monitoring.
- Presentation unclear (further assessment recommended).
- Autism confirmed: formulation made, needs identified and diagnosis determined; with recommended interventions specified.

† Any elements of assessment previously conducted under Tier 1 do not need to be repeated/updated unless there is an identified clinical reason. Assessments conducted by private providers can be accepted subject to them complying with the approach outlined in this protocol.

## Table 5: Autism Continuing Assessment Tier 3

### Autism Continuing Assessment – Tier 3

**Who?**

- Child/Adult whose presentation is not understood following an Extended Assessment, due to a possible confounding or complicating influence requiring additional assessment.

**Where?**

- Should be conducted in primary care or disability services.
- In Mental Health Services assessments may be conducted in the context of differential diagnosis.

**How?**[†]

1. **As per Autism Extended Assessment – Tier 2.**

AND:

2. Additional specific or generalised standardised measures to determine or exclude the role of additional factors.
3. Possible assessments by clinicians not routinely involved in the assessment team.
4. Clinical Judgement.

**Timescale Recommendation for Tier 3 Assessment:** Unspecified

**What outcomes?**

- Autism out-ruled (with support pathway for any identified concerns).
- Recommendation for further review following a period of intervention, development, or monitoring.
- Autism confirmed: formulation made, needs identified and diagnosis determined; with recommended interventions specified.

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[*] As above in Figure 3.

[†] Any of elements of the subsequent assessment previously conducted under Tier 1 or Tier 2do not need to be repeated/updated unless there is an identified clinical reason. Assessments conducted by private providers can be accepted subject to them complying with the approach outlined in this protocol.

## Tier 1: Autism Assessment

These assessments should be considered default assessments for individuals with relatively clear presentations of Autism and/or who are already well known to services. Sometimes formal standardised observations or interviews will not be required.

If a child has had numerous previous assessments and the referral letter, file, developmental history and clinical interview and assessments are all in keeping with autism and it is possible to clearly document this, then there is no need to repeat these assessments. The person making this decision must be appropriately experienced and knowledgeable about autism assessments, including specific training and experience in conducting standardised assessments.

While standardised assessment instruments may be used at the discretion of the clinician in Tier 1 assessments, as noted, sometimes their use may not be required. In such cases we do however require the assessment to be able to achieve the same threshold of confidence regarding formulation, diagnosis and recommendations for services. Table 11 indicates the essential components that must be covered and which may be available from previous assessments, and which in the clinician(s) judgement are still relevant to the person’s current presentation.

Many assessments are likely to be completed within ten hours of clinical contact, report writing and feedback time, across the disciplines involved. Clinicians undertaking these assessments alone, or those with greater experience, are likely to complete these assessments in less time, but sometimes they may also take longer.

The need for a Tier 1 assessment may emerge in the context of differential diagnosis, where a co-occurring mental health condition (such as moderate to severe anxiety or depression) may be the primary reason for referral to mental health services, but where it is prudent to also consider the possibility of Autism. A differential diagnosis is unlikely to fulfill the requirements of an autism assessment at Tier 1, 2 or 3. Where this is the case an assessment at the appropriate Tier should also be conducted. A differential diagnosis does not fulfill the requirements for an autism assessment under this protocol.

Following referral for services and supports which seek to address differences/difficulties/needs arising from or associated with Autism, the team providing these interventions should continually reformulate their understanding of the person, based on the impact of the actions taken. Such reformulation may support, refine or indeed question the categorisation/diagnosis of Autism.

Any assessment is a series of snapshots and more information is provided through the response to interventions over time. An assessment from any tier does not represent a definitive end of assessment process, but rather the beginning of engagement with services which prioritise intervention, allowing such interventions to further inform the understanding of the person’s difficulties and/or needs, and if necessary, revise the formulation and/or diagnosis.

(See Appendix 13 for information on ‘Frank’ (or clear) presentations.)

## Tier 2: Autism Extended Assessment

These assessments are indicated where the presentation of Autism is less clear and may be related to other conditions associated with neurodiversity and/or other types of disability and/or mental health problems. These presentations require more intensive assessment, incorporating structured standardised assessments (such as the ADOS for observation and the ADI-R for interviews).

Tier 2 assessments will embrace relevant developmental assessment and corroborating information, as well as sensory and language assessment as judged necessary by clinicians. For all Tiers, clinicians should seek liaison with referrers/others involved in providing service(s), if needed.

When the use of standardised psychometric or other assessment instruments is involved, clinicians should be cognisant of the groups on which these instruments have been normed and the legitimacy with which standardised scores can be used to interpret an individual’s performance on the instrument. Norms for autism are generally less representative of females, older people, people who are masking, and those with co-occurring conditions. The interpretation of a person’s performance may also be more difficult if they are anxious or traumatised, people who may be non-speaking, if they do not have English as their first language, or speak limited English in the case of recent immigrants, refugees or asylum seekers. As noted by Bishop and Lord (2023, p. 836) “There are many situations in which the use of any given tool might not be possible. As such, requiring the use of specific tools, without exception, is discriminatory and damaging’.Clinicians should consider any reasonable accommodations that may be provided to support assessments, and the Protocol’s Pro-Forma reporting form provides a box to indicate this.

(See also Appendix 14 for information on masking - or camouflaging - which can affect the viability of psychometric instruments and provide assessment challenges to clinicians.)

These Tier 2 assessments will usually involve several disciplines and are likely to be completed within twenty hours of clinical contact, report-writing time and feedback time, across all the disciplines involved, including Tier 1 assessment time. However, assessment may take less or more time than this, depending both on the individual being assessed and on the experience of the team undertaking the assessment.

## Tier 3: Autism Continuing Assessment

Autism assessment may take place in the first instance at either Tier 1, or may commence with Tier 2, with the appropriate level being determined by the clarity of presentation. Assessments may also move from Tier 1 to Tier 2.

Tier 3 assessments only occur when an assessment has been undertaken at a lower tier, and usually Tier 2. Tier 3 will therefore always constitute continuing assessment and will often include neuropsychological or cognitive assessment, or other types of assessments carried out by disciplines that are not routinely members of the assessment team.

The hours of clinical contact, report writing and feedback time, across the disciplines involved, may vary considerably across cases and it is not possible to give an expected time frame.

Occasionally after completion of a Tier 3 assessment it may still not be clear if a person is autistic, or not. This may be especially likely to happen in the context of co-occurring early trauma, intellectual disability or specific cognitive difficulties. A team review of the assessment to date should take place. Such team members should be highly skilled in autism assessment and complex presentations. In some cases, it may be deemed necessary to pause the autism assessment. The team working with the individual should provide further supports or interventions based on the understanding of the person's needs to date (e.g. trauma informed psychotherapy or occupational therapy). Information gathered may be helpful in clarifying formulation, diagnosis and further service recommendations. At this time, the team providing the core service must be involved in the review of the evidence, along with the autism assessment team (if such a team has been involved), and it may be possible to decide whether the service user is autistic and to develop a formulation. If not, further services or supports should be provided as clinically indicated, as per previous steps.

It is also recognised that continuing assessment may not bring greater clarity to understanding unclear presentations, and that identifying helpful interventions, services and supports may be more important than a definitive formulation and/or diagnosis. How a person responds to particular interventions, services or supports may also provide very helpful information for establishing a more appropriate formulation or diagnosis at a later stage.

## Services conducting assessments

**All referrals for assessment must be made on the appropriate Pathway for Autism Assessment Referral (PAAR) Form** – see Table 6 below

Table 6: Assessment Referral Form

| |
|---|
| **Pathway for Autism Assessment Referral (PAAR) form**<br>This form must be completed by all referrers to trigger the assessment process. |
| 1) Person’s name and contact details |
| 2) Reason for referral |
| 3) Nature of the presentation<br>Describe presentation<br>Indicate aspect that are of clinical concern |
| 4) Relevant prior assessments and outcomes from these pathways |
| 5) Rationale for choosing the particular referral pathway |
| **Referrers for Autism assessment must select a single referral pathway for the assessment. The use of more than one pathway will nullify the referral, resulting in it being returned to the referrer.** |

### Complimentary Autism Assessment Initiatives

This protocol includes elements of a separate but very complementary initiative which also sought to enhance access to Autism assessment. The initiative is one component of a design-led children's services (Disability, Mental Health and Primary Care Services) project that was undertaken by service users, clinicians and managers in the area formerly known as CH08, supported by HSE Spark Innovation Programme, from 2024–2025.

Here the term "In-Reach Team" describes how a multidisciplinary in-reach team can support services to provide assessments where the capacity or experience to provide this is not actually available within the appropriate pathway for the person to receive services.

Following a Human Centred Design methodology, the In-reach approach has been prototyped and tested in the former Community Health Organisation area 8, establishing proof of concept. The result of this work will soon be available. This will further inform the implementation of the in-reach services for Autism assessment in each of the Regional Health Areas as part of the implementation workshops for the Autism Protocol.

Primary care services, and on occasions disability services, may receive this In-Reach support to undertake Tier 1, 2 or 3 assessments, as required.

In mental health services assessments are undertaken in the context of differential diagnosis; and this may be achieved in different ways depending on local service configuration, experience and resources; as described below.

## Referrals to Mental Health Services

Referrals to mental health services are made, according to the National Access Policy (NAP), on the basis that the person being referred is believed to have a **moderate to severe mental health difficulty**[1], requiring a specialist Mental Health service.

At times a person referred to mental health services may have a **co-occurring condition(s)**, such as a neurodivergent experience that also warrants assessment. People with such co-occurring conditions should only be referred to mental health services when **the primary concern is a moderate to severe mental health difficulty,** or another condition is **associated with a moderate to severe mental health difficulty.**

If it is suspected that Autism may be co-occurring then assessment for Autism may happen in a number of different ways in mental health services:

### A. Single point of access

As part of the Child and Youth Mental Health action plan a single point of access for all mental health referrals is being developed. A review group comprised of primary care, disability, mental health practitioners and VCS partners are meeting regularly to agree the most appropriate service pathway(s) for a particular person. The outcome of this process may involve more than one team jointly assessing a person (and may also include an In-Reach Team – see C, below).

### B. Mental Health Teams undertaking differential diagnosis

As part of a comprehensive assessment for mental health problems some teams also consider and diagnose co-occurring conditions, including Autism. As these assessments are intended to distinguish between mental health difficulties and other possible conditions, they are primarily concerned with differential diagnosis. As noted previously a differential diagnosis should not be considered as equivalent to an Autism Assessment at Tier 1, 2 or 3; and where this is the case such a diagnosis should be followed by such an appropriate Tier of assessment.

### C. Mental Health Teams receiving in-reach support

Some mental health teams either do not have the experience and/or resources necessary to undertake any assessments for Autism, or feel that they would benefit from external expertise as part of their assessment process.

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[1] A moderate to severe mental health difficulty ‘has a significant impact on your daily life. It stops you from doing things you want to do and need to do. For example, seeing friends and going to school’ in the case of younger people (CAMHS), or seeing friends and going to work in the case of older people (AMHS). Referrals to CAMHS or AMHS should only be for persons with moderate to severe mental health difficulty. Those with milder mental health difficulties should be seen in primary care or disability services.

Where these teams receive a referral and believe that Autism may possibly be part of the clinical presentation, and the person is also presenting with a moderate to severe mental health difficulty, they call on an In-Reach Team (described above) to undertake the assessment in collaboration with the mental health team. This supportive service has been developed to assist community teams where they feel such support is needed. Such In-Reach Teams will work within a Regional Health Area supporting and building capacity within community services, including mental health and primary care teams, but also sometimes disability teams. They will support the Single Point of Access approach described above (A) and work across child and adult community services.

In all instances, **mental health services may refer onward those suspected or identified as Autistic,** to primary care or disability services **for Autism further assessment, services and supports** (according to the National Access Policy criteria).

If a person is identified through mental health services as being **Autistic but not having moderate to severe mental health difficulties**[1] **they should not be 'held' in mental health services, but should be immediately transferred to the appropriate pathway for those already assessed and identified as Autistic and in need of services or supports, from primary care or disability services** (and not requiring reassessment).

## Provision of Interventions

While this protocol seeks to facilitate timely assessment and to indicate the pathways for accessing interventions, services and supports, it does not specify what type and range of intervention, services and supports should be provided.

A separate but complementary manual will be developed through the Service Improvement Programme Board for the Autistic Community and this work will be prioritised following the completion of this protocol.

Interventions, services and supports for Autism should be provided in line with the National Access Policy, and ideally by the same team which undertakes the assessment. However, where such interventions, services or supports are not available in Primary Care or Mental Health Services, then referral should be made to Disability Services to provide these, either though in-reach to the assessing service, or as a referral out to Disability Services.

To promote person-centred services, we appreciate that in the case of mental health and Autism, these are often not simply co-occurring independent conditions, but rather they are *interlinked* with each other, and each will benefit from supports and services for the other being delivered in a person-centred, holistic and fully integrated manner.

If an Autistic person is referred to Mental Health Services (for a moderate to severe mental health difficulty) by Primary Care or Disability Services, then Mental Health Services may take this referral into their own team to address the mental health difficulties. Mental Health Services take on the care of the person with respect to the management of their mental health until their difficulties are no longer in the moderate-severe range. This may involve joint working or shared care with Primary Care or Disability Services, who retain responsibility for supporting the person with respect to their Autism needs.

Mental health services may also respond to a referral via an in-reach consultation to Primary Care or Disability Services that may result in specific action (such as prescription and management of medication or provision of therapy) while the person remains with the referring team.

Regardless of whether people are seen in primary care, disability, mental health or indeed acute settings, reasonable accommodations (UNCRPD, 2006) should be afforded to all persons. The Service Improvement Programme for the Autistic Community established a working group which has produced training videos now hosted on HSeLanD. This ‘Autism Awareness Training’ has been co-developed with service users and is delivered primarily by autistic people. We strongly recommend that all those working with Autistic people (in all roles) undertake this training, which is comprised of three thirty-minute modules.

The training is available on HSeLanD by searching in the course catalogue for “Autism Awareness Training” – See below

### Autism Awareness Training

This programme has been created to support staff and service providers to raise awareness and understanding of experiences and to be able to better communicate with autistic people.

It is aimed at all staff and service providers working within health and social care. It is not just for clinical staff.

This programme contains three modules. All modules must be completed and a final assessment passed at 80% pass mark to receive a certificate of completion.

Table 7 indicates some possible presentations that may be appropriate for different tiers of assessment. These brief profiles are given simply as examples, while much more detail would be required to make a decision about the appropriate tier for assessment.

**Table 7: Typical Presenting Profiles or Circumstances that may be associated with different tiers of assessment**

| Tier of Assessment | Typical presenting profiles or circumstances |
|---|---|
| **Tier 1**<br>**Autism Assessment** | **Existing Convergent Evidence:** evidence from home, school, and clinic all agree - few queries or contradictions.<br>OR<br>**Clear Service History:** Older children or children known to services with a lot of intervention or previous assessments to draw on in formulating and opinion/diagnosis.<br>BUT ALSO<br>**Assessment Challenges:** while there may have been longstanding concerns about autism it is known in advance that formal assessment (e.g. the ADOS) will be unlikely to provide additional quality evidence of autism. This may be because of<br>1) a history of masking;<br>2) the person being non-speaking, or<br>3) severe anxiety, resulting in the child being unlikely to engage in more formal assessment. |
| **Tier 2**<br>**Autism Extended Assessment** | **Contradictory Evidence:** from home, school, or clinic.<br>(Tier 1 may still be appropriate in some cases where the school sees no evidence of Autism but there is ample evidence from home and clinic observations – in this case additional Tier 2 measures add little to the diagnostic formulation).<br>OR<br>**Difficult Differential Assessment:** for instance, between Autism & another neurodevelopmental condition (e.g. ADHD)<br>OR<br>**Contested Diagnosis:** possibly due to a complaint, or stakeholder investment in a particular outcome, where assessment decisions need to be made on a case-by-case basis |
| **Tier 3**<br>**Autism Continuing Assessment** | **Complicated Family History:** this may include known or possible experiences of trauma, neglect, or abuse, whereby a more autism-specific assessment tool is required along with an ADOS (e.g. ADI-R, DISCO) and possibly other forms of assessment.<br>OR<br>**Multiple Services Involved:** instances where more than one service is required to complete the assessment (e.g. CAMHS/ PC/CDNT) due to the presence of moderate to severe mental health difficulties.<br>OR<br>**Need for cognitive or neuropsychological assessment:** |

# Autism protocol competencies for each tier of assessment

All practitioners involved in conducting assessments using the Autism Protocol (whether in public, independent or private settings) must comply with the requirements of the protocol for their assessment to be recognised as fulfilling the requirements for Autism assessment regarding access to social welfare, education or health benefits or services. Publicly funded services are responsible for ensuring governance of the competencies as outlined below. For the reports of private practitioners to be accepted by publicly funded agencies, they should include in reports written declaration of how they meet the standards below.

Relevant practitioners should be registered with CORU NMBI, IMC or PSI. In addition (during transitional arrangements for psychologists registration with CORU all psychologists involved in Autism assessments must have completed a recognised practitioner training (to Masters or Doctorate level) in clinical, counselling or educational psychology, and fulfil eligibility criteria to be employed as a psychologist within the HSE. The safe and effective implementation of this protocol requires that appropriate clinical supervision and clinical governance structures are in place and staffed.

All practitioners should also be familiar with assessments for reaching expected developmental milestones. See here.

Work with nominees of the professional bodies is ongoing to develop a more detailed competency framework for autism assessment. The group has currently agreed the likely components of a competency framework. See framework which is available on www.hse.ie.

In addition to these general requirements, practitioners should fulfil the following criteria for competence in undertaking assessments at each of the tiers of assessment.

## Tier 1 competence

This tier may be undertaken by individual practitioners, or those working in teams with other disciplines, usually comprising of **occupational therapists, psychologists and speech and language therapists,** along with other disciplines, as required.

This assessment requires at least one practitioner to have **prior experience** of undertaking Autism assessments within the context of a multi- or interdisciplinary team, so that they are familiar not only with different types of Autistic presentation, but also under what circumstances it is necessary to have different disciplines involved in the assessment.

Tier 1 assessments require at least one practitioner should also be experienced in undertaking **differential assessment and diagnosis** related to Autism and possible co-occurring conditions. Clinicians are also required to have gained such experience under clinical supervision such that the supervisor can confirm that the appropriate skills for undertaking an assessment have been acquired and can be executed competently.

Training should have been undertaken within professional training or completed as a specific certified training to acquire competence in the use of specific assessment instruments used in Autism assessment (for example ADOS or ADI-R).

Conventionally, competence in differential diagnosis requires a professional training in **psychology (clinical, counselling or educational), paediatrics, psychiatry,** and in some cases, is also held by community medical doctors. Where other professions have undertaken specific certified further training to acquire this competence, this may also be considered.

## Tier 2 competence

As this level requires the use of formal psychometric instruments, such training should have been undertaken within professional training, or completed as a specific certified training to acquire competence in the use of specific assessment instruments used in Autism assessment (for example ADOS or ADI-R).

Tier 1 requirements also apply.

Tier 2 assessment will usually comprise of **occupational therapists, psychologists and speech and language therapists,** along with other disciplines, as required.

## Tier 3 Competence

As this tier may require more intensive and broader assessment with a range of standardised psychometric instruments (including possibly tests of neuropsychological and cognitive functioning) a significant level of experience and advanced training in assessment is required.

It may also be necessary to integrate a broad range of information across disciplines outside the usual assessment team.

# Team constitution and competencies

(adapted from *Three Rivers PCAAT*)

While professional regulation usually focuses on the competence of a particular profession, many assessments and interventions are provided through interdisciplinary or multidisciplinary teams. The competent team working of different professions is therefore also important to consider, along with the ethos of co-working across professions.

Both the shared clinical skills and unique professional contributions of team members are acknowledged and respected.

By virtue of their clinical training and experience, shared competencies must include:

- Knowledge of Autism, Autism assessment and neurodiversity
- Conducting comprehensive clinical interviews with families, professionals and young people
- Conducting clinically informed observations and interactions with children and young people
- Using clinical information to inform and contribute to formulation
- Providing person-centred feedback to families and young people on the outcome of assessments
- Providing information and guidance to families regarding Autism, neurodiversity and supportive approaches
- Providing training as appropriate

It is acknowledged that team members may vary in the development of the above competencies, and so could be considered to demonstrate these skills on a scale ranging from introductory to advanced levels. Where a team member would like support to enhance their competency in any of the above levels, a professional development plan may be formulated with the relevant discipline manager, supported as appropriate by team colleagues – such as CPD, enhanced supervision, shadowing, co-working etc. – to promote further competency development.

In addition to the above, there are clinical skills that are unique to different disciplines, and therefore requests for completion of specific assessments will be directed to the discipline with the appropriate training.

## Autism Protocol Competency Declaration

Each practitioner is required to make a brief statement to their Head of Service asserting: (See Appendix 17 for competency declaration)

1) Their claimed competence level(s) in terms of tiers of assessment
2) How they comply with the competency requirements,
3) Indicate how the above can be verified (professional body, professional qualification, specific training certificates, etc.)
4) Indicate supervision relationships and clinical governance supporting their practice.

## The process for assessment

We now describe the steps associated with Autism assessment and provide more detail on each tier of assessment.

### Step 1 – Screening

Screening may take place in health, educational or social care service. As there are no well-validated screening measure for Autism, the use of a formal screening measure is not recommended. However, the US Center for Disease Control and Prevention (2019) has identified several characteristics that may suggest an onward referral for Autism assessment is warranted. Many of these characteristic are linked to developmental milestones, other can apply also to adults but may be presented in more subtle ways. Some are likely to be difficult to detect in people who are 'masking' their presentation. (See appendix 14 for more information on masking).

Characteristic that may therefore be considered for screening include:

- Not responding to their name by 12 months of age
- Not pointing at objects to show interest (for example pointing at an airplane flying over) by 14 months
- Not playing 'pretend' games (pretending to 'feed' a doll) by 18 months
- Avoiding eye contact and wanting to be alone
- Having trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills

- Repeating words or phrases over and over (echolalia)
- Giving unrelated answers to questions
- Getting upset by minor changes
- Have ‘obsessive’ interests
- Flapping their hands, rocking their body, or spinning in circles (stimming)
- Having unusual reactions to the way things sound, smell, taste, look, or feel

Where a number of these characteristics are present a referral for assessment should be made.

For *older children and adults,* screening should include an exploration of neurodivergence across settings in the areas of:

### Social communication

An autistic person shows differences in how they prefer to communicate/ interact with others. They might:

- Prefer not to look at others while talking
- Understand language in a literal way, e.g. it’s raining cats and dogs
- Find it difficult to interpret facial expression or body language
- Find it hard to “read others”.
- May not see the point in or value of “small talk”.
- Place a high value on honesty.
- Be happy and content not to interact with others or to interact only a little with others and in certain conditions
- Prefer to follow particular routines to help make the world seem more predictable and less scary.
- Be very anxious about situations where there are certain social expectations.
- Respond to others in a different way.
- Have good language skills or not use language at all to communicate.
- Find it hard to understand the “unwritten” social rules/expectations within society. These “rules” can make the world seem very unpredictable and confusing.

- Communicate using echolalia if they use verbal communication, (repeating what others have said or phrases from TV, etc.)
- Need time alone if overwhelmed by being around others.
- Form friendships and relationships with others in different ways, e.g. meeting up only once every few months out of school as opposed to every week, play alongside each other doing the same activity.
- Find abstract/vague concepts or sarcasm/humour difficult to understand.
- Need extra time to process information/answer questions.

### Attention Allocation preferences

Autistic people can often focus on one thing to the exclusion of everything else, and have strong preferences for how they spend their time.

### Sensory Processing differences

Autistic people can have different way of experiencing sensory information. This can either be overwhelming when sensory input doesn't match the person's needs, or can help the person to regulate when they seek out sensory preferences.

- There are also positive aspects to sensory processing e.g. seeing beauty in a light beam or gaining intense pleasure from a sensory experience.

### Stimming Behaviours

Repetition of physical movements, sounds, words, objects. Examples: hand flapping, pacing, rocking your body, finger tapping, spinning, etc.

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[1] The word 'referral' relates to routine referrals exclusive of applications that come through the Assessment of Need (AoN) process, while 'AoN referrals' relate to those that are received as AoN applications.

## Step 2 – Processing referrals

### Children

Most children will be referred to either Primary Care services or to Children's Disability Network Teams (CDNTs). Children who present with moderate to severe mental health difficulties may be referred to Child and Adolescent Mental Health Services (CAMHS). The pathway to accessing CAMHS services is outlined in the CAMHS Operational Guideline (2025).

Referrals of children from various stakeholders will require the completion of three forms:

1. Pathway for Autism Assessment Referral (PAAR) form
2. The *National Policy on Access* Children's Services Referral form
3. One of the five National Policy on Access (HSE, 2019) age-appropriate 'Additional Information forms, as follows;
    - Birth to 11 months;
    - 12 months to 2 years 11 months;
    - 3 years to 5 years 11 months;
    - 6 years to 11 years 11 months; or
    - 12 years to 17 years 11 months.

The service that receives the referral needs to ensure that these forms are completed and considered. If a child is identified (using the above referral forms) as having 'complex needs' or 'one or more impairments that contribute to a range of significant functional difficulties that require the services and support of an inter-disciplinary healthcare team' *(National Policy on Access, HSE 2019, p.17)*, the child will be assessed by a Children's Disability Network Team [CDNT].

If a child is identified (using the above forms) as having 'non-complex' needs, the child will be seen for assessment by relevant practitioners in Primary Care services.

If the child's primary presenting need is a moderate-to-severe mental health problem, the child should be referred to CAMHS for review, assessment and/or intervention for that need.

It is expected that the implementation of this protocol will coincide with a Single Point of Access (SPoA) to services operating in some areas, but not in others. Where the service pathway is unclear, local engagement should occur to determine the most appropriate pathway, including shared services options. Failing agreement, the referral should be referred to the area Integrated Children's Services Forum (ICSF) to determine assignment.

### Adults

Referral pathways would in principle operate in the same way for adults as for children. Screening and Autism assessment or differential diagnosis may take place through any service which the person is currently receiving, such as primary care, mental health, or disability services. The in-reach model described earlier – an Access Within Pathway In-reach Team has the advantage of assessments being delivered within the same service as the client is currently using, where such services currently exist. Where more detailed assessment is required, referral to disability or primary care services is warranted.

However, in most areas adult disability services do not have teams that can undertake Autism assessments, and regretfully this generally means seeking a private assessment, for those with means. This inequitable situation should be addressed so that in each of the six Regional Health Areas, at least one public service team is available to conduct adult Autism assessments.

Concerns about Autism may be self-identified by an adult. In such cases of self-referral assessment for Autism should be undertaken at the tier which the practitioner believes to be appropriate.

## Step 3 – Link worker

Where practicable, each person will be assigned a nominated link worker who will act as an immediate point of contact, support the child and his/her family or the adult (for example to provide a clear route of access to other clinicians); facilitate continuity of service and address individual concerns as they arise.

The role of the link worker becomes increasingly important as the child transitions into adulthood.

This should be a competency-based role, assigned to a member of the CDNT or Primary Care team or the equivalent in other services *(see discussion of link worker role, later in this protocol).*

## Step 4 – Psychoeducation

Psychoeducation is associated with all tiers of assessment. In conjunction with the formulation process and regardless of whether the assessing practitioners have determined a complete understanding of a person's needs, all service users should be offered psychoeducation or generic interventions, based on their presenting needs. Such interventions will provide general support, recommendations and skills, rather than being Autism-specific. These will often be the first interventions or supports that can be more readily accessed and come under the heading of 'Universal Supports and Services' (see Figure 3 above). In cases of children where it is inappropriate from a developmental perspective to fully profile an individual's needs, such interventions may also provide improvement in relation to their specific needs before their assessment concludes.

Universal supports and services

- Provided as a first step, where capacity permits, these low-intensity interventions will be provided to service users and families who are waiting on their assessment or who have begun assessment.
- These proactive interventions will facilitate early (if minimal) intervention for General difficulties.
- Examples of such universal interventions include support and guidance on common themes (potentially based on a digital platform), advice on environmental accommodations based on individual needs, community supports and sibling/parental support groups.
- These interventions provide a foundation of knowledge that can help prevent difficulties from arising that can be built on by additional interventions if and as required. In their absence, future interventions may be less effective.

## Step 5 – Autism Assessment - Tier 1 (more detail)

The protocol uses the concept of tiers – this is not related to difficulty or level of supports needs. Rather, it refers to the assessment intensity which is appropriate for the clarity of presentation. Support needs can vary over time and may depend on the environment, but where possible, the team working with the child and family will try to maintain continuity of service, unless referral to another team is indicated.

An assessment for Autism may include various elements (see Table 1).

## Table 8: Tier 1 Forms of Assessment

| Autism Assessment Tier 1 | |
|---|---|
| **Potential Element** | **Suggested Modality*** |
| **Review of the three referral forms** | Email / Desktop |
| **Review of any available previous reports** | Desktop |
| **Interview with parent(s) / caregiver / individual**<br>• Considering current presentation, context and the individual's personal development and history. | Video call / face to face |
| **Assessment Measures**<br>• Use of any assessment measures or notes that provide clear documentary evidence of personal characteristics that support the formulation, diagnostic decision and service recommendations. | Email / Desktop |
| **Observation**<br>• Use of behavioural observation instruments that provide clear documentary evidence of personal characteristics that support assessment decisions. | Video call / face to face |
| **Feedback**<br>• Feedback to person/family may be provided by one (or sometimes more) clinician(s). | Video call / face to face |

The interview(s) undertaken by clinicians are required to develop a formulation (see next section). Clinicians are required to report the formulation on the Pro-Forma report document. The interview will also ascertain important information relating to diagnosis (ICD or DSM, as described elsewhere in this protocol), wellbeing and possible self-injurous at behaviours. Clinicians are required to report a diagnosis (where possible) on the Pro-Forma report document. Table 11 outlines the range of issues that should be covered in the clinical interview.

## Step 6 – Formulation and diagnosis

The assessing practitioner(s) will, using all information gathered, formulate or provide an overview of an individual's presentation, including a consensus on the support needs of the presenting individual. This is a collaborative exercise with the child/family/person.

The formulation should follow the '5 Ps' approach (or some structured alternative). "Formulation provides a holistic and individually focused understanding of a person's difficulties and leads to a person-centred and effective package of interventions. Formulation highlights the aspects of Autism that are most prominent for the individual, and when and under what circumstances they are problematic". (BPS, 2021). In general, formulation includes the personal meaning and the impact of the differences or difficulties that people experience, while also relating to broader interpersonal and environmental elements. The 5 Ps are intended to prompt practitioners to consider key elements of formulation, but other elements may also be incorporated.

The 5 Ps are:

**Predisposing factors:** Internal or external historical factors which may increase the likelihood of developing certain differences or difficulties.

**Protective factors:** Internal and external resiliency and strengths, helping maintain well-being.

**Precipitating factors:** Internal or external triggers associated with differences or difficulties.

**Presenting issues:** A description of the presenting differences or difficulties.

**Perpetuating factors:** Internal and external factors maintaining presenting issues.

To learn more about formulation see: Clinical formulation: Where it came from, what it is and why it matters | BJPsych Advances | Cambridge Core

The clinician should also recommend **intervention(s)**/management strategies for a period of 3–9 months, monitor the response and thereafter re-consider their formulation and/or diagnosis in conjunction with service users/families as appropriate. Sometimes a person's diagnosis may change, based on a different understanding of their experiences over time.

Where possible, a person should be formally identified as experiencing Autism ('Autism Spectrum Disorder') where they fulfil the **diagnostic criteria** as set out in the latest editions of the International Classification of Diseases (ICD-11, WHO, 2022) or (the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-5-TR 2022, APA, 2022). Ireland is required to provide data to WHO annually, using ICD criteria. (see Step 9 for diagnostic criteria).

Where provisional support needs and associated interventions require further refinement or formulation strengthened, the assessing clinicians may

- Need to again review collated information; and/or
- Consult/liaise with other clinicians or teams who are recognised as being highly competent regarding identifying Autism and this may involve an onward referral.
- Undertake further assessment (see Extended assessment – Step 7).

This process of formulation can be reviewed in an iterative manner as informed by emerging evidence (such as developmental gains, influence of interventions or changes in environmental factors).

## Step 7 – Autism Extended Assessment (Tier 2)

In cases where some initial evidence of Autism or functional needs has been gathered but further and more specific information is required to inform interventions or establish a diagnosis, an individual may be referred for further assessment.

Where a Tier 1 assessment is anticipated to yield insufficient clarity to make a formulation, identify needs, determine diagnosis or specify interventions, a person may enter directly into a Tier 2 assessment. This more in-depth review may include various elements (see Table 9). In general the Autism Extended Assessment should normally build on, rather than repeating, elements of a prior 'Autism Assessment – Tier 1' (Step 5), where this has already been done. Where an assessment starts at Tier 2 this effectively becomes step 5 in the process.

The majority of standardised autism assessment instruments tend to be focused on, and/or normed on, children and teenagers. Appendix 22 provides a list of instruments sometimes used to contribute to the assessment of adults for autism.

### Table 9: Tier 2 Forms of Assessment

Autism Extended Assessment Tier 2 - where more than one form of assessment is available, the suggested recommended alternative(s) is/are indicated in italics.

| **Potential Element** | **Suggested Modality*** |
|---|---|
| **Structured developmental history interview with parents/ carers** – such as<br>• Autism Diagnostic Interview – Revised [ADI-R]; Rutter et al., 2003; 90 minutes to administer | Phone / Video call<br>Note: Remote options can be used but face to face may be preferable for some |
| **A formal observation** – such as<br>• Autism Diagnostic Observational Schedule – Second Edition [ADOS-2]; Lord et al., 2003; for ages 12-months and older; 90 minutes to administer | Face-to-face |
| **Behavioural observation in a naturalistic setting** (e.g., home, school) – school observations won't be possible by video call. | Video call / face to face |
| **Intellectual Ability** – such as<br>• Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 2011;<br>Two- and four-subtest forms - 15 and 30 minutes to respectively administer | Face-to-face |
| **Formal developmental assessment** – such as<br>• *Bayley Scales of Infant and Toddler Development* – Third Edition (Bayley-III; Bayley, 2006) for ages 1 to 42-months; 45-60 minutes to administer;<br>• Griffiths Mental Development Scales (Extended Revised; GMDS-ER; Luiz, Barnard, Knoesen, Kotras, McAlinden, & O'Connell, 2004) for ages 0 to 8-yrs and 11-months | Face-to-face |
| • **Adaptive behaviour assessments** – such as *Adaptive Behaviour Assessment System* – Third Edition (ABAS-3; Harrison & Oakland, 2015; 15-20 minutes to administer | Video call |
| • **Vinelands 3** (3rd Edition) - measures of adaptive functioning, for communication, daily living, socialization & motor skills Ages range: 0-90/3-90 Parent/Caregiver /3-21 Teacher form. (Sparrow et al., 2016); 10—40 minutes to administer | Video call / face to face |
| • The **RAPT** (Renfrew Action Picture Test; Renfrew, 1997) assessment of expressive language for ages 3-yrs 6-months to 8-yr 5-months | Video call / face to face |
| **Formulation and team discussion** | Video call / face to face |
| **Face to face feedback to person/family** may be provided by one (or sometimes more) clinician(s). | Video call / face to face |

* While any form of assessment may be conducted face-to-face, some forms of assessment may also be legitimately undertaken through other modalities, as required.

## Step 8 – Autism Continuing Assessment (Tier 3)

In cases where there is mixed evidence of Autism (such as conflicting feedback from different environments or variable demonstrable functional difficulties) or evidence of other influencing factors (such as history of trauma; co-occurring presentations or significant environmental factors), an individual may be referred for continuing assessment that may include various elements (see Table 10).

### Table 10:Tier 3 Forms of Assessment

| Autism Continuing Assessment Tier 3 - Some of the following assessments may be appropriate | |
|---|---|
| **Potential Element** | **Suggested Modality*** |
| **Intellectual Ability**<br>Wechsler Preschool & Primary Scales of Intelligence (WPPSI; Wechsler, 2013; ages 2-yrs 6-months to 7-yrs 7-months; Core Subtests: ages 2-yrs 6 month to 3-yrs 11-months; 30–45 Minutes; Ages 4- yrs to 7-yrs 7-months; 45–60 Minutes) | Face-to-face |
| • The Wechsler Intelligence Scale for Children – Fifth Edition (WISC-V; Wechsler, 2014; 45-65 minutes to administer) | Face-to-face / Video call1 |
| **Behavioural assessment**<br>• e.g., risk assessment; functional assessment | Video call |
| **Medical assessment** | Video call |
| **Auditory assessment** | Video call |
| **Mental Health assessment** | Video call |
| **Other Assessments** – such as<br>Dietary / nutritional assessment / joint hypermobility / etc<br>SALT<br>OT | Video call |
| **Sensory profile** (where there are sensory sensitivities) | Video call |
| **Formulation and more in-depth inter-disciplinary team discussion** | Video call |
| Face to face feedback to person/family may be provided by one (or sometimes more) clinician(s). | Video call / face to face |

* While any form of assessment may be conducted face-to-face, some forms of assessment may also be legitimately undertaken through other modalities, as required.

## Step 9 – Report completion

The prof-forma Autism Protocol Assessment Report, to be used in reporting assessments for all tiers, is provided below.

# Autism Protocol Assessment Report

*(for all tiers of assessment)*

*This report is private and confidential and only intended for the person who is being assessed, their parents (for children), the service conducting the assessment and for those who have the person's/parent's consent to read it.*

*The report must contain clear documentary evidence of personal characteristics and circumstances, to support the formulation, diagnosis and recommendation for services.*

| | |
|---|---|
| **Name of person:** | |
| **DOB:** | |
| **Address:** | |
| **Dates of assessment:** | |
| **Date of report:** | |
| **Assessor(s) involved:** | |
| **Assessor(s) providing feedback and date** | |

## Referral information

### Self-referral or referrer role and contact details

### Nature of differences/delays/difficulties described on referral

## Background Information

### Personal and family history and circumstances

### Educational experience and school information

### Developmental History and Milestones (if not covered above)

### Clinical therapy information

### Any screening instruments completed

### Medical history and most recent medical review

### Any current formulation or diagnosis

## Assessment procedure

**Review of previous clinical reports/correspondence**
– Summarise clinical reports, clinician, date

**Clinical interview**
focused on relevant characteristics associated with Autism (indicating if any standardised instruments used)

**Observational assessment**
(indicting any standardised instruments used and in which settings – clinic/school/home/other).

**Parent/other feedback and discussion**

**Additional assessments if undertaken**

**Accommodations used**
(assessment conducted in other than first language, use of interpreter, use of AAC – augmentative and alternative communication, other factors mediating assessment?)

## Formulation of the person’s presentation

A short narrative description considering how the person’s presentation is related to possible predisposing, precipitating, perpetuating and protective factors, including how these may reflect sociocultural, psychological and biological factors. Other systematic approaches to formulation may also be used at the clinician’s discretion. The formulation should be authenticated with the person/parent.

## Profile of strengths, difficulties and needs

**Which particular strengths are apparent?**

**Which particular difficulties are apparent?**

**Which needs have been identified?**

**How might strengths be incorporated in addressing needs?**

**Does the person fulfil the ICD 11 (or DSM 5) criteria for Autism ("Autism Spectrum Disorder"):**

## Diagnosis

We provide here the diagnostic language used in ICD 11 (similar language is used in DSM 5), as it is important for clinicians making a diagnosis to be clear about the descriptions of the behaviours as used in the diagnostic manual.

However, where we feel this language is deficit/disease/disorder focused, we have used a strike through, with a more strengths-based alternative language provided.

We recommend that this more neuropositive language is used when discussing diagnosis or formulation with those who have been assessed, or family members.

*Please provide clear evidence relating to the headings for each of the below boxes.*

1. **'Persistent [differences or difficulties] ~~deficits~~ in initiating and sustaining social communication and reciprocal social interactions'**

2. **‘Persistent ~~restricted, repetitive and inflexible~~ patterns of behaviour, interests or activities that are clearly atypical ~~or excessive~~ for the individual’s age and sociocultural context, are an essential component’.**

3. **‘~~Onset of the disorder~~ [Occurs] during the developmental period – typically in early childhood – but ~~symptoms~~ [characteristics] may not become fully manifest until later, when social demands ~~exceed limited capacities~~ [are not met]’.**

4. **The characteristics result in significant difficulties in personal, family, social, educational, occupational or other important areas of functioning. Some individuals with Autism are able to function adequately in many contexts through exceptional effort, such that their differences or difficulties may not be apparent to others. A diagnosis of Autism is still appropriate in such cases.’**

Any indication of intellectual disability that should be assessed?

Yes ☐ No ☐

Any indication of language difficulties that should be assessed?

Yes ☐ No ☐

Any indication of loss in previous functioning that should be assessed?

Yes ☐ No ☐

Any indication of other differences or difficulties that should be assessed?

Yes ☐ No ☐

If required, see other diagnostic categories and Autism codes here.

## Recommendations

| |
|---|
| 1. |
| 2. |
| 3. |
| etc. |

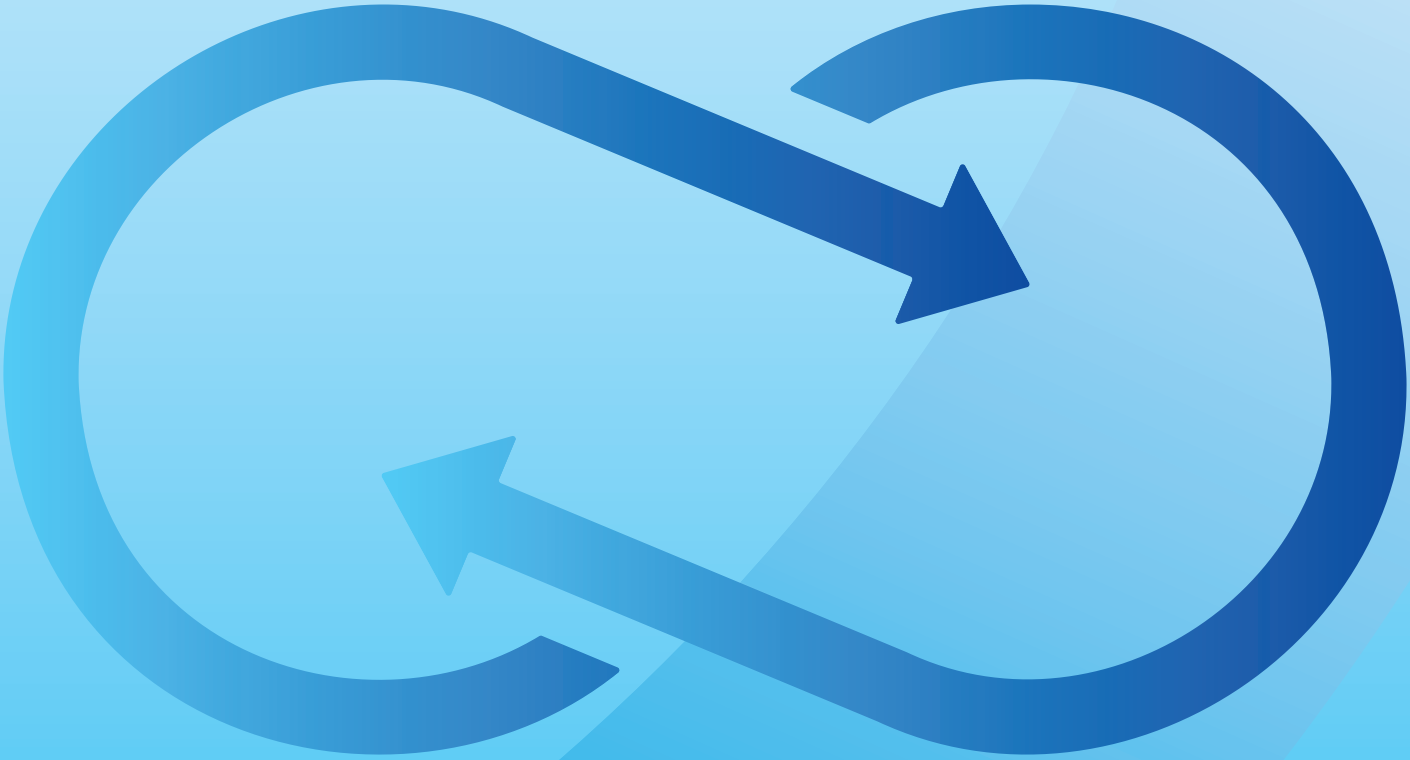
---

1. This form has benefited from the incorporation of features drawn from local forms produced by The Tree Rivers PCAAT, Spraoi CDNT, PC North Dublin and Castleknock PCAAT.

### Table 11: Autism Assessment Scope

| |
|---|
| **Autism assessments should provide all of the information required to complete each of the boxes in the Autism Protocol Assessment Report.**<br>**The completion of the Autism Protocol Assessment Report will require the below information and activities for all Tiers of assessment.**<br>**On some occasions assessments may occur without the use of standardised instruments.**<br>**Some of this information may be available from prior assessments.** |
| Clinical interview with the individual (with or without parent (s) if child) which should cover:<br>Reason for referral and person's/ family's expectations<br>Impact of past and current features associated with autism and any modifiers for these<br>Current concerns and the onset<br>Development history<br>Information about what life was like growing up<br>General day to day functioning<br>Education and/or occupation<br>Hobbies and passions<br>Needs and difficulties<br>Strengths, resilience factors and person's coping resources and styles<br>Social circumstances, friendships and relationships<br>Physical and mental health and emotional wellbeing<br>Risk to self and others, including possible self-harm and suicidal ideation. |
| Corroborative information (must include developmental information) |
| Screening measures (cannot be used as diagnostic tools as none have been found to meet criteria for this) may be helpful but not essential. |
| Standardised behavioural observations – may not be possible or need to be modified (e.g. for a non-speaking individual). Further observation if required (e.g. school observation) |
| Identification of need for additional assessment tools if required; for instance in females and older peoples' presentations (e.g. in the context of masking). |
| 5 Ps Formulation (or another structured approach to formulation) |
| Diagnosis including differential diagnosis for co-occurring conditions, including mapping of features onto diagnostic criteria (ICD/DSM) |
| Identification of need for additional assessments from other disciplines, |
| Service Recommendations |
| Feedback session with the person assessed |

# Pathways Protocol development cycle



# Pathways Protocol development cycle

## 1.1 Purpose

As part of the implementation process, the Service Improvement Programme Board is sponsoring the establishment of an Operational Framework Working Group with responsibility for making specific recommendations relating to Autism assessment and intervention, piloting and capacity building for frontline professionals relating to the agreed assessment and intervention approach.

Specifically, the subgroup is charged with:

Designing and supporting the implementation of the following recommendations contained in the review report – that is Recommendations 2, 3, 5 and 6.

Please note that the following recommendations are transcribed exactly from the review report entitled *The Review of the Irish Health Services for Individuals with Autism Spectrum Disorder, 2017.*

We note that some of the terminology used in that 2017 report is now outdated and that more progressive neuroaffirmative terminology has been adopted in the current report).

### Recommendation 1

Engagement and collaborative working, where all services work together with service users to meet their needs. In order to meet their changing needs, people with ASD and their families need easy, typically simultaneous access to various parts of the health and wider services (for example education and social welfare). However, as supported by consultation feedback, their experience is often characterised by fragmented and sometimes duplicated care, particularly due to different services working in silos. The Sláintecare Health Service reform blueprint and the new HSE governance structures around the advancement of community healthcare create an opportunity for more joined-up service provision. The HSE needs to ensure that people with ASD and their families have easy access to various healthcare providers so that they get the right service at the right time. As highlighted by the academic literature (NICE, 2014) and consultation feedback, the voice of people with ASD and their family members must be heard. They must be consulted in a meaningful way about the design of ASD services.

### Recommendation 2

Clear and functioning pathways to services – meaning a need to facilitate timely access to services. There is also a need to delineate clear pathways to services, so that there is universal understanding of the most appropriate care pathway for children and their families. This is particularly important for young children and for those in transition.

### Recommendation 3

A tiered approach to assessment – where timely access to diagnostic assessment can be promoted, yet with diagnostic accuracy being retained by shifting away from highly intensive ASD assessments towards a tiered approach to assessing ASD. Assessments can take place in primary care with the facility to access more specialist services, dependent on presentation.

### Recommendation 4

The use of performance management/governance structures. ASD services need to have a strong emphasis on performance management at all levels within the organisation. Areas of underperformance in services must be highlighted and addressed. As ASD services are often delivered by multidisciplinary teams, it is essential to have clarity on the roles and responsibilities of various team members and indeed various services within the stepped-care model. Governance structure need to encompass provision of clinical supervision and performance appraisal that includes a focus on individualised objectives and personal development plans that will help chart future professional and personal development consistent with organisational goals and strategy and service user needs. In addition, the HSE needs to provide training to staff and managers on the value of complaints and on its complaints procedures, thereby ensuring that complaints are welcomed and are used to improve services.

**Recommendation 5**

Services for adults with ASD are minimal to non-existent in many countries (ministries of health and education, 2016); the National Autistic Society, 2009). Consultation respondents, including parents, professionals, and community healthcare organisations, highlighted how Ireland was also devoid of such services, despite there being approximately 16,379 – 23,079 adults living with ASD in Ireland, with many of these remaining undiagnosed (NDA, in press). Hence, there is need to provide both a diagnostic services for adults with query ASD and to provide basic supports, such as help to secure employment, linking these adults with mainstream services that may sustain independent living and obviate the need for referral to specialist services. Regarding other interventions, services need to ensure that adults and their families are involved in making decisions about their care and determining what interventions may be effective (for example social skills training, social groups, befriending, vocational opportunities and SIGN, 2016).

**Recommendation 6**

The review has found that healthcare and other professionals need to improve their competencies to work with individuals with ASD. Training is necessary to address this. Additionally training for family members should also be available. Mapping and agreeing on a standardised service, user journey and the implementation of a consistent core service offering across those providing services to people with Autism. This will help teams deliver an Autism service based on agreed standards, promote national equity for service users and enable future service improvement initiatives to be implemented consistently across all relevant teams, (incorporating additional recommendations 1, 4, 7, 8 and 9).

**Recommendation 7**

This is about communication, information and awareness. Many parents noted significant frustration with the lack of communication from HSE-funded and other service providers about what supports/services they could access, what services they might need to access and about their child’s (current and anticipated) clinical progress (for example, assessment findings). While often because of poor inter-agency working, such communication deficits partially reflected a lack of knowledge among service providers about what supports/services were available, and/or a lack of adequate time to sufficiently communicate with parents. There was also frustration caused by a lack of information about vocational opportunities. Consultation feedback also highlighted the need for information about clinical aspects of ASD and how to manage these. For example, what a diagnosis of ASD means; ASD and behaviour that challenges; ASD and anxiety; how to promote language development; ASD and sensory processing; ASD and socialising and what were evidence-based interventions for ASD (ones that actually work). These factors will also promote high quality and evidence-based interventions.

### Recommendation 8

This is about evidence-based interventions. It is critical that service users and their families are provided with evidence-based assessments and interventions or those that have been shown to be effective. While the evidence base for both assessment practices and interventions for children is relatively well-established (for example parent-mediated; communication; behavioural/psychological; NICE, 2011), that for adults is less so (for example ministries of health and education 2016; the National Autistic Society,2009). As profiled by respondents, some parents have accessed both public and/or private interventions (at considerable expense) that have yielded minimal improvements, if any at all. Hence it is important to establish that assessment practices are evidence-based and accurately profile the needs of individuals with ASD; and likewise that interventions are evidence-based, implemented in the manner that they were designed to be implemented and prove to be effective.

### Recommendation 9

This is about supporting service users and their families. Given that the ability of parents of a child with ASD to cope is related to the resources and supports available to them, every effort needs to be made to support parents/families who have a child with ASD. So in addition to the training noted in Recommendation 6 and given the disproportionate stress on such families and associated mental health concerns (for example , Hamlyn-Wrights et al., 2007), services need to provide access to respite care (Doig et al., 2009) residential or otherwise, independent living facilities and employment facilities for adults with Autism (Peters, 2000) along with individual and/or family counselling to help sustain families.

The role of the working group is to provide recommendations, building on existing reports and recent experience of assessment, around the implementation of a ‘Standard Assessment’ approach.

## 1.2 Scope

**Target audience**

This protocol is designed to assist clinicians in how to best assess for Autism in Irish Health Services; including those provided by the HSE, Section 38 & 39 organisations funded by the HSE, and private providers, where appropriate. The Assessment and Pathways Working Group has consulted widely with stakeholders in the design and formulation stage of this project; this is particularly important in the context of the implementation of a tiered approach to assessment. Membership included 3 lived experience/parent representatives, representatives of the disciplines most commonly involved in the assessment of Autism working in primary care, disability or mental health. It also included senior operational managers and heads of service from those care groups. Appendix 2 attached outlines the membership of the Working Group.

## 1.3 Autism Assessment Protocol Development Group

An Autism Assessment and Intervention Pathways Working Group was set up to develop a clinical framework and associated assessment protocol and intervention pathway. Membership of this group can be found in Appendix 2 attached.

The terms of reference for the group was as follows:

a) The meetings will be held every two weeks initially, but as the project progresses they will be held in line with project needs/updates.

b) The HSE Adviser on Autism Protocol Development and Implementation will chair the working group

c) The chair will convene and administer the required meetings either virtually or in accessible locations to be agreed.

d) The chair is responsible for reporting to the Programme Board

e) The working group will monitor risks/targets/delivery plans/budget

f) The project manager will present project status updates on progress

g) Members should be prepared to commit to the lifetime of the project and be available to attend all meetings.

h) Meetings will be noted by way of actions agreed.

i) The working group may, with the approval of the SIP Board Chairperson, consult with service users and providers, through the Disability Advisory Group of the NCPPD.

j) The consultative group, because of capacity issues, do not need to attend all meetings. However, they will need to approve and sign off documentation prior to it being sent to the SIP Board for ratification.

k) The membership will work on the basis of seeking positive solutions and will take a consensus approach to their deliberations. Where consensus cannot be realised, the SIP Board will decide on matters referred to it for consideration.

## Autism Assessment and Intervention Pathways Governance Group

Oversight of the process was by the Service Improvement Programme Board for the Autistic Community. Membership of this group consists of the following:

| Board member | Role/organisation |
|---|---|
| John Fitzmaurice | Integrated Healthcare Area Manager Sligo, Leitrim, West Cavan, South Donegal. Chair of the Programme Board |
| Aoife O'Donohue | Assistant National Director Disability Services – Transformation & Programme Coordination |
| Brian Higgins | Assistant National Director: Mental Health – Adult Mental Health Services |
| Amir Niazi | National Clinical Adviser and Group Lead – Mental Health |
| Rosemary Gowran | National Clinical Lead – Disabilities |
| Donan Kelly | Assistant National Director – Child and Youth Mental Health |
| Maeve Raeside | Assistant National Director, Primary Care Access and Integration |
| Mac MacLachlan | Maynooth University, Assisting Living and Learning Institute and Department of Psychology<br>HSE Adviser on Autism Protocol Development and Implementation |
| Adam Harris | Person with lived experience |
| Mary Maher | Parent of Autistic person |
| | **Programme Board support** |
| Anne Tighe | Business Manager, Programme Office, Access and Integration |
| Sharon Barry | Service Improvement Lead/Project Manager, Access and Integration |

# Autism Assessment and Pathway Protocol Briefing Session

## 1.4 Supporting evidence

The development of this protocol builds on a significant number of reports already commissioned by the HSE and others. This protocol therefore seeks to streamline and synthesise prior recommendations in the context of the current state of knowledge. The evidence supporting this protocol is readily accessible and the following documents form the basis of the development of the protocol.

- *The Review of the Irish Health Services for Individuals with Autism Spectrum Disorder*
  - (https://reviewoftheirishhealthservicesforindividualswithasd)
  - This major review of the services available to those with Autism was published in November 2017.
- *Review of assessment instruments and models in use*
  - As part of the stakeholder consultation process involved in the Review of the Irish Health Services for Individuals with Autism Spectrum Disorder (ASD) in 2017, feedback regarding the various assessment instruments and models for assessing Autism in both Ireland and other countries was collated. In a separate survey, the nine Community Health Organisations were asked to profile their Autism best practice models, including how Autistic children were assessed.
- *HSE Autism Spectrum Disorder Diagnostic Protocol – discussion paper*
  - Initial discussion paper (2018) collating the findings from:
    - Review of the Irish Health Services for Individuals with Autism Spectrum Disorders
    - The review of assessment instruments and models in use in Ireland
    - Further to extensive feedback from multiple stakeholders (for example, a clinical reference group, professional bodies, recognised academics) in 2018 to this initial discussion paper, this document was redrafted to include more details of a proposed Autism assessment model (for example assessment instruments and work processes).

- *NCPPD Digital and Assistive Technology use in Disability Services during Covid-19: A Report on the Experiences of 120 service providers, 2020*
- *NCPPD Interim Guidance on Conducting Assessments in Disability Services, 2020*
- *NCPPD Assessment of Clinicians' Experiences of Conducting Assessments during Covid-19, January 2021.*
    - https://www.hse.ie/eng/about/who/cspd/ncps/disability/programme-publications/
- *A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs, 2020.*
    - https://www.oco.ie/app/uploads/2020/10/15438_OCO_Assessmnet_of_Need_Report_Interactive.pdf
- *Prototypical Case Assessment and Intervention Scenarios – currently under development.*

### Legislation

The Disability Act; The Epsen Act 2004; the Assisted Decision-Making Act (2015); The Health Act (2007).

### Policies

National Access Policy, Slaintecare, UNCRPD, EDS – European Disability Strategy

## 1.5 Glossary of terms (See earlier in the document)

# Development of the protocol

## 2.0 Development of the protocol

## 2.1 The purpose of the protocol

(See earlier in the document)

## 2.2 Describe the literature search strategy

(See Appendix 6)

## 2.3 Describe the method of appraising evidence

The methodology involved re-examination of the original “ASD Diagnostic Protocol - Discussion Paper” (2018) which had engaged with numerous stakeholders at the time. Ref 2.2 above. In addition the Assessment and Pathways Working Group is made up of multiple stakeholders with an interest and significant knowledge of Autism assessment. Membership on the group also includes people with lived experience of Autism.

## 2.4 Formulation of Recommendations

Describe the process the Assessment and Pathways Working Group used to formulate recommendations

The working group was made up of multiple stakeholders with an interest and significant knowledge of Autism assessment. Fortnightly meetings were held initially to discuss different aspects of the work, and regular discussions took place. As the project progressed, the Working Group met based on the needs of the project. The group also benefitted from people with lived experience on the group.

### 2.5 Provide a summary of the evidence from the literature

Not applicable

### 2.6 Detail resources necessary to implement the protocol recommendations

While existing healthcare staff will implement this protocol, some may also need to avail of once-off or ongoing training and clinical supervision.

# Governance and approval

## 3.0 Governance and approval

### 3.1 Outline formal governance arrangements

The Working Group reports to and is accountable to the Service Improvement Programme (SIP) Board for the Autistic Community. The Programme Board will provide oversight and support to the Working Group via the Project Manager and Chair of the working group. SIP Board reports to the National Director Access & Integration.

There is a standing item on the Monthly SIP Board agenda requesting an update from the Working Group.

### 3.2 Method for assessing the protocol in meeting the standards outlined in HSE National Framework for developing the protocol

The SIP Board for the Autistic Community will after twelve months commission an evaluation of how this PPPG is working.

The SIP Board undertakes an annual review of the implementation of the protocol, once nationally in use.

# Communication and Dissemination

## 4.0 Communication and dissemination

### 4.1 Describe communication and dissemination plan

The National Director of Access & Integration will issue the relevant information to the Regional Executive Officers, supported by HSE Communications.

# Implementation

## 5.0 Implementation

### 5.1 Describe implementation plan listing barriers and /or facilitators

The protocol will be supported by a full implementation plan in each of the six regions.

### 5.2 Describe any education/training required to implement the protocol

The competence required to implement the protocol should be supported by clinical supervision provided through an appropriate clinical governance structure.

### 5.3 Identify lead person(s) responsible for the Implementation of the protocol

Regional Executive Officers within Regional Health Areas.

### 5.4 Outline specific roles and responsibilities

Roles and responsibilities will be outlined in the supporting implementation plan.

# Monitoring, audit and evaluation

## 6.0 Monitoring, audit and evaluation

## 6.1 Describe the plan and identify lead person(s) responsible for the following processes

- Monitoring
- Audit
- Evaluation

Regional Executive Officers to identify an Implementation Group / Lead per RHA who will report back to the Service Improvement Programme Board on an annual basis

## 7.0 Revision / Update

The protocol will be subject to annual revision as described later in the protocol

## 8.0 References

(See Appendix 7)

# Appendix Listings

## 9.0 Appendix listings

| | |
|---|---|
| Appendix 1 | Signature sheet |
| Appendix 2 | Membership of the Working Group |
| Appendix 3 | Conflict of Interest Declaration Form |
| Appendix 4 | Membership of the Approval Governance Group |
| Appendix 5 | Role of the Link Worker |
| Appendix 6 | Literature Review and Relevant Strategy Documents |
| Appendix 7 | References cited in this document |
| Appendix 8 | National Access Policy Referral Forms |
| Appendix 9 | Recommendations of the review report |
| Appendix 10 | Assessment Summary Report |
| Appendix 11 | Service Users Pathway Diagram |
| Appendix 12 | Autism Pathway Information Document |
| Appendix 13 | About 'Frank Autism Presentations' |
| Appendix 14 | About Masking/Camouflaging in Autism |
| Appendix 15 | Brief psychometric instruments that could be used as part of a Tier 1 assessment by Community Medical Doctors |
| Appendix 16 | Sources suggested by Lived Experience Members who have contributed to the development of the protocol |
| Appendix 17 | Autism Protocol Competency Statement |
| Appendix 18 | Indicative profiles for different assessment pathways |
| Appendix 19 | Annual Review Process of the Autism Assessment and Intervention Pathways Protocol – Factors to be considered for inclusion |
| Appendix 20 | Form for Sharing with HSE or HSE-funded services Psychologist Assessments of Possibly Autistic Children undertaken in Other Service Sectors |
| Appendix 21 | Possible Assessment Instruments in Tier 2 Assessments |
| Appendix 22 | Possible Instruments that can contribute to the assessment of autism in adults |

# Appendix 1: Signature sheet

*I have read, understand and agree to adhere to this policy, procedure, protocol or guideline:*

| **Print name** | **Signature** | **Area of work** | **Date** |
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# Appendix 2: Membership of the Working Group

| **Working group member** | **Role** |
|---|---|
| Mac MacLachlan | HSE Adviser on Autism Protocol Development and Implementation |
| Brian Higgins | Assistant National Director Mental Health – Adult Mental Health Services |
| Rachel Kenny | Lived Experience/Parent Representative |
| Grainne Morrison | Parent Representative |
| Adrian Carroll | Lived Experience |
| Gillian Farrelly | Senior Leader from Primary Care (HOS) |
| Dervila Eyres | Senior Leader from Mental Health (Head of Operations Mental Health) |
| Mairéad O'Neill Lyons | Senior Leader from Mental Health (HOS) |
| Pauline Ackermann | Senior Leader from Mental Health (GM) |
| Olive Hanley | Senior Leader from Disability Services (HOS) |
| **The following representatives represent disciplines working in either primary care, disability or mental health services:** | |
| Anne Hughes Kazibwe | Occupational Therapist |
| Graham Connon | Principal Psychologist |
| Judy Purkiss | Public Health Nursing |
| Vicki Callanan | Speech and Language Therapy |
| Bridget O' Hara | Social Worker |
| Nicole Dyrssen | Manager Disability Services |
| Edel Flanagan | Senior Clinical Psychologist |
| Angela O'Neill | Head of Disability Services<br>*previously National Disability and Family Team* |
| Michael Byrne* | Previously National Disability Children and Families Team |
| Lorraine Seery | Principal Psychologist |

Additional input was sought and provided for the review of the protocol through the NCAGL Mental Health, Executive Clinical Directors and Clinical Lead for Paediatrics, with specific input provided by Psychiatry and several paediatricians and educational psychologists sourced through the NEPS office.

Input provided from The 'Deep End' GPs Group

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*Michael Byrne made a significant contribution to the development of this protocol prior to his death in 2022

# Appendix 3: Conflict of Interest Declaration Form

This must be completed by each member of the PPPG Development Group as applicable

## Title of PPPG being considered

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**Please circle the statement that relates to you**

**1. I declare that I DO NOT have any conflicts of interest.**

**2. I declare that I DO have a conflict of interest.**

**Details of conflict (please refer to specific PPPG)**

---

(Append additional pages to this statement if required) signature, printed name, registration number (if applicable) date

The information provided will be processed in accordance with data protection principles as set out in the Data Protection Act. Data will be processed only to ensure that committee members act in the best interests of the committee. The information provided will not be used for any other purpose. A person who is covered by this PPPG is required to furnish a statement, in writing, of:

(i) The interests of the person, and

(ii) The interests, of which the person has actual knowledge, of his or her spouse or civil partner or a child of the person or of his or her spouse which could materially influence the person in, or in relation to, the performance of the person's official functions by reason of the fact that such performance could so affect those interests as to confer on, or withhold from, the person, or the spouse or civil partner or child, a substantial benefit.

# Appendix 4: Membership of the Approval Governance Group

Please list all members of the relevant approval governance group (and title) who have final approval of the PPPG document.

| | |
|---|---|
| **Mac MacLachlan**<br>**Chairperson** – Autism Assessment & Intervention Pathways Working Group | **Signature:**<br>M MacLachlan |
| | **Date:** 25th March 2026 |
| **John Fitzmaurice**<br>**Chairperson** – Service Improvement Programme Board for the Autistic Community | **Signature:**<br>John Fitzmaurice |
| | **Date:** 25th March 2026 |

# Appendix 5: Role of the Link Worker

Each child or adult will be assigned a nominated Link Worker who will act as an immediate point of contact, supporting the child or adult and his/her family, if appropriate (for example in providing a clear route of access to other clinicians). It will also facilitate continuity of service and will address individual concerns as they arise.

The role of the Link Worker becomes increasingly important during life transitions, such as when a child transitions into adulthood, adults transition into older age, employment opportunities, or new locations.

The Link Worker should be a competency-based role assigned for children by a member of the CDNT, or the CDN Manager; and by the equivalent adult or older people's services. The role of link work should be envisaged as being part of a service rather than based on an individual.

Given that the child and parents, or the adult, can move between several care or service groups across the lifespan, the role needs to be flexible enough to work across a number of such groups. The main functions of the role are:

- To act as the single point of contact for the child/family or Autistic adult;
- To work with the clinical team who have main responsibility for providing services and supports to the child or adult
- To facilitate communication across the team and across care/service groups.
- To coordinate the implementation of interventions/service plans as agreed with the multidisciplinary team.
- To advocate for and navigate through the system on behalf of the child or adult.
- To maintain professional standards in relation to confidentiality, ethics and legislation.
- To operate within the Scope of Practice – seeking advice and assistance from the overarching service with any issues that prove to be beyond the scope of his/her professional competence, in line with the principles of best practice and clinical governance.

The role needs to be supported within the governance structures of the team, and individuals who provide the service should receive regular supervision relating to their role. Regular reviews will also be necessary to measure the impact of the role on other clinical duties. This can vary across service continuum, where pinch points along the pathway may have a greater or lesser impact on the role. Examples include all points of transition, like primary school, secondary school, graduating from child to adult services, changes in presentation or personal circumstances of child/family or adult.

Training may be needed for the Link Worker and will need to take account of best practices and knowledge, skills and attitudes required for the role. This can be provided through multiple platforms, including formal courses, shadowing and mentoring.

# Appendix 6: Literature Review and Relevant Strategy Documents

It was not the role of the Working Group to carry out or commission any additional research or evidence-gathering. Ref 1.7 above for list of supporting documents.

However, the 2018 discussion document had carried out a comprehensive evidence-based review of key documents and policies that require consideration when formulating an assessment protocol for Autism. Where appropriate, this has been supplemented by relevant literature in the intervening period. Where necessary and appropriate (meaning other than quotations) we have also revised the terminology to align with the ethos of the current protocol.

## Primary Care Strategy

The Department of Health and Children (2001, p.15) defined primary care as 'an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis/classification, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social wellbeing'.

Primary care services play a central role in co-ordinating and delivering a wide range of integrated services, in collaboration with other HSE-funded services. Primary care teams are the central point for service delivery that actively engages to address the health and social care needs of its defined population, in conjunction with a wider range of Health and Social Care Network services.

## A Vision for Change: Report of the Expert Group on Mental Health Policy

Published by the Department of Health and Children (2006), many services to individuals with Autism were provided through the mental health services, even in circumstances where service users did not have another mental health problem. This policy recommended that 'the role of child and adolescent community mental health teams in Autism can be defined as consultation on difficult diagnoses and specialist episodic treatment of acute mental disorders' (p.89). Hence, this policy recommended that not all children or adults who are Autistic necessarily require access to mental health services, unless they also had moderate or severe mental health difficulties, which cannot be met by disability or primary care services.

## Sharing the Vision 2020 / 2025 Implementation Plan

An Expert Evidence Review, commissioned by the Department of Health, was carried out in 2016 to provide evidence to determine the policy direction for a refresh of *A Vision for Change,* both in terms of international best practice and the experience of implementing *A Vision for Change* to date. The document recommends that there should be further development of early intervention and assessment services in the primary care sector for children with ADHD and/or Autism to include comprehensive multi-disciplinary and paediatric assessment, and mental health consultation with the relevant CMHT where necessary.

## Progressing Disability Services for Children and Young People

While still being implemented, this national programme (HSE, 2010) will make access to services equitable for all children with a disability through a consistent structure of services across the country. *Coterminous with Community Healthcare Networks in each of the nine Community Healthcare Organisations, geographically defined,* Children's Disability Network teams will provide services to children with complex needs who have a wide range of disabilities – including, but not limited to – intellectual disability, physical disability, sensory disability and Autism.

## Best Practice Guidelines for the Assessment and Classification of Autism Spectrum Disorders for Children and Adolescents (birth to 18 years)

The Autism Spectrum Disorders Special Interest Group of the Psychological Society of Ireland (PSI) developed these best practice guidelines (Second edition - 2022) as a guide to psychologists regarding the identification, assessment and classification of Autism in 0-18-year-olds in Ireland. Its recommendations were based upon findings from international Autism best practice research, discussions at Autism Special Interest Group meetings, and considerations of changes in Autism practice over the years (PSI).

## National Policy on Access to Services for Children and Young People with Disability and Developmental Delay

Still being implemented in some services, this policy (HSE, 2016 updated 2019) provides a referral pathway to services for children with disability or developmental delay. Children with 'non-complex' needs will be referred to Primary Care services and children with 'complex' needs to Children's Disability (Network) Teams (CDNTs). Non-complex needs are defined as one or more impairments giving rise to functional difficulties that result in mild restrictions in participation in normal daily living. Complex needs refer to one or more impairments that contribute to a range of significant functional difficulties that require the services and supports of an inter-disciplinary disability team.

This policy also proposes establishing local Integrated Children's Services Forums. These are a 'meeting of relevant services and disciplines across the Healthcare Divisions such as Primary Care, Disability and Mental Health Services and across relevant Hospital Services and other Agencies/Departments such as Tusla (the Child and Family Agency), Education and others which provide a mechanism for deciding where the child or young person's needs will be best met at any particular time, where it is unclear as to the pathway for a child or young person to receive service(s)' (HSE, 2019, p.18).

### Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services

The primary goal of this joint working protocol (HSE, 2017b) was to standardise guidelines regarding the management of cases between Primary Care, Disability Services, and Child and Adolescent Mental Health Services (CAMHS). More specifically, its primary recommendations included:

1. Ensure clarity of roles and responsibilities of each service;
2. Facilitate timely access to services to prevent duplications of referrals and in turn wait lists;
3. Make referral processes more seamless and timely by services collaborating and ensuring open communication channels between parents, service users and the services themselves;
4. Hold consultation meetings for cases where more than one service will be involved in the care of individuals;
5. Conduct joint assessments for cases where there is a significant possibility of a differential classification or co-occurring condition;
6. An Integrated Children's Service Forum in each area will provide a mechanism that will allow services to discuss cases, the needs of which are unclear or complex.

## Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders

Minister Harris commissioned a review of Irish health services for individuals with Autism. Informed by nearly 400 submissions, over 200 of which came from parents and carers, the resultant (cross Divisional) HSE report made thirty-six recommendations (2017). These included timely access to classification assessment by shifting away from highly intensive Autism assessments towards a tiered approach to assessing Autism. It also stipulated that assessments can take place in Primary Care, with the facility to access more specialist services dependent on presentation. The current protocol is one response to this recommendation. More specifically, the assessment-related recommendations were:

- Introduce an assessment pathway where all referrals to Primary Care services with query Autism are triaged, resulting either in determining whether Autism is present or absent (as supported by consultation with secondary care colleagues) or onward referral to Secondary Care Services.
- Introduce a tiered approach to assessment in secondary care services whereby the required intensity of a classification process is determined by the complexity of presenting difficulties and clinicians' judgement of these.
- For co-occurring presentations (such as questioning Autism with moderate-to-severe mental health issues) different secondary care services (such as Children's Disability Teams, CAMHS) will undertake conjoint assessments.
- Formulate evidence-based guidelines for how privately sourced Autism classification assessments are conducted, and evaluate whether these are adhered to and whether such out-sourcing provides value for money.

### Children’s Disability Services Procedures and Processes

To support the *National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (HSE, 2016),* the Social Care Division within the HSE developed core procedures of service delivery, like the work processes that those services would have to adopt to facilitate implementation of the national policy. These include areas such as alignment with existing policies/ documents; referral pathways to children’s disability teams; prioritisation, wait list, initial contact, individual family service plan (IFSP) and AoN referrals.

### Progressing towards Outcomes-Focused Family Centred Practice – An Operational Framework

This document provides an operational framework or guide for how Children’s Disability Network Teams (CNDTs) can work to progress outcomes-focused Family-Centred Practice (FCP). FCP is concerned with a collection of care processes (such as clinical inputs, practices, supports, resources and experiences) with corresponding or consequent outcomes (including the positive consequences of these processes to children and their families).

## Literature review

### What is Autism?

Autism is the experience of lifelong neuro-developmental difficulties or differences that affect how an individual reacts to and relates to the world around them. In the last twenty years there has been a considerable change in the way in which people think about Autism. Happe & Frith (2020) identified ‘seven major changes in how Autism is thought of, operationalised, and recognised’ (p.1). These transitions are:

- From narrow to wide: a broader range of experience is now accepted as part of the Autism experience.
- From rare to common: the prevalence of Autism is now thought to be much greater, although still possibly under-recognised in females.
- From childhood to lifespan: this also reflects the incorporation of Asperger’s Syndrome into ASD.
- From discrete to dimensional: Autistic experience is seen as less distinct and may overlap with other developmental difficulties, along with some aspects of general development, as indicated by its spectrum (dimensional) rather that categorical (discrete) conceptualisation.
- From one to many: Autism in different individuals may well have different causes, and in a particular individual different core experiences (or ‘symptoms’ as they are described in a ‘medical model’) may have different origins.

- From pure to complex: Autism rarely occurs without associated difficulties. ‘Diagnostic overshadowing’ has inappropriately led clinicians to simplistically identify a ‘primary diagnosis’ rather than formulating a more complex understanding of interacting experiences and factors.
- From developmental disorder to neurodivergence: rather than being characterised purely in terms of deficits, it is now recognised that difference in a neurotypical context often creates disabling experiences for Autistic people, who also have considerable strengths – sometimes directly associated with their neurodivergent attributes.

## Autism and intersectionality

The experience of Autism does not occur in a social vacuum. Rather it is patterned by the diversity that exists in our society. This may include the experience of additional barriers associated with being a member of one or more marginalised groups; such as being female, LGBTQ+, being a member of an ethic minority group, including being a Traveller; or living in a rural area which has poor access to services and supports, or living in poverty. So, for instance, salient aspects of an individual’s identify may include being an Autistic person, being gay, and being black. Intersectionality therefore sees identities as usually interacting, not as separate identities, not rooted simply in the most oppressed identity, but patterned by their combined experience (Pearson, 2010). The experience of being an Autistic Traveller woman, will be different to the experience of being an Autistic settled man, at least in some regards. The societies and subcultures in which we live contribute to both constructing what it means to be Autistic and how it feels to be Autistic and what barriers or facilitators are present. The importance of intersectionality in Autism in increasingly being recognised (Cascio et al, 2021) and should be considered and discussed with people during the assessment process.

## Models of disability, neurodiversity and terminology

### Models – medical, social and rights-based

Disability has been conceptualised though a number of different frameworks, including the medical model, the social model and the human rights model of disability. The medical model views disability as an illness, deficit or disorder, associated with limitations within the body.

In contrast, the social model of disability views disability as socially constructed by a person’s environment. It sees disability as a consequence of physical, social and attitudinal barriers that prevent Autistic people from fully participating in all aspects of mainstream life. In the social model, inability to function in society is not a result of personal defects, disorders or impairments, but rather it arises because of societal and environmental barriers. The social model therefore see disability as a social experience, not a personal attribute.

The human rights model promotes the agency of Autistic people, their rights to access services and opportunities, as well as the need to address physical, social and attitudinal barriers. It also recognises that people’s personal experience of their body may be of some form of impaired functioning (such as through chronic pain) and independent of barriers. The human rights model places obligations on government to provide the supports and services necessary to each individual’s own situation (‘reasonable accommodations’) to allow them to manage impairments and overcome barriers to realise their right to live independently.

Both the social model and the rights-based models influenced the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), one of the most innovative and far-reaching pieces of legislation (Berghs et al, 2019) developed in the realm of disability and intended to directly counter the medical model of disability. While the convention uses person-first rights-based terminology, it also asserts rights to address the barriers identified in the social model. In the context of health and social services in Ireland, the National Clinical Programme for People with Disabilities seeks to support the constructive interaction between the social and rights-based models (see Shakespeare, 2007).

## Neurodiversity

Many Autistic people and Autistic self-advocates identify with neurodiversity. The term ‘neurodiversity’ was introduced in 1998 by Judy Singer, an Autistic Australian social scientist, and the term has gained popularity in recent years (Dawson et al, 2022; Baron-Cohen, 2019). This concept has led to more positive perceptions about the Autistic population and especially an appreciation of how diversity and difference can produce strengths – like, for example, the use of stimming (repetitive or unusual moments or sounds) to prevent emotional deregulation (McMahon et al 2021). Autism rights organisations in many countries now consider Autism more as a natural variation within the range of human diversity, rather than as a disease, disorder or deficit to be cured. The neurodiverse movement distinguishes between the biological underpinnings that may support neurodiversity in Autism, and the social oppression (disability) rooted in social, economic and political arrangements designed for neurotypical people, but not suitable for neurodiverse people (Runswick-Cole 2014).

There are differing views over the use of the terms ‘neurodiversity’, ‘neurodivergent’ and ‘neurotypical’. Neurodiversity refers to everybody. Neurology just like other aspects of the body, differs between people and people are diverse. Just as there is no ‘typical body’ there is no ‘typical’ neurology. However, sometimes the word ‘neurotypical’ is used to refer to those whom some people consider to be neurologically ‘average’. The reasoning then goes that people who have neurology different from this hypothetical average – for instance, those with ADHD, dyslexic, or Autistic traits – are ‘neurodivergent’ people. That is, there is a categorical difference (divergence) between them and the ‘neurotypical’ people. So while the idea of ‘neurodiversity’ is consistent with the idea of a continuum and variety of neurological functioning, the idea of ‘neurodivergence’ implies a difference in category between some people and others – in other words that neurodivergent people are in a different category of ‘neurodiversity’ from ‘neurotypical’ people.

While this may sound like a rather academic concern, its implications are very real and practical, relating to how we identify neurological differences and the significance we give to them. For instance, a needs-led approach which stresses the importance of identifying a person’s needs and the supports and services that should be provided to them, is more concerned with a person’s functioning than their neurology. A diagnostic approach is more concerned with identifying categories that may – on average – be related to certain types of functional difficulties or differences, and then determining service needs. While a diagnostic approach to neurodivergence may lack scientific credibility it may have benefits for advocacy.

The cut-off on a continuum of neurodiversity is necessarily arbitrary and moveable, and this ‘movability’ and changing diagnostic conventions may well be related to the dramatically increasing prevalence of Autism, (Atladottir et al, 2015; Wang et al, 2022) with less divergent ‘neurodivergence’ being more commonly diagnosed/classified as Autism. The very practical implications of this is that there are also dramatically longer waiting lists for assessments and services.

Many workplace employers acknowledge the concept of neurodiversity within the Autistic population and recognise that their skills and abilities can be utilised in their employment (Hough and Koenig 2014; Lee et al. 2019; Scott et al. 2015, 2018 as cited in Lee 2020). Divergent and creative thinking (Lee et al 2020) has also been found to be linked to Autism; meaning that Autistic individuals often perceive problems and challenges in new ways, challenging the status quo in many workplaces (Lee et al 2020). The announcement of the designation of World Autism Day on 2nd April by the United Nations has brought wide international attention to Autistic people. UN Secretary General Ban Ki-Moon said ‘This international attention is essential to address stigma, lack of awareness and inadequate support structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realise their potential’. (Council of Europe 2020).

### Why non-medical-model terminology?

The terminology used by the public, practitioners and Autistic people often reflects historical practices rather than the thinking of the CRPD or the neurodiversity movement. The medical model of disability has historically been associated with deficit, disease and impairment thinking, at times leading to the institutionalisation of people with disability, as well as the use of restrictive practices, including the over-use and inappropriate use of medication.

There are also many positives in the provision of medical expertise to people with disabilities who may of course also have medical problems, or aspects of their disability which requires medical services and supports. However, problems arise when people refer to disabilities as if they were the same things as medical illnesses or diseases. Thus terms such as ‘Autism Diagnosis’ or ‘Autism Comorbidities’ are medical-model terms which construct Autism as a disease, disorder or deficit. Each time we repeat these terms we are reinforcing medical-model thinking, both in ourselves and in others with whom we communicate. However, there are always more appropriate alternatives – such as ‘identified as Autistic’ or experiences ‘co-occurring with Autism’. If the use of more cause-neutral terminology feels clunky or awkward, it is likely that this is because people have been so strongly socialised into a medical-model way of thinking, that challenging the habit of such terminology seems uncomfortable or wrong. In a similar way the term ‘chairperson’ used to feel wrong to many people who were socialised into a male-dominated culture which presumed and felt that ‘chairman’ was the ‘right’ word to use. Changing terminology changes the way people think and changes their expectations of, for instance, chairing roles. The same principle applies to people with disability.

The description of Autism by Happe and Frith (2020) – summarised above – also supports the UNCRPD view of disability, which strongly advocates for a social and rights-based approach. As Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018, it is noteworthy that the State is now bound by that convention and is accountable to the United Nations for its adherence to it. The UNCRPD recognises the importance of people with disability receiving the appropriate medical expertise and the services they require – just as any other person should receive such services if they have medical problems. But it is strongly opposed to the conceptualisation of disability as a medical condition, and to the use of disease or deficit terminology to describe the occurrence or experience of difficulties or disability.

It is noteworthy that the Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard for physical and mental health, Dainius Puras (who is a professor of psychiatry), submitted in accordance with Human Rights Council resolutions 6/29 and 33/9 on16th July 2019, recommends ‘training healthcare workers on human rights and service provision for persons with disabilities is therefore essential. Inclusive health training requires modules on the Convention on the Rights of Persons with Disabilities, human rights and the right to health and a disability inclusion approach with specific interventions to address the needs of persons with disabilities in every sector of healthcare’. (p.12). It is therefore a priority to ensure that the approach taken to Autism assessment and intervention in Ireland fulfils our obligations to the UNCRPD.

### The authority of cause neutral terminology

It is noteworthy that neither the Disability Act (2005) nor the Education for Persons with Special Needs (EPSN) Act (2004) use the term ‘diagnosis’ to refer to any type of disability, including Autism. It is important that Autistic people’s access to health, educational, welfare or any other services or supports, is not predicated on the use of outdated medical terminology which is inconsistent with the relevant Irish legislation, with the CRPD and with the neurodiversity movement. Where terms such as ‘identified as Autistic’ or ‘classified as Autistic’ – or derivatives of these terms – are used in this protocol, and when they are used as an outcome of an assessment process following this protocol, such terms should be recognised as being *more authoritative, definitive and professional* than the atavistic use of medical-model terminology which we now discourage for the reasons outlined above. Thus ‘identified as Autistic’ or ‘classified as Autistic’ should be given the same significance as the older terminology ‘diagnosed as Autistic’. And this should confer access to the same services and supports, where such access is still predicated on a categorical basis, rather than on the preferred needs-based assessment.

## Prevalence of Autism

There are mixed findings regarding the prevalence of Autism in children in Ireland. For example, a study by Sweeney and Staines (2016) involving mainstream schools (excluding special education schools) estimated this figure to be approximately 1 per cent of the general child population (n=8,000). This is in line with the 1 per cent prevalence figure estimated for the United Kingdom, which was based on a study of 10,000 children aged 9-10 (Baird et al., 2006).

In contrast, Gavin and O'Dea (2017) estimated this figure to be approximately 1.7 per cent, as established by examining the caseloads of geographic-specific school age and early intervention teams. This estimate is similar to that of the Centre for Disease Control's (CDC), Autism and Developmental Disabilities Monitoring (ADDM) Network, who estimated that approximately 1.5 per cent or 1 in 68 people in the United States are identified as Autistic (Christensen et al., 2016). However, the latter was based on a population of 346,978 children in the United States aged 8 years, and has been subject to scrutiny over methodological issues such as varying types of source records. Only children of 8 years of age were studied and surveillance areas were chosen through a competitive selection process and hence may not have been representative of children aged 8 years overall in the United States (Christensen et al., 2016). Although some believe that the prevalence of Autism has in fact increased in recent years, such findings may be attributable to an increase in Autism awareness, surveillance, knowledge and research, as well as changes in classification criteria – all of which may have contributed to higher detection rates (Hansen et al., 2015).

Since the above paragraph was written in 2022, CDC's most recent data suggest that 1 in 36 young people are Autistic (see CDC, 2024). Similarly, O'Nions et al (2023) have reported that almost 3 per cent (1 in 34) of 10 –14 year-olds in England were identified as Autistic. Furthermore, while historically research has pointed to sex differences in the incidence of Autism (more prevalent in males) recent research questions this. Barrows et al (2022) found that the ratio of male/female was equal for both social communication and repetitive and restrictive behaviours in what they described as 'high-concern cluster[s]' (Barrows et al, 2022). This may be associated with practitioners becoming more familiar with Autism presenting in different ways, including greater awareness of use of 'masking' or 'camouflaging' behaviours in females (see Appendix 14). To illustrate further the complex and changing picture of Autism, a research study in Northern Ireland has identified amongst the highest prevalence in the world, with 5 per cent of the school-aged population being identified as Autistic in 2022/23. But here males were almost three times more likely to be identified with Autism than females. Autism was also more prevalent in the urban population compared to the rural population, and in the most deprived areas (40 per cent higher than the average). The report also found that 18 per cent of children diagnosed with Autism did not have any special educational needs. In 2025 the Department of Education has indicated that it is using a prevalence of 5 per cent for service planning.

## Best practice debates

Through the consultation process undertaken in developing this protocol, concerns have been raised about the protocol deviating from ‘internationally accepted best practice’. If this were the case it would certainly undermine the acceptability and effectiveness of the protocol. So it is worth briefly considering the evidence for such a claim.

The plethora of assessment and classification instruments that may be used with people with Autism is indicative not only of differing preferences between clinicians, but also of a lack of established best practice in the assessment of Autism. While the utility and validity of Autism diagnosis/classification has itself been questioned (Waterhouse, London, and Gillberg, 2016), Conner, Cramer, and McGonigle (2019) assessed the predictive validity of Autism measures against clinical diagnosis/classification by using sensitivity, specificity and area under the curve (ARC) analyses. They reported that the best instrument was ‘fair at best’, while the poorest ones were not predictive at all, concluding that ‘none of these measures are very accurate’ (p.1).

Penner, Anagnostou, Andoni, and Ungar (2017) have provided the only review of national guidelines and reported:

> *‘This systematic review is the first to demonstrate inconsistencies in recommendations pertaining to all aspects of the ASD diagnostic assessment, including whether ASD must be diagnosed by a MDT, the composition of the MDT, and the timeframe for completion of the assessment. The review also found discrepancies in the recommendations pertaining to screening and diagnostic tools.’*

Because of this conclusion they state that:

> *‘Clinicians performing diagnostic assessment are left with the difficult task of determining how to proceed in the face of limited empirical evidence and disparate clinical guidance. In light of this, clinicians should be mindful of local resources and wait times, eligibility requirements for ASD services (which may include results from specified standardised tests), and the wishes of families when deciding on how best to assess for ASD.’*

In a related but separate review, Hayes, Ford, Rafeeque, and Russell (2018) reviewed twenty-one guideline documents in use in the UK and found that they ‘varied in recommendations for use of diagnostic tools and assessment procedures’ (p.1); and concluded ‘We would not recommend greater rigidity within CPGs (Clinical Practise Guidelines) when *evidence for best diagnostic practice is inconsistent’* (p.23; italics added).

These reviews indicate no requirement to use specific instruments and no internationally accepted best practice in terms of instrument use (see also Henderson et al, 2023; Hartman et al, 2023 for recent reviews of the literature). Perhaps one of the most prominent people associated with Autistic assessment has also recently stated: Bishop and Lord (2023, p.836) ‘There are many situations in which the use of any given tool might not be possible. As such, requiring the use of specific tools, without exception, is discriminatory and damaging’.

The National Institute for Health and Care Excellence (NICE) provides evidence-based guidelines for service provision. In relation to Autism it suggests that clinicians ‘consider’ using psychometric instruments, but does not require them to and does not specify which ones to use. The Scottish Intercollegiate Guidelines Network (SIGN), also a respected evidence-based source for guidelines, suggest that clinicians ‘may’ use psychometric instruments to assess for Autism, but again does not require them to and does not specify which ones to use.

This protocol does not require the use of formal psychometric instruments for Tier 1 assessments (but leaves it to the discretion of the clinician to decide if they wish to use them or not), but it does require the use of such instruments at Tier 2 and Tier 3. As such this protocol may be considered to set a more stringent standard than existing guidance and the appropriateness of this needs to be empirically tested through annual review of the protocol.

It is also hopefully clear that this protocol is in no way discouraging the use of psychometric instruments. Rather, if, when and what type of formal instrument to use is solely at the discretion of the assessing clinicians. Results from psychometric testing and formal diagnosis (using ICD or DSM) are however quite distinct and the latter is the only internationally agreed basis on which a diagnosis can be given. This requires clinical judgement which may of course be informed by the use of formal instruments, but should not be dependent on them.

As well as evaluating the overall protocol, research on the appropriateness of psychometric instruments currently in use in Ireland is urgently required. None of the instruments routinely used in Autism assessment in Ireland have Irish norms, most are insensitive to masking, and are gender and ethnicity-biased due to sampling legacy. There are no psychometric norms for adult Autism assessment.

References to deviating from ‘best practice’ are illusory, and perhaps inadvertently, misleading and worrisome for service users. The idea of “best-practice” from elsewhere should not deter us from identifying and refining good practices in our own context and developing a structured and systematic approach to assessment and intervention, which is continually monitored and evaluated from a range of different stakeholder perspectives.

Within Ireland, as elsewhere, therefore, ‘the question should not be ‘what is best practice?’ but rather ‘what is sufficient to provide the services needed, in a fair way, to the range of people needing them, within the resources available?” (MacLachlan, 2021). This should not prevent advocacy for enhanced resources in future, but it should also focus efforts on developing an approach that can address needs in the present.

The independent review of the Autism Protocol carried out by the Centre for Effective Services found that within pilot sites waiting times for assessment prior to the protocol being introduced was an average of 3.2 years, and assessments were taking place on average between the ages of 8–9 years of age. In some areas waiting times are much longer than this and assessments are taking place much later in life. Childhood assessments should be taking place more quickly and much earlier (between the ages of 3–4). This protocol thus seeks to improve the current system (for instance, by matching assessments to presentations, reducing waiting times and prioritising timely interventions) while fully acknowledging that the current level of resourcing does not allow for a perfect system to exist.

## Classification criteria

Clinicians working in Irish health services currently typically use one of two internationally recognised classification systems. It should, however, be noted that these classification systems – being products of medical model thinking – continue to propagate disease, disorder or deficit terminology in their titles and in some of the terminology used to describe some of the ‘disorders’. However, across successive revisions of these classification systems the use of medical terminology has progressively declined. For instance, it is noteworthy that in the most recent editions Autistic experience is no longer conceived of as an all-or-none disease-like ‘diagnostic category’ which somebody either has or does not have, but instead as a continuum which people may vary on, regarding the intensity of different types of experiences considered to cluster together and to constitute Autism. Thus while the most recent versions of the internationally accepted classification systems (discussed below), lag behind the ethos of the UNCRPD, they nonetheless guide practitioners’ conceptualisation and approach to assessing for and identifying Autistic individuals.

## International classification of diseases: diagnostic criteria for research (ICD-11)

ICD-11 mirrors the DSM-5 approach, with some key differences which are viewed as improvements (Zeldovich, 2017). For all Autism classifications, an overarching criterion is whether the observed symptoms are sufficient to undermine the individual's functioning in everyday life. A clinician may decide, for instance, that a person's mild problems of social communication and slight repetitive behaviours and interests are not sufficiently disruptive to merit assessment. Also ICD-11 differentiates Autism with and without intellectual disability. It merges communication and social interaction into one social communication symptom cluster. Clinicians had found it hard to categorise symptoms as either, as the difficulties are interrelated. ICD-11 has included sensory difficulties as a classification criterion.

(https://www.open.edu/openlearn/ocw/mod/oucontent/view.php?id=98815&section=_unit4.2.2)

## Diagnostic Statistical Manual, Fifth Edition (DSM-5)

DSM-5 (American Psychiatric Association [APA], 2013; see Appendix B) reconceptualised previous categorical syndromes of DSM-IV (APA, 1994) such as Asperger's syndrome, Autism, and pervasive developmental disorders not otherwise specified (PDD-NOS) into the continuum of the Autism Spectrum. In doing so, terms such as Asperger's syndrome and PDD-NOS are no longer used. Based on DSM-5 (APA, 2013), individuals may fall somewhere along a spectrum of severity and/or functional impairment (see Table 1, p. 7). Furthermore, it distinguishes between Autism and social and pragmatic communication disorder based on the absence of restrictive and repetitive behaviours in the latter. Disturbances in social communication and social interaction can present as deficits in social-emotional reciprocity, non-verbal communication and difficulties developing, maintaining, and understanding relationships (APA, 2013). Indicators of restrictive and repetitive behaviours include stereotyped or repetitive motor movements, use of objects or speech, as well as inflexibility around routine, having ritualised patterns, and having difficulty with change. Additionally, hyper- or hypo-reactivity to sensory input is also included in the latter. In addition to the above criteria, such symptoms must also cause significant clinical impairment in social, occupational, and/or other areas of functioning. Such disturbances must also be present during early development, and not explained by intellectual disability or developmental delays.

**Table 12: DSM-5 severity levels for Autism spectrum disorder (APA, 2013) (Here we use ‘classification’ in place of ‘severity’)**

| Classification level | Social communication | Restricted, repetitive behaviours |
|---|---|---|
| *Level 3*<br>‘Requiring very substantial support’ | Severe deficits in verbal and non-verbal social communication skills cause severe impairments in functioning<br>Significantly impaired initiation of social interactions and minimal response to social overtures from others<br>For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches | Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/ repetitive behaviours markedly interferes with functioning in all spheres<br>Great distress/difficulty changing focus or action |
| *Level 2*<br>‘Requiring substantial support’ | Marked deficits in verbal and non-verbal social<br>communication skills<br>Social impairments apparent even with supports in place<br>Limited initiation of social interaction.<br>Reduced or abnormal responses to social overtures from others<br>For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests and who has markedly odd non-verbal communication | Inflexibility of behaviour, difficulty coping with change, or other restricted/ repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts<br>Distress and/or difficulty changing focus or action |

| **Classification level** | **Social communication** | **Restricted, repetitive behaviours** |
|---|---|---|
| *Level 1*<br>'Requiring support' | Without supports in place, deficits in social communication cause noticeable impairments<br>Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others<br>May appear to have decreased interest in social interactions<br>For example, a person who can speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful | Inflexibility of behaviour causes significant interference with functioning in one or more contexts<br>Difficulty switching between activities<br>Problems of organisation and planning hamper independence |

As Ireland is required to report its health-related statistics to the World Health Organisation annually in terms of ICD categories, clinicians are encouraged to use this classification system. However, the DSM system is preferred by some and these codes can be translated into ICD codes at data collection, although there remain some differences between the two systems.

## What is a strengths-based approach?

### What is a strengths-based approach to neurodiversity?

According to Alex Fox, CEO of Shared Lives: ‘A strengths-based approach to care, support and inclusion says let’s look first at what people can do with their skills and their resources – and what can the people around them do in their relationships and their communities. People need to be seen as more than just their care needs – they need to be experts and in charge of their own lives’.

### Table 13 below distinguishes between what a strengths based approach is, and what it is not:

**Table 13: Contrasting a strengths and a non-strengths-based approach**

| A strengths-based approach is … | A strengths-based approach is not … |
|---|---|
| Applicable to any intervention, setting, type of level of need or profession. | An outcome |
| Identifying personal, family and community strengths and supporting the individual linking with these. | About signposting to others |
| A focus on *what matter to you* – the person receiving services and supports. | About ‘what is wrong with you’ |
| Embracing with risk enablement and positive risk taking | About shifting responsibilities to family and/or carers |
| Appropriate to individual circumstances and how these may change – in other words, flexible. | About avoiding talking about problems or issues |
| It’s about *how to do things* rather than how to fix things. | About apply the same approach to all – no scripts. |
|  | Adapted from *Strengths-based approach: Practice Framework and Practice Handbook*<br>UK Department of Health and Social Care (2019). |

Ginsburg (2020) states that ‘Our words matter. And they can make all the difference’ as a conclusion to some useful tips to better reflect a strengths-based approach in how we talk about Autism. These tips are shown in Table 6

## Contrasting Deficit and Strengths Language

### Table 14: Contrasting Deficit and Strengths Language

| **Contrasting Deficit and Strengths Language** | |
|---|---|
| Deficit language | Strengths language |
| She has severe meltdowns. | She feels emotions intensely. |
| He is obsessed with cars. | He is very passionate and enthusiastic about cars. |
| She is perseverating on the fan spinning. | She is fascinated by the fan spinning. |
| He displays restricted and repetitive behaviours. | He enjoys moving his body in the same way over and over again. |
| She is rigid with his routines. | She prefers consistency and sameness. |
| He is an extreme picky eater with severe food aversions. | He has a sensitive palate and specific food preferences. |
| He is non-verbal. | He is non-speaking. Here’s how he communicates ... |
| He is low-functioning. | He needs a higher level of support. |
| | *Adapted from Ginsberg (2020)* https://www.jessieginsburg.com/post/how-to-use-a-strengths-based-approach-to-talk-about-Autism |

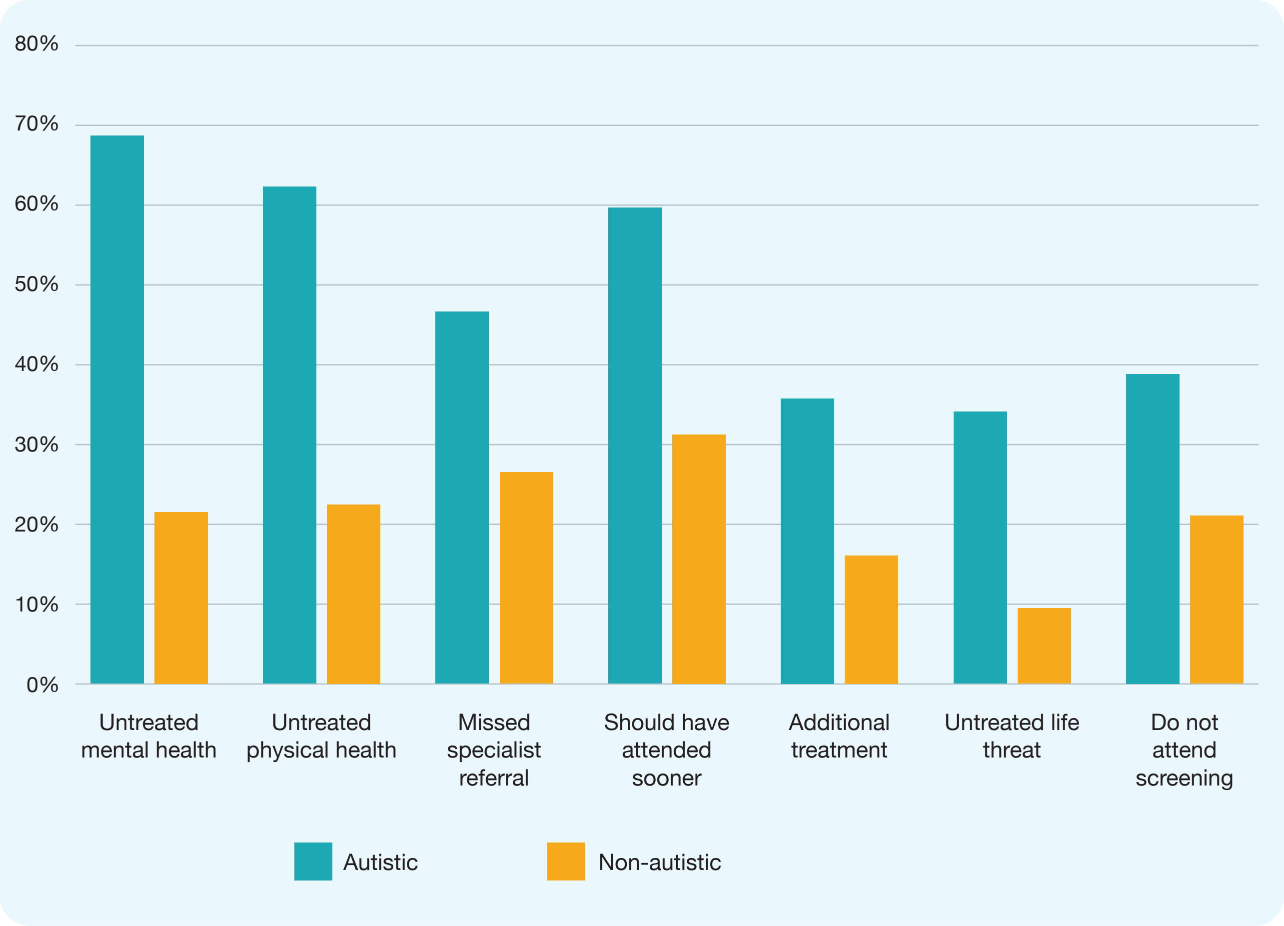
Ginsburg (2020) states that ‘Our words matter. And they can make all the difference’ as a conclusion to some useful tips to better reflect a strengths-based approach in how we talk about Autism. These tips are shown in Table 6

## Creating Autism-friendly service settings: SPACE for Autism

While the development of this protocol has been guided by consultations and inputs from a broad range of people with lived experience of Autism and a broad range of practitioners with expertise in providing Autism services, we have also been very fortunate to be informed by the experience of Autistic practitioners (see Doherty, et al, 2021, Haydon et al, 2021). For medical doctors, Ireland has played a leading international role in recognising and supporting Autistic doctors – see https://Autisticdoctorsinternational.com.

Autistic people often experience very significant barriers to healthcare, and these are associated with adverse health outcomes. Research lead by Irish anaesthetist, Mary Doherty, has established both the extent of this and some strategies for addressing it (Doherty et al, 2023; 2022).

### Adverse outcomes in delayed and additional healthcare treatment



Adapted with permission (from Doherty et al, 2022)

Autistic people, just as anyone else, need access to a range of health and social care services. It is well established that sometimes these environments can deter people with Autism from attending them. Many Autistic people experience sensory phenomenon in a different or unique way. Differences in sensory perception or processing may be one reason for Autistic people not accessing services. A useful acronym for remembering the main elements in producing an Autism-friendly environment is ‘Autistic SPACE’, which stands for Sensory needs, Predictability, Acceptance, Communication and Empathy, plus physical, processing and emotional space; as illustrated below.

The table below illustrates in more detail the sorts of sensory differences or difficulties which should be taken into account – by providing reasonable accommodations for people attending health or social care settings.

### Table 15: Autistic sensory differences

| Sensation | Considerations |
|---|---|
| **Sight** | Visual sensitivities are common. Bright lighting (particularly fluorescent) is a common challenge. Visual stimuli which may go unnoticed by non-autistic people, such as the flickering of fluorescent lighting or computer screens, an overhead rotary fan, or highly patterned surfaces, may all cause sensory stress. |
| **Sound** | Autistic people experience auditory sensitivities and auditory processing differences. Environmental noise can cause intense distress, particularly when sudden or unexpected. Sounds unnoticed by non-autistic people, such as the humming of electrical equipment, may be perceived by autistic people without 'fade' (where inconsequential sounds are no longer noticed over time). Autistic people may not filter out environmental sounds and therefore may struggle to hear a conversation in a noisy room. |
| **Smell** | Autistic people are often highly sensitive to smell and may perceive olfactory stimuli that others do not. Common and usually inoffensive smells may be perceived as highly noxious. In contrast, some autistic people are hyposensitive to smell and may enjoy smelling pungent objects. |
| **Taste** | Autistic people may be hypo- or hyper-sensitive to taste, needing either highly flavoured or very bland food. Food texture is important, as is predictability (see below). Autistic people commonly enjoy colloquially termed 'same foods', which may explain a limited diet and negative reactions to a change of brand or recipe for a known brand of food. |
| **Touch** | Tactile sensitivities range from inability to tolerate the sensation of certain fabrics to an inability to be touched, particularly by strangers. This leads to predictable challenges in a medical consultation where physical examination is required. Knowing the tactile sensitivity profile of a patient is helpful because difficulties commonly arise with light touch, whereas a strong deep touch may be more acceptable. |
| **Temperature** | Thermal sensitivity is common and may lead to apparently inappropriate or out of season clothing. The range of tolerated temperatures is likely to be person-specific. |
| **Proprioception** | Proprioception appears different for autistic people. Some may need lots of proprioceptive input leading to a tendency to climb, swing, rock or jump. Others will avoid such movements and may experience balance difficulties during day-to-day activities. |
| **Interoception and pain** | A particular challenge for some autistic people is accurately interpreting internal bodily sensations. This can lead to difficulties noticing hunger, thirst, tiredness, or a need to urinate or defaecate. Difficulties with pain perception can lead to unrecognised injury, but it must be emphasised that while reduced pain sensitivity occurs for some, others experience increased pain sensitivity, and this should never result in under-treatment of pain for autistic patients. |

The next table illustrates some of the ways in which service providers can improve the accessibility and comfort of settings where assessments, services or supports are provided.

| SPACE framework aspect | | Recommendations for implementation |
|---|---|---|
| **Sensory** | **Sight** | Turn off or turn down artificial lights |
| | | Remove flickering or oscillating environmental features |
| | | Avoid highly stimulating decor |
| | | Promote the use of sunglasses |
| | **Sound** | Consider environmental sounds |
| | | Reduce auditory clutter |
| | | Avoid conversation in noisy environment |
| | | Promote the use of noise cancelling headphones and ear plug |
| | **Smell** | Avoid wearing perfume or highly scented cosmetics or toiletries |
| | | Avoid aerosols or chemical “air fresheners” |
| | | Avoid highly scented cleaning products |
| | | Consider ventilation, open windows where possible |
| | **Taste** | Respect sensory preferences when considering nutrition |
| | | Consider taste and texture of medications |
| | | Consider non-standard medication formulations where necessary |
| | **Touch** | Ascertain tactile preferences and modify examination technique |
| | | Avoid casual touch |
| | | Promote sensory friendly clothing choices |
| | | Sensory aids such as weighted blankets may be helpful |
| | **Temperature** | Consider environmental temperature |
| | | Adjust temperature where required |
| | **Proprioception** | Understand the need for proprioceptive input |
| | | Avoid making inferences from unusual body posture |
| | **Interoception and pain** | Ask directly about internal sensations but understand that answering may be difficult |
| | | Pay attention to verbal reports of pain where possible |
| | | Be aware that non-verbal expression of pain may be different |
| | | Consider the need for adapted pain scales |
| **Predictability** | | Give realistic information in advance |
| | | Ensure clear and accurate directional signage in physical spaces |
| | | Provide photographs or videos of the physical environment and staff |
| | | Allow waiting in a familiar environment (e.g., a patient’s own car or outside) |
| | | Ensure care is provided by staff familiar to the patient where possible |

| SPACE framework aspect | Recommendations for implementation |
|---|---|
| **Predictability** | Give realistic information in advance |
| | Ensure clear and accurate directional signage in physical spaces |
| | Provide photographs or videos of the physical environment and staff |
| | Allow waiting in a familiar environment (e.g., a patient's own car or outside) |
| | Ensure care is provided by staff familiar to the patient where possible |
| **Acceptance** | Neurodiversity-affirmative approach beneficial |
| | Understand autistic stimming and monotropism (monotropic thinking patterns) |
| | Facilitate need for detailed factual information |
| | Understand distress behaviour |
| **Communication** | Understand autistic verbal & non-verbal communication differences |
| | Know that communicability is reduced by anxiety & sensory stress |
| | Clear unambiguous communication required |
| | Avoid phone-based appointment systems |
| | Promote use of Augmentative & Alternative Communication (AAC) |
| **Empathy** | Recognise that autistic people feel empathy but may display it differently |
| | Empathy towards autistic patients may be more challenging for non-autistic healthcare providers |
| **Physical space** | Expect a need for increased personal space |
| | Avoid proximity to other people where possible |
| **Temporal space** | Allow increased time to respond to questions |
| | Allow increased time for decision making |
| **Emotional space** | Expect differences in emotional expression |
| | Allow space to recover (without additional input) if distressed |

## Confidentiality

Clinicians involved in Autism assessment should abide by the ethical procedures outlined by their professional bodies. Of particular importance is respecting the confidentiality of any material gathered during the assessment processes. The sharing of such material should be for clinical or service improvement purposes only and must comply with GDPR regulations. Where this material is to be shared with a third party, permission for this should be gained from the client/service user, unless the legal obligations of the service provider preclude this.

## Specific cohorts

This section presents considerations for several specific cohorts.

### Females

(please also see Appendix 14 for additional guidance on masked presentations)

Research suggests differences in the prevalence of Autism, with Autistic females being under-reported because of misclassification/diagnoses (Dworzynski et al., 2012; Van Wijngaarden et al., 2014). Autism has also been found to be identified later in females in comparison to males (Shattuck et al., 2009). This is despite the finding that Autistic females tend to display a higher level of cognitive impairment than males (Mandell, Novak, and Zubritsky, 2005). Research has suggested that the latter be attributable to a lack of sensitivity of Autism assessment measures for identifying Autistic experiences in females (Scottish Intercollegiate Guideline Network [SIGN], 2016). The following outlines noted differences in Autism presentation between males and females (SIGN, 2016):

- Although both males and females have difficulty in forming and maintaining friendships, girls have been found to display a heightened desire for peer companionship in comparison to males;
- Difficulties or differences observed in play behaviour in both groups are less pronounced in females, possibly due to females' tendency to imitate play behaviours of their typically developing peers (Kirkovski et al., 2013);
- Females are found to cope better with Autistic experiences than males, thus resulting in certain experiences remaining unidentified by others until later years in life. Particularly, females without behavioural issues or intellectual disability (ID) may fail to meet the classification criteria for Autism (when such a classification may be warranted); and
- Autistic experiences, such as differences of difficulties relating to Theory of Mind (ToM) and repetitive and restrictive behaviours, may be less prevalent in females.

It may also be the case that girls’ special interests tend to be more socially acceptable (for example horses, pop bands, reading, etc.) so that these ‘differences’ are less noticeable than the interests of boys. Girls may also decompensate in the early teenage years, often with self-harm, which can send them down other service pathways, such as into mental health services.

## ‘High functioning’ Autism

Although ‘high functioning’ Autism is not recognised as an official classification category, and not a term we recommend using, it is a term sometimes used to describe individuals with Autism who display typical language development, average or above average intelligence, and typical adaptive functioning. Such individuals often remain unidentified as being Autistic until the later years in development and in adulthood, when the social demands of occupational and/or educational settings exceed that of their capabilities to cope, or when their marked social difficulties and behavioural difficulties become evident when compared to their typically developing peers. Common characteristics of such individuals includes unusual use of language, for example, large spoken vocabularies, difficulties in conversation pragmatics, and difficulties in social communication skills (Paul, Orlovski, Marcinko, and Volkmar, 2009; TagerFlusberg et al. 2005). It is important to be sensitive to the fact that some members of the Autistic community dislike the term ‘high functioning Autism’ and so this should only be used if an Autistic person is identifying themself in this way.

Because such individuals display several features of typical development, many may not be identified by common developmental screening tools (Missouri Autism Guidelines, 2010). However, the ‘high functioning’ Autism Spectrum Screening Questionnaire (ASSQ; Ehlers, Gillberg, and Wing, 1999) (Appendix S) and the Childhood Autism Rating Scale-Second Edition-High Functioning Scale (CARS2-HF; Schopler, Van Bourgondien, Wellman and Love, 2010) are two possible screening and assessment tools respectively which can be used with individuals suspected of being Autistic who display normal language and cognitive features. It is also recommended that multiple sources of information such as behavioural observation, developmental history and possibly more in-depth assessment procedures, be in such cases of suspected Autism (Missouri Autism Guidelines, 2010).

### Level of intellectual disability

Individuals with severe intellectual disability (such as an IQ below 20), may display some behaviours that are often associated with Autism, and thus it can be difficult to distinguish between the two types of experience (Howlin, 2000). This is attributable to the difficultly in determining whether the individuals' lack of social and communication skills, and presence of stereotyped/ repetitive behaviours, are due to the presence of a severe intellectual disability, or to co-occurring Autism (Howlin, 2000; Sappok et al., 2014). Research has found that increased severity of intellectual disability is positively correlated with the occurrence of Autistic experiences (Bertelli et al., 2015; Vig and Jedrysek, 1999). It is important for the individual's optimal future functioning that such a distinction be made during the assessment process, to enable appropriate targeted individualised intervention to be developed. The following steps have been identified as necessary components during assessment when a distinction needs to be made between an intellectual disability and Autism (Howlin, 2000):

1. Detailed assessment of cognitive ability, which includes verbal and non-verbal measures and assesses receptive and expressive language abilities;
2. A detailed developmental history which covers the individual's development from birth – possibly using a standardised instrument such as the ADI-R;
3. Observation of the individual;
4. Medical/genetic screening;
5. Consideration of other relevant psychosocial factors.

Importantly, the clinician/multidisciplinary team must determine, based on evidence from the above factors, whether the individual's behaviour is appropriate for their chronological language and mental age (Howlin, 2000). If not, individuals displaying differences or difficulties in play/social skills/ communication and presence of repetitive and/or stereotyped behaviours must be further explored. Additionally, a clinician should use knowledge of typical and atypical developmental patterns in forming a differential classification (Howlin, 2000).

As the incidence of Autism has increased, the proportion of Autistic people with intellectual disability has fallen, with some recent reports suggesting that only around one in five Autistic people also have an intellectual disability (Doherty and Berney, 2022).

### Birth to 5 years

Research has found that Autism can be identified in children as young as 2 years of age (Ozonoff et al., 2015; Lord et al., 2006; Moore and Goodson, 2003; Stone et al., 1999). Preliminary research has also suggested that Autism can be reliably identified from as young as eighteen months of age (Ozonoff et al., 2015). Such early identification and subsequent early intervention has been found to facilitate management of challenging behaviours, and improved functional outcomes (Estes et al., 2015). Therefore, practitioners in close contact with children in this age range need to be vigilant for early signs of Autism and maintain regular contact with parents about their child's development (Ministries of Health and Education, 2016). Additionally, practitioners need to take parents' initial concerns about their children seriously and refer cases onto the appropriate services as required (Ministries of Health and Education, 2016). Multiple developmental delays can serve as markers or 'red flags' for Autism:

- Lack of babble, pointing, or showing of objects by twelve months (Missouri Autism Guidelines, 2010);
- Lack of display of meaningful gestures by eighteen months (Rescorta and Schwartz, 1990);
- An absence of spontaneous two-word phrases by twenty-four months (Missouri Autism Guidelines, 2010);
- Any loss of language or social skills at any point during development (Filipek, 1999);
- Feeding difficulties

Other early signs of Autism include lack of smiling, or eye contact, or imitation, or responsiveness; a dislike for being touched or picked up; and a preference for isolation from others (Missouri Autism Guidelines, 2010). Further indicators include communication difficulties, including difficulties in language development; unresponsiveness to own name and lack of non-verbal communication (Ministries of Health and Education, 2016).

Suitable screening measures for this age group include the Social Responsiveness Scale (SRS); Constantino & Gruber, 2012) for 4–18-year-olds and the Modified Checklist for Autism in Toddlers (M-CHAT; Robbins, 2008) for eighteen to thirty-month-olds (see referral forms & supporting annex for additional screening tools). The Autism Diagnostic Observational Schedule Second Edition (ADOS-2; Lord et al., 2012) (twelve months and older module) is also a suitable instrument to identify Autism for this age range. Often these assessment measures are deficit-focused and so it is important to also identify the strengths and potential of the child, as these may be provide crucial traction for supports and services to be effective.

### Children 6–11 years

Often Autism in children may remain unidentified into late childhood or adolescence, or until the social demands of school and social activities highlight their difficulties. Key indicators of Autism in children of this age include communication difficulties such as unusual language development/limited use of language; social difficulties such as lack of engaging with other children during play, lack of implicit knowledge about social norms, such as in the classroom, hypersensitivity to sensory stimulation and enjoying personal space (Missouri Autism Guidelines, 2010).

Suitable screening measures include the Social Communication Questionnaire (SCQ; Rutter et al., 2003) for those aged 4 years and older, the Social Responsiveness Scale (SRS-2; Constantino & Gruber, 2012) for 4–18-year-olds, and the Childhood Autism Spectrum Test (CAST; Scott, BaronCohen, Bolton, and Brayne, 2002) for 4–11-year-olds. The ADOS-2 (Lord et al., 2012) can be used as an Autism classification instrument for this age group.

### Adolescents 12–19 years

As mentioned previously, individuals with Autism may remain unidentified into adolescence until difficulties in social interaction become apparent in comparison to their peers. Common characteristics to be aware of include being socially naive in comparison to peers, atypical speech, difficulties initiating and maintaining social relationships, highly specific/restricted interests and difficulty using imagination (Ellison-Wright and Boardman, 2015). Suitable screening measures include the Social Responsiveness Scale (SRS-2; Constantino and Gruber, 2012) for 4–18-year-olds, and the Social Communication Questionnaire (SCQ; Rutter et al., 2003) for those 4 years and older. The ADOS-2 (Lord et al., 2012) is a suitable classification instrument for this age group.

### Adults

Research undertaken as part of a UK National Autistic Society ‘I Exist’ (2009) campaign for Autistic adults found that adults without an intellectual disability are often left without services and experience a lack of support. It was found that a person-centred approach is most suitable for meeting the needs of Autistic adults. This includes social skills training programmes, support groups and social activities (Health and Social Care Board, 2013; National Autistic Society, 2009). Although it should be noted that social skills training is deficit-focused and that many Autistic people do not have such interaction ‘deficits’ with other Autistic people (Crompton et al, 2020). Therefore a greater appreciation of the range of interaction styles across the Autistic and non-Autistic spectrum may be equally important.

As with children, inter-disciplinary team assessment is recommended for assessing adults suspected of being Autistic where possible (Rescorta and Schwartz, 1990). Some best practice guidelines outline four main elements that constitute a classification assessment for adults (for example Health and Social Care Board, 2013; NICE guidelines CG 142, 2012):

1) A neuro-developmental history obtained from a family member or relative.
2) A direct Autism assessment with the individual while considering possible differential classifications for their difficulties.
3) An observational assessment.
4) Use of clinical judgement in formulating a classification, based on evidence collected.

The ADOS-2 (Lord et al., 2012) may be used with adults. It is recommended that numbers 2–4 listed above constitute the minimum requirement level of assessment for adults (Health and Social Care Board, 2013). Furthermore, additional assessments may also be conducted which measure adaptive functioning and cognitive ability where necessary, to gain an overall understanding of an individual’s ability to work and live independently (Health and Social Care Board, 2013; Ministries of Health and Education, 2016). For example, assessment of an individual’s functioning in different settings such as the home, workplace, or education settings. The WAIS-IV (Wechsler, 2008) is a useful measure that can be administered to establish the presence of an intellectual disability in adults.

### Special interests

Autistic people often show an intense focus on special interests which can have major benefits for themselves and society. It can lead a person to excel in their topic of interest, along with an acquisition of knowledge and expertise. Strength-based programmes promote Autistic people’s special interests, which can help them develop skills to inform career guidance and meaningful employment. Specific interests (such as arts or sports) have been reported to facilitate coming in contact with other people and improving social interaction skills among Autistic people (Mahdi et al, 2018). An important reason for the success of a surprising number of Autistic people is that they may concentrate strongly on some special interests (Overskeid 2016). Such special interests can motivate learning, be a valuable source of enjoyment, help to overcome anxiety and promote social inclusion. One of the strengths possessed by some Autistic people is in the ability to acquire knowledge and facts, and this can be an effective way of reducing anxiety (Attwood, 2006). Such special interests may be of great practical value, for example, restoring antiques or writing computer programmes. Such interests can occupy time, reflect intelligence and facilitate conversation. The interest may also be more playful, for instance, it could be creation of an alternative world for Autistic children who are interested in periods of history where they become the character who is popular, happy and successful.

## Abilities and strengths

When undertaking assessments, it is important to capture the entire spectrum of functioning in Autism, not only from a clinical perspective but also to affirm a person's abilities and strength profile. Exploring strengths can also help to balance out difficulties; facilitating interventions that are less stigmatising and focused more on reinforcing already existing individual strengths (Mahdi et al, 2018). Even though Autism is primarily defined by challenges in various aspects of daily life, it may also entail specific strengths, such as attention to detail, (Baron-Cohen et al, de Schipper et al 2016), enhanced visuo-spatial skills (Happe and Frith 2009), creativity and excellent memory (Mahdi et al, 2018). Autistic traits that contribute to persistence and a strong focus on goals can enhance a person's chance of reaching ambitious objectives (Overskeid, 2016). Fictional depictions of Autism often focus on savants (Draaisma 2009) reinforcing the commonly-held myth that all people with Autism have a special talent or savant skill (Stern et al 2019). However, Autistic people, like others, may possess many admirable characteristics, including a strong sense of morality, loyalty, trustworthiness, single-minded determination and an impressive ability to memorise facts.

## Autism and co-occurring conditions

Autism can co-occur with a range of developmental, genetic, mental health and other conditions. For example, approximately 18 per cent of Autistic people in a Scottish population study were found to have a co-occurring intellectual disability (Dunn et al, 2019), and approximately 10 per cent were identified as having co-occurring epilepsy (Liu et al, 2022), However, Liu et al's systematic review found that prevalence estimates varied between 19 per cent and 7 per cent, depending on the service and setting where the data was collected, with confidence intervals varying from 4 –35 per cent across studies. Autism and Attention Deficit Hyperactive Disorder (ADHD) share similar difficulties with social skills and arousal regulation. Approximately 28 per cent of Autistic children are found to have co-occurring ADHD (Simonoff et al., 2008) although more recent research has suggested that this co-occurrence is much higher (Hours et al., 2022 ). Research has also found gastrointestinal problems such as GI reflux, colitis, esophagitis, gastritis, celiac, inflammatory bowel disease (IBD), constipation, diarrhoea and vomiting to commonly co-occur with Autism (9-70 per cent, Edeleson, 2016).

Autism has also been found to co-occur with certain genetic disorders. For instance, Autism prevalence rates have been found to be higher in individuals with the following genetic disorders: Fragile X syndrome (21–50 per cent); Rett syndrome (40–97 per cent) and Down syndrome (39 per cent); Moss & Howlin, 2009). Further common Autism co-occurrence include gastro-intestinal problems (24 per cent; Molloy and Manning-Courtney, 2003); feeding problems (33 per cent; Ledford and Gast, 2006) and sleep difficulties (50 per cent–80 per cent; Couturier et al., 2005; Fombonne, 2005; Mannion and Leader, 2013). Language 'disorders' (that combines DSM expressive language disorder and mixed receptive-expressive language disorder) and social (pragmatic) communication disorder also have a higher prevalence rate in Autistic individuals compared with the general population (Taylor and Whitehouse, 2016). And while evidence is limited, there is a relatively higher prevalence rate of Autism in children and adolescents with gender dysphoria (7.8 per cent; De Vries et al., 2010; Glidden, Bouman, Jones and Arcelus, 2016). Additionally, developmental coordination disorder has also been identified in individuals with Autism more commonly than the general population (Cairney and King-Dowling, 2015). Clinicians need to factor in the potential presence of such co-occurring conditions when assessing for Autism.

## Mental Health, Suicide and Autism

Research suggests a higher prevalence of mental health difficulties among individuals with Autism (Bradley et al., 2004). Approximately 70–80 per cent of Autistic children (Simonoff et al., 2008) and adults (Lever and Geurts, 2016) have mental health difficulties, with depression and anxiety being the most prevalent co-occurring conditions (Simonoff et al., 2008). The latter can significantly hinder one's level of social functioning and negatively impact on one's quality of life, thus affecting one's level of wellbeing (Mattila et al., 2010). However, as many as 62 per cent of Autistic young people with mental health concerns may not know how to access appropriate support services and of those who do access services, they may experience long delays, poor transitioning supports between services, and a lack of knowledge and understanding from staff about Autism (Crane et al., 2017).

Research has also suggested that the experience of Autism may be associated with self-harm and/or suicidal ideation. Crane et al (2019)2 found that young Autistic people may find it difficult to evaluate their own mental health and that they may experience high levels of stigma. Coupled with this they may also face considerable obstacles if they wish to access mental health supports. In a large-scale population study in Denmark, Kõlves et al (2021)[3] reported significantly higher rates of attempted suicide and suicide among people with Autism compared to the general population. The rate of attempted suicide in Autistic girls and women was higher than with Autistic boys and men. Such rates were especially high for people with Autism who also experienced anxiety and depression.

These findings are clearly concerning and highlight the need for clinicians to consider the possibility of self-harm, suicide ideation and mental health needs among people with Autism and especially females, across the age span. Importantly, Kõlves[2] et al (2021) also found that factors traditionally predictive of, or protective for, suicide in the general population did not apply in the same way for Autistic people. This may make it more difficult to identify self-harm or suicidal ideation as older Autistic children and adults may be more effective at masking their mental health needs: and so clinicians should explore the possibility of feelings about self-harm and suicide ideation. Hirvikoski et al. (2020) found the risk for suicidal behaviours was most increased in Autistic people with co-occurring ADHD, and without an intellectual disability. For this group there was a seven-fold increased likelihood of suicide attempts, a twelve-fold increased likelihood of being admitted as an inpatient, and a thirteen- fold increased likelihood of death by suicide.

In a population study in England of those who had died by suicide, Cassidly et al (2022) found that either diagnosed Autism or the likely presence of Autistic traits, was associated with close to a twenty-fold increase in the likelihood of suicide. Importantly they also found that 'characteristics of those who died were largely similar regardless of evidence of Autism, with groups experiencing a comparably high number of multiple risk markers before they died' (p.683), suggesting that suicidal thoughts or actions are not inherently linked to Autism, but rather they are associated with the experience that Autistic people have of the world.

Conceptualising the relationship between mental health difficulties and Autism as simply co-occurring or 'co-morbid' conditions is to suggest that these are independent conditions that happen to coincide for some people. However, in reality they are usually *interlinked and interrelated*. For example, the ways in which an Autistic person may struggle with some sensory experiences may influence their social-communicative behaviour, and this may in turn be associated with withdrawal, or worries about how others evaluate them. This may then develop into depression or anxiety. The *interlinked* nature of Autism and mental health conditions means that it is incumbent upon our services to meet people where they are, rather than shunt them across services to address different aspects of their interlinked behaviour. Mental health conditions also often arise from the experience that Autistic people have of stigma and marginalisation and indeed a lack of or delayed access to services. Mental health difficulties may therefore be 'iatrogenic'– caused by the very system that is intended to help.

## Differential classification considerations

A *differential classification* is the distinguishing of one cluster of experiences from others that present with similar clinical features. As experiences associated with Autism are common to other difficulties (see Table 2), the process of determining whether an Autism classification is warranted requires assessing for co-occurring presentations and possible alternative classifications (Miriam Foundation, 2008; Missouri Autism Guidelines, 2010; PSI, 2022). For example, hand flapping and repetitive movements may be due to global developmental delay, obsessive compulsive 'disorder' (OCD), severe anxiety, or stereotypic movement 'disorder' (Missouri Autism Guidelines, 2010). Furthermore, difficulties in communication and language abilities may be due to global language delay or intellectual disability, for example (Foss-Feig and Macpartland, 2016), and attachment difficulties, such as insecure or disorganised attachment may explain other behaviours thought to be associated with Autism (BPS, 2017, NICE, 2015). Many factors are involved when determining a possible differential classification such as the use of clinical judgement by experienced clinicians, extensive knowledge of typical and atypical development, and the use of psychometric measures (Ministries of Health and Education, 2016; Miriam Foundation, 2008; Van Schalkwyk et al., 2015).

### Determining a differential classification

When determining a differential classification, an individual’s behaviour needs to be considered in terms of their overall developmental history, as do the use of evaluation procedures (Ministries of Health and Education, 2016; Missouri Autism Guidelines, 2010). Clinicians also need to be knowledgeable about presentations of both Autism and common co-occurring conditions and alternative classifications across the lifespan (Ministries of Health and Education, 2016; Missouri Autism Guidelines, 2010). For example, when a period of typical development of two or more years has occurred, the possibility of other disorders such as selective mutism, disintegrative ‘disorder’, or schizophrenia should also be considered (Rutter et al., 1994). Consideration of an individual’s full developmental abilities is an important factor during an Autism assessment, so parents need to provide specific examples of behaviours throughout their child’s development to help determine an accurate classification (PSI, 2022; SIGN, 2016).

In relation to assessment tools, cognitive or neuro-psychological assessments can provide useful information about an individual’s overall level of cognitive ability and level of functioning, and may also aid in identifying, for example, the presence of an ID (SIGN, 2016) Additionally, the Coventry Grid Interview (CGI) was developed to aid in, and supplement a clinician’s ability to differentiate Autism from attachment difficulties or identify the co-occurrence of both (Flackhill, James, Soppitt, and Milton, 2017). The CGI was developed for use with individuals having average to mild rather than severe difficulties, and for use to aid and supplement a formulation rather than for use as a classification tool (Flackhill et al., 2017). The CGI is developed from the Coventry Grid which has been found to have reasonably wide clinical acceptance and face validity, being originally developed and used by Moran (2010; 2015). However, further research is needed to establish its construct validity (Flackhill et al., 2017).

## Possible differential classification and co-occurring conditions associated with Autism

### Table 16

| **Type of difficulties** | **Possible associated conditions**<br>*While the term 'disorder'or 'deficit' are not preferred in this protocol, they are nonetheless used below to avoid confusion, where they are currently the formal name of possible associated conditions.* |
|---|---|
| Associated with multiple areas of difficulty | • Childhood onset dementia<br>• Early onset psychosis<br>• Intellectual disability<br>• Reactive attachment disorder<br>• Schizophrenia<br>• Traumatic brain injury |
| Associated with difficulties in language and/or communication | • Selective mutism<br>• Social (pragmatic) communication disorder<br>• Developmental language disorder (DLD)<br>• Specific language disorder |
| Associated with social interaction problems | • Attention Deficit Hyperactivity Disorder (ADHD)<br>• Depression<br>• Personality disorders<br>• Reactive attachment disorder<br>• Social anxiety disorder<br>• General anxiety disorder |
| Associated with restricted interests or repetitive behaviours | • Obsessive compulsive disorder<br>• Stereotypic movement disorder<br>• Tourette's syndrome |
| Associated with Autism | • Developmental coordination disorder<br>• Gender dysphoria<br>• Physical disability |

| **Type of difficulties** | **Possible associated conditions**<br>*While the term 'disorder'or 'deficit' are not preferred in this protocol, they are nonetheless used below to avoid confusion, where they are currently the formal name of possible associated conditions.* |
|---|---|
| Possible co-occurring difficulties associated with Autism | • Intellectual disability<br>• Physical disability<br>• Sensory processing dysfunction<br>• Attention deficit hyperactivity disorder<br>• Affective disorders<br>• Obsessive compulsive disorder |
| Possible medical conditions associated with Autism | • Degenerative neurological or metabolic conditions<br>• Down Syndrome<br>• Epilepsy |

### Required Autism classification competencies

In terms of risk management, to identify clinicians who are competent in accurately identifying Autism using their informed clinical judgement, the Missouri Autism Guidelines Initiative (2010, pp.46-47) recommend that competent clinicians should possess the following skills and characteristics:

- Fully licensed and qualified to give a classification based on receiving appropriate training and experience in assessing Autism;
- Extensive knowledge regarding typical and atypical development, Autism presentation in individuals of differing levels of cognitive ability, possible differential classification of Autism, and Autism presentation across the lifespan;
- A commitment to regular reviews of new research and being knowledgeable about current best practice guidelines;
- Participant in on-going education and training;
- Willing to learn about and source the latest screening and classification instruments, being aware of new methods of assessments and intervention and maintaining an awareness of local and regional community resources.

- A self-awareness of the limits of their professional clinical competencies by being able to determine instances where he/she can provide an Autism classification based on their informed clinical judgement and when additional standardised assessment tools are required to inform the classification decision.
- Familiarity with neuroaffirmative concepts, language and practices.

A further important consideration in terms of managing risk is to ensure that healthcare clinicians are appropriately trained, and supported in gaining the necessary skills and competencies to assess for Autism. The *'Autism Training Framework: Optimising Outcomes'* (NHS Education for Scotland, 2014) has outlined the appropriate level of skills and knowledge required by professionals working at different levels of Autism service delivery. The framework discusses four main levels of expertise (as per Table 3, p.15). This framework is included to give a broad understanding of different levels of skillsets often involved in services that may encounter Autistic individuals; from teachers, special needs assistants, and general practitioners, to professionals who work at a more specialist or 'expert' level of Autistic services such as Autism assessment and classification; for example, psychologists, psychiatrists, and paediatricians, speech and language therapists, and occupational therapists.

## Levels of expertise for professionals working with Autistic individuals

### Table 17: Based on the Autism Training Framework's levels of expertise for professionals working with Autistic individuals

| Level of expertise | Definition | Broad description of role |
|---|---|---|
| 1. Autism informed | Basic Autism general awareness knowledge required by all health and social care professionals | • Likely to work in a role which may encounter Autistic individuals on a daily basis<br>• Having an awareness of such features/behaviours and their possible relatedness to Autism and adapting work environment and own behaviours accordingly<br>• Examples: dentists, nurses, etc.<br>*Knowledge and skills:* Autism awareness |

| Level of expertise | Definition | Broad description of role |
|---|---|---|
| 2. Autism skilled | Knowledge required by professionals who have frequent contact with Autistic individuals | • Those who work in a service who may encounter Autistic individuals Need to be able to identify behaviours and signs related to Autism to be considerate of this in terms of environment and own behaviours<br>• Being able to identify individuals who may need referral for Autism assessment Examples: mental health staff, GPs, other types of medical doctors, dietitians, audiologists, etc.<br>*Knowledge and skills:* Autism awareness, administration of screening measures/ screening procedures |
| 3. Autism enhanced | Refers to staff who have more regular/ intense contact with Autistic individuals and whose role focuses specifically on working with said individuals, providing intervention and managing care | • Role may involve participating as part of MDT assessments and/or conduct initial screening and assessment of individuals<br>• Involved in referring for further assessment to specialist services, for differential classification assessment, or for second opinions<br>• Examples, social workers, occupational therapists, speech and language therapists and psychologists<br>*Knowledge and skills:* Screening and classification assessment of Autism, possibly being involved in differential classification/ comorbidity assessments, knowledge of Autism prevalence and different presentations |

| Level of expertise | Definition | Broad description of role |
|---|---|---|
| 4. Autism expert | Highly specialist knowledge required by professionals who play a specialist role in Autism care, management, and support of Autistic individuals | Professionals who regularly conduct assessments and offer differential classification opinions of complex cases as well as training and supervising others in assessment and classification<br>Likely, but not limited to those who work in specialist services or those who have responsibility in expert classification assessment and managing other staff<br>Likely to be involved in training and consultation of other staff members<br>Examples: Psychologists, psychiatrists and paediatricians<br>*Knowledge and skills:* Knowledge in administration of a range of screening and assessment tools, of possible differential diagnoses, co-occurring conditions, current scientific evidence, trainer qualifications, consultancy/supervision roles |

Note: The above table gives a broad and brief description of such skill levels and associated disciplines. Associated disciplines involved in Autism service delivery can be much broader than those listed, and while being conscious of working within one's professional competencies, may be involved in different levels of Autism service delivery in which they are suitably qualified and trained.

## Training

Research has found that many primary healthcare professionals may have misconceptions regarding characteristics of Autism such as social/emotional problems, cognitive dysfunction, general descriptive features of Autism (Stone, 1987), and identification and treatment of co-occurring conditions (Mazurek, Brown, Curran and Sohl, 2017). Furthermore, gaps in training for professionals working with Autistic individuals has been reported, which has been identified as a key barrier to services for Autistic individuals and can lead to service delivery being less effective (Mazurek et al., 2017; SIGN, 2016). Given that primary healthcare professionals are well placed to identify early signs of Autism in children, it is necessary that they receive adequate training to improve their competencies in delivering Autism care at a primary level (Johnson and Myers, 2007). Likewise, those working in secondary care services (such as Children's Disability Teams, CAMHS) are often assumed to be competent and confident in screening, assessing and identifying Autism when often this may not be the case. In such instances, it is important that professionals be aware of the limits of their competencies and that each service undertakes a skills audit of team members to highlight required training needs.

In response to the identified training needs of healthcare professionals, various training models have been developed. For example, Mazurek et al. (2017) successfully implemented the Extension for Community Healthcare Outcomes (ECHO) model in primary healthcare services to improve the competencies of professionals working in such services in the areas of: (1) screening and identification of Autism symptomatology; and (2) management of common co-occurring conditions and differential diagnoses associated with Autism. This involved running weekly ECHO clinics where, via secure video-conferencing, specialists provided education to primary healthcare professionals on the above factors through best-practice treatment protocols, case-based learning, and co-management of cases (Mazurek et al., 2017; Sohl, Mazurek and Brown, 2017). This mentoring relationship between specialists and primary healthcare providers allowed for the implementation of high quality Autism service delivery at primary care level, a tiered model of service delivery and facilitated early intervention for service users (Mazurek et al., 2017).

The *Training Plan for ASD* (NHS Education for Scotland, 2014) was also developed, detailing the specific training needs of health and social care professionals based on the four appropriate levels of skills and knowledge outlined above.

## Supervision

In addition to training, competence can also be developed through ongoing supervision and consultation with experienced clinicians (NICE, 2011; Rogers et al., 2017). Supervision has been defined as ‘the provision of monitoring, guidance, and feedback on matters of personal, professional, and educational development’ (Kilminster and Jolly, 2000). Clinical supervision has been identified as a significant factor in the careers of both trainee and practising psychologists (Norcross, Hedges and Castle, 2002), doctors, speech and language therapists, occupational therapists, and other healthcare professionals (Kilminster and Jolly, 2000). For example, a competency-based clinical supervision framework is employed in health and social care disciplines, whereby professionals are required to work only within the scope of their competencies. Additionally, professionals are required to work in line with their associated disciplines’ professional conduct guidelines and ethical standard regulations – for example, the Psychological Society of Ireland (PSI), the Medical Council for medical professionals in Ireland, the Irish Association of Speech and Language Therapists (IASLT), and the Association of Occupational Therapists Ireland (AOTI) for occupational therapists.

## Flexibility of assessment practices and triaged pathways

Debate and conflicting recommendations exist between guidelines concerning the need for the use of psychometric instruments in Autism assessment and the extent which informed clinical judgement should play in Autism assessment. Certain best practice guidelines recommend the use of one of more standardised tools, such as the Autism Diagnostic Inventory-Revised (ADI-R; Rutter, Le Couteur and Lord, 2003) and the ADOS-2 (American Academy of Neurology, 2000; British Columbia, 2003; NICE, 2011). In contrast, others such as the Miriam Foundation (2008, p.49) recommend the ADI-R and ADOS as ‘gold standard’ assessment tools, but to also allow flexibility whereby classification assessments by competent clinicians with suitable expertise that do not involve using standardised instruments ought to be accepted. However, others strongly disagree with the idea that there is a ‘gold standard’ in Autism assessment, noting a range of shortcomings of all assessment instruments and an over-reliance on the scores arising from these instruments rather than on broader clinical judgement which is more focused on the specific experiences of the individual being assessed (Henderson, Wayland and White, 2024).

The American Academy of Child and Adolescent Psychiatry (2014) document, *Practice Parameters for the Assessment and Treatment of Children and Adolescents with Autism Spectrum Disorders* Volkmar et al., 2014) provides a list of available assessment tools while highlighting the importance of the use of informed clinical judgement in the assessment process, and recommends that the use of such instruments supplement and not replace clinical judgement (Volkmar et al., 2014). Similarly, the British Psychological Society (BPS; 2015) further highlights the importance of using informed clinical judgement during the interpretation of psychological assessment results, that is whether derived scores reflect an individual's true abilities and whether presentations may be related to other causes such as trauma etc. (p.22).

Overall, research has concluded that although best practice guidelines such as NICE (2011) and SIGN (2016) argue for the use of 'gold standard' assessments, this may not be necessary for all cases, such as those where Autism is clearly apparent during initial developmental assessments and for non-complicated cases (Missouri Autism Guidelines Initiative, 2010; Rogers, Gibney, O'Connor, and Byrnes, 2017; Rutherford et al., 2017; Rutherford et al., 2016). Non-complex cases may be defined as those with an absence factor such as co-occurring conditions and a lack of contextual factors such as neglect or family/ professional disagreement (Rutherford et al., 2017). As such, it was found that inflexibility about the use of standardised assessment tools (such as mandating the use of such tools when assessing for Autism) and practices may result in inefficiency of already stretched resources and can leave clinicians with little room to tailor services to the specific needs and presentations of individuals (Penner et al., 2017; Woolfe et al., 1999). The need for flexibility in Autism assessment procedures and increased use of clinical judgement was also highlighted in terms of ability to be less resource intensive and its potential to decrease waiting lists (Rogers et al., 2017).

In response to this, an 'abbreviated pathway' has been suggested as possibly more appropriate for cases where Autism is clearly apparent during a developmental assessment or those which are non-complicated (Rutherford et al., 2017). This abbreviated pathway would involve a less complex assessment, usually carried out at a local level, using reports and observations in a range of contexts and a classification confirmed by at least two clinicians without further referral to specialist teams (Rutherford et al., 2017). As noted by Rutherford et al. (2017), additional research would be needed to validate whether such abbreviated assessment pathways are robust and reliable. However, Rogers et al. (2017) concluded that the accuracy of Autism assessments in correctly identifying Autism will be maintained through clinical supervision by highly competent clinicians in contrast to standardisation of the assessment process. A study by Wieckowski et al (2021) entitled *The First Five Minutes* …', explored clinicians' initial impression of whether a child was Autistic or not (recorded after five minutes of seeing a child in this study). In this case 92 per cent of cases initially thought to have ASD fulfilled the criteria following a full evaluation. However, in 24 per cent of cases that were initially thought not to have ASD, the criteria were also subsequently met. This suggested that after five minutes clinicians are more accurate in identifying, rather than ruling out Autism (see also the previous discussion on clear or ‘frank’ presentations).

It should be noted that clinicians who are involved in Autism classification assessment must have extensive experiencing in working with Autism and be suitably trained and qualified to conduct such assessments (ETS, 2013; Lord et al., 2012). Best practice guidelines have also highlight the importance of having competent professionals who use their clinical judgement in informing whether a classification of Autism is warranted (Ministries of Health and Education, 2016; Missouri Autism Guidelines Initiative, 2010). Informed clinical judgement requires knowledge in the following areas (Missouri Autism Guidelines Initiative, 2010):

- Typical and atypical development;
- Presentations of Autism in different cohorts, such as girls, those with varying levels of cognitive ability, and those with co-occurring conditions;
- Differential classification of Autism from other difficulties and disabilities, including mental health problems, developmental disturbances, and intellectual functioning; and
- Presentations of Autism across the lifespan.

### Inter-disciplinary and inter-agency working

As noted above, debate exists within the literature and best practice guidelines regarding recommendations for the use of MDT assessments (Penner et al., 2017). Research has found that although many guidelines recommend multi- or inter-disciplinary team assessments (such as Ministries of Health and Education, 2016; Miriam Foundation, 2008; NICE, 2011; SIGN, 2016), there is little empirical evidence at present that suggests such practices are superior in quality to that of a sole clinician in all circumstances (Penner et al., 2017). However, it has been noted that MDT assessment is often required to accurately develop a neurodevelopmental profile of a child’s strengths and weaknesses (Dua, 2003; Miriam Foundation, 2008; NICE, 2011), for consideration of differential classification (Miriam Foundation, 2008), and for assessing for co-occurring conditions (Miriam Foundation, 2008; Volkmar et al., 2014).

Considering this, and while acknowledging the scarcity of resources in geographical areas, certain guidelines allow for flexibility in practices surrounding MDT assessments. For example, the Miriam Foundation (2008) notes that assessment practices need to be flexible (for example in accepting findings from assessments conducted by sole clinicians) for cases where an Autism classification is clear or ‘obvious’ (p.39), or in circumstances where inter-disciplinary team assessment cannot be accessed. Additionally, the New Zealand ASD Guidelines (Ministries of Health and Education, 2016) and the American Academy of Paediatrics (2001) both indicate that although multi-disciplinary team assessment is preferred, there is flexibility for a competent clinician to carry out assessments by themselves. It should be noted, that the acknowledgement of the need for flexibility in practice does not undermine the need for multi-disciplinary team assessment (and use of standardised assessment measures) in instances where co-occurring conditions and differential classification considerations are mandated (Miriam Foundation, 2008; NICE, 2011). On this note, it has been recommended that clinicians consider multiple domains when assessing for Autism and a decision to be made on appropriate assessment procedures (see Table 4; NICE, 2011).

**Table 18: Domains requiring consideration when assessing ASD**

| | |
|---|---|
| • Feeding problems/gastrointestinal issues<br>• Nutrition<br>• Adaptive behaviour<br>• Challenging behaviour<br>• Sociability<br>• Sleep problems<br>• Vision and hearing impairments | • Communication<br>• Fine and gross motor skills<br>• Mental health<br>• Hyper- or hypo-reactivity to sensory stimulation<br>• Speech and language<br>• Intellectual ability and learning style |

Common members of the MDT in Autism services includes paediatricians, psychologists, speech and language therapists, occupational therapists, physiotherapists, dieticians, nurses, social workers (National Clinical Programme for Paediatrics and Neonatology, 2011). To ensure that areas of concern are assessed in an integrated manner (with service users not being ‘bounced around’ the healthcare system), effective interdisciplinary and inter-agency working is a necessity (Cowley et al., 2001; HSE, 2017a, 2017b). The following facilitators of effective interdisciplinary and interagency working are recommended:

## Facilitators of interdisciplinary working

- All team members report to a team manager who is accountable for team performance;
- A team manager role is competency-based rather than restricted to a particular profession;
- No single profession or individual assumes a domineering role in team discussions;
- All team members have access to appropriate training and clinical supervision;
- Team members also agree on shared roles, where different team members can undertake some of the same tasks, depending on availability, or rotation;
- The team has access to designated administrative support (such as scheduling of appointments; typing of reports);
- Team members are co-located;
- Joint working and consultation for cases where a practitioner identifies the need for additional advice and liaison (HSE, 2017b);
- Team members agree on individual professionals' roles or 'who does what';
- Team members are specifically designated to work on only one team;
- There are protocols detailing work processes for meeting service users goals;
- There is 'parity of esteem' whereby all team members and their input is equally valued;
- Team members are committed to interdisciplinary team working; and decision-making is evidence-informed, inclusive and timely.

## Facilitators of interagency working

- There is consistent adherence to inter-agency working protocols between health (such as Primary and Secondary Care Services); and other services (such as Tusla; educational and vocational);
- There is a commitment to timely discussion and resolution of disputed issues (such as Integrated Children's Services Forum); and
- Assigned to each service user, a named contact team member provides a point of contact for all parties involved. Referred to as a Link Worker in this protocol

While the most commonly recommended personnel for an Autism assessment have been found to be physicians for a medical assessment, a speech and language therapist for a language assessment and a psychologist for a cognitive assessment (Penner et al., 2017); it has also been noted that the skill set required to assess an Autistic individual is not exclusive to specific disciplines, but rather derived from appropriate experience and training (SIGN, 2016). With appropriate training and support other disciplines may also have a key role to play, as indicated in our protocol.

### Pre-assessment intervention

Providing generic interventions for people with possible Autism prior to concluding an Autism assessment can facilitate early intervention that in turn can improve functional outcomes, relative to delayed intervention (Penner et al., 2015). Additionally, early intervention may be very cost-effective in terms of reducing future intervention needs of individuals (Penner et al., 2015).

Providing pre-assessment intervention is also supported by Autism guidelines such as the Six Steps of Autism Care (Health and Social Care Board, 2011).

Research has identified the following characteristics of interventions that may yield positive outcomes (Howlin, Mawhood and Rutter, 2000):

- Enhances an individual’s strengths;
- Employs natural reinforcers;
- Use of structured behavioural approaches;
- Conducts functional analysis of communication;
- Are predictable and consistent;
- Result in modification of the environment;
- Promotes engagement with typically developing peers; and Parent-mediated/ carer involvement.

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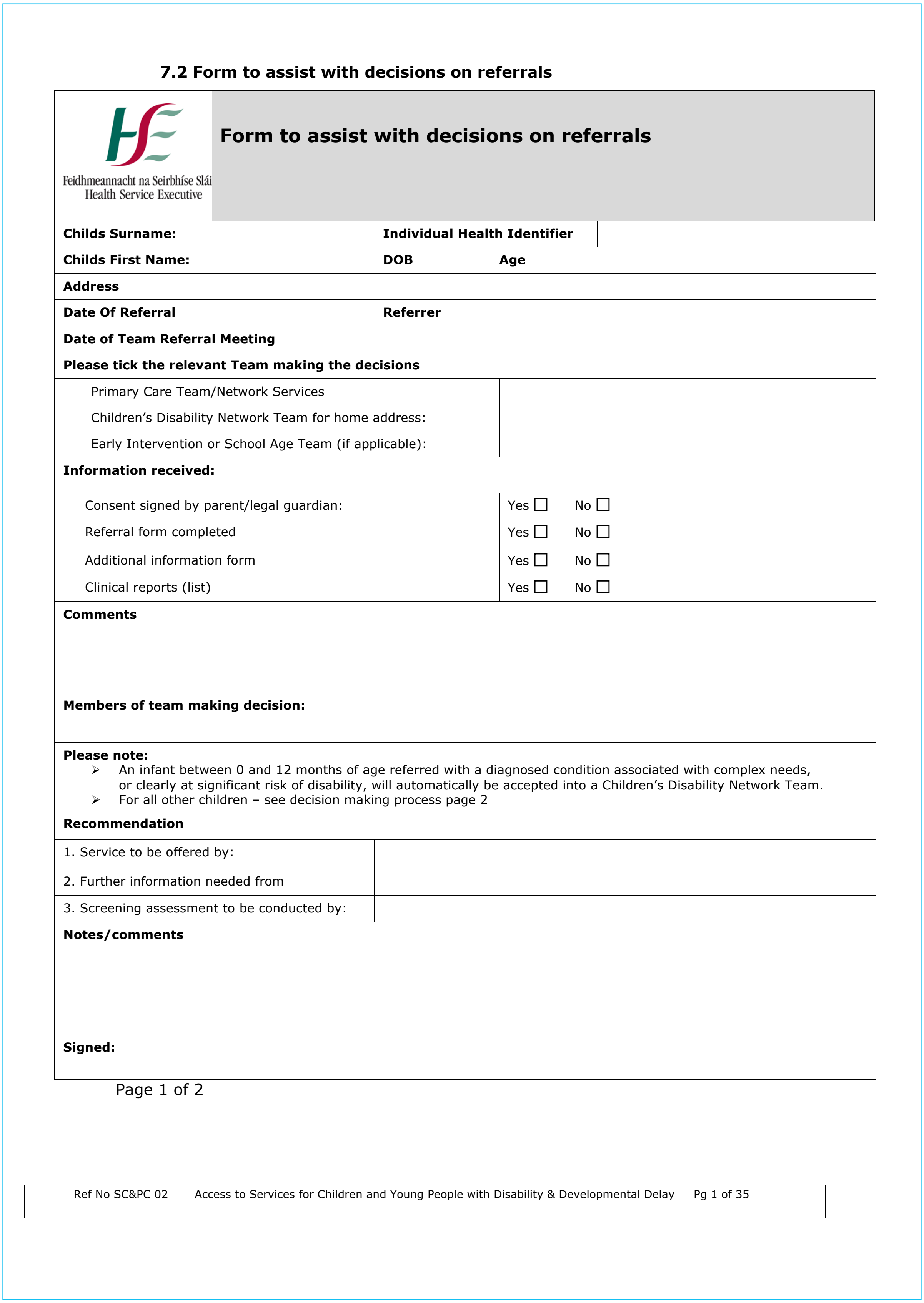
# Appendix 8: NAP referral forms

## Form to assist with decisions on referrals



### 7.2 Form to assist with decisions on referrals

Feidhmeannacht na Seirbhíse Slái
Health Service Executive

**Form to assist with decisions on referrals**

| | | |
|---|---|---|
| **Childs Surname:** | **Individual Health Identifier** | |
| **Childs First Name:** | **DOB** | **Age** |
| **Address** | | |
| **Date Of Referral** | **Referrer** | |
| **Date of Team Referral Meeting** | | |
| **Please tick the relevant Team making the decisions** | | |
| Primary Care Team/Network Services | | |
| Children's Disability Network Team for home address: | | |
| Early Intervention or School Age Team (if applicable): | | |
| **Information received:** | | |
| Consent signed by parent/legal guardian: | Yes ☐ No ☐ | |
| Referral form completed | Yes ☐ No ☐ | |
| Additional information form | Yes ☐ No ☐ | |
| Clinical reports (list) | Yes ☐ No ☐ | |
| **Comments** | | |
| **Members of team making decision:** | | |
| **Please note:**<br>➢ An infant between 0 and 12 months of age referred with a diagnosed condition associated with complex needs, or clearly at significant risk of disability, will automatically be accepted into a Children's Disability Network Team.<br>➢ For all other children – see decision making process page 2 | | |
| **Recommendation** | | |
| 1. Service to be offered by: | | |
| 2. Further information needed from | | |
| 3. Screening assessment to be conducted by: | | |
| **Notes/comments**<br><br>**Signed:** | | |

Page 1 of 2

Ref No SC&PC 02 Access to Services for Children and Young People with Disability & Developmental Delay Pg 1 of 35

## Identifying complexity of the child's needs

**Child's Name:** **DOB:**

| | | | | | | |
|---|---|---|---|---|---|---|
| | **Area of function and participation (see Explanatory Guide to assist with decisions on referral)** | **Range & extent of child's functional difficulties and medical needs (put a tick or number in *one* column only for each row)** | | | | |
| | | **A** | **B** | **C** | **D** | **E** |
| | | **Insufficient information *(tick)*** | **No difficulty *(tick)*** | **Some difficulty = 1** | **Significant difficulty = 2** | **Highly significant difficulty = 3** |
| **1** | **Movement (Gross motor skills)** | | | | | |
| **2** | **Fine motor skills** | | | | | |
| **3** | **Communication** | | | | | |
| **4** | **Social interactions relationships and play** | | | | | |
| **5** | **Daily Living Skills** | | | | | |
| **6** | **Behaviour & emotions** | | | | | |
| **7** | **Learning & applying knowledge and skills** | | | | | |
| **8** | **Vision and hearing** | | | | | |
| **9** | **Sensory Processing** | | | | | |
| | **Medical needs** | | **None (tick)** | **Some Needs=1** | **High Needs =2** | **Very high needs = 3** |
| | **Summary**<br>**Totals for each column** | [redacted] | [redacted] | | | |
| | **Total =** | | | | | |
| | **All decisions on the most appropriate service for a child must be based on clinical judgment. This form and the suggested scoring is only to be used as a guide.**<br>**1-2 Primary Care is likely to be the appropriate service to meet child's needs**<br>**3-6 Decision to be informed by needs for interdisciplinary team and by family, environmental and other factors. Needs may be met by Primary Care Services or Children's Disability Network Team or jointly.**<br>**7 -30 Children's Disability Network Team is likely to be the appropriate service to meet child's needs**<br>**Comments** | | | | | |

### 7.3 Explanatory guide for form to assist with decisions on referrals

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Health Service Executive

## Explanatory guide for using the form to assist with decisions on referral

**The form is only intended to provide a consistent means of organising the available information about the child at the time of referral and for no other purpose. It is not appropriate for use to determine ongoing intervention or discharge/transfer from a service.**

### Referral Form

There is one national referral form and four age appropriate forms for additional information (birth to 12 months, 1 year to 5 years 11 months, 6 years to 11 years 11 months and 12 years to 18 years). These forms ask for information about the child and family, what the family's concerns are, what they would like their child to gain from attending the service and details of the child's development. This information will be provided by the parents/family, assisted where necessary by a professional. The level of detail requested supports the decision making process to determine the most appropriate service to meet the child's needs and also provides baseline history and information, which will not subsequently have to be sought by members of the team.

Referrals with insufficient information will not be accepted as services cannot direct the referral to the appropriate service and prioritise the referral. The referral form, additional information forms and local information leaflet for referrers with local contacts should be distributed widely and regularly to referral agents and local Health Centres.

### Form to assist decision making on referrals

The form has been developed to assist Primary Care Services, Children's Disability Network Teams and the Integrated Children's Service forums to make consistent decisions on which would be the appropriate service to meet the needs of each referred child. It also provides transparency on how the decisions are made. However decisions on referrals must always be made on the basis of clinical judgement.

Using the information from the referral form and any accompanying reports, the clinician or team will score each domain.

Columns 1 and 2

A tick should be placed in the relevant column i.e. in column 1 if there is insufficient information about that particular area of development or in column 2 if there are no difficulties identified according to the information.

Columns 3 – 5

If the child has some difficulty in communication place a 1 in Column 3, if he or she has significant difficulty place 2 in Column 4, and if there is a highly significant difficulty place 3 in Column 5.

**Every domain (row) should have a tick or number in *one* of the columns only.**

Decisions:

A score of 1 - 2 indicates the child’s needs are likely to be best met at Primary Care level.

A score of 7 – 30 indicates the child’s needs are likely to be best met at Children’s Disability Network Team level.

The most appropriate service for children with scores between 3 and 6 should be considered in terms of factors such as needs for interdisciplinary disability team intervention and social and family circumstances. Needs may be met by Primary Care Services or Children’s Disability Network Team or jointly as agreed by the Integrated Children’s Services Forum.

**Scoring according to the form must never be regarded as conclusive on its own. In all cases clinicians must use their own professional judgment in deciding the most appropriate pathway for a child.**

If after due consideration it is unclear which is the most appropriate service for a child, the referral and all supporting documentation may be brought to the Integrated Children’s Services Forum for a decision. (See Section 5.4).

The decision made on referral may be reviewed and changed when the child’s needs have been further assessed by a clinician or after a period of intervention.

## Definitions of Each Domain

The following definitions should be interpreted in the context of cultural variations and norms that may exist for individual children and their families/communities.

**1. Gross motor skills** refers to the physical abilities of the person, for example, to access their environment and participate in activities that require whole body movements or movements involving the large muscles of the body. These would include fundamental movement skills; such as walking, kicking, throwing, catching, maintaining balance, and jumping. It also involves the person’s ability to learn new motor skills or improve upon basic motor abilities.

**2. Fine motor skills** refer to actions involving the small muscles of the hands, wrists and fingers and the coordination of hand and eye movements. They include smaller actions such as picking up objects between the thumb and finger, playing, holding a fork to eat, using a pencil to write carefully and communicating using gestures or signs.

**3. Daily Living skills (Activities of Daily Living)** refer to those skills required to do everyday tasks such as feeding ourselves, bathing, dressing, grooming, playing, doing school work and taking part in leisure activities.

**4. Communication** refers to the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems. Good communication skills are essential to support learning and to develop and maintain social relationships.

**5. Behaviour and Emotions**

Behaviour refers to the child's observable actions and reactions/responses in various environments

Emotions refer to the child's ability to express (verbally or non-verbally) and recognise, label and regulate the expression of internal states, e.g. joy, sadness, anger.

**6. Social interactions and Relationships, Play and Leisure**

Social interaction and relationships refer to the child's ability to interact and relate with children and adults, by verbal or non-verbal means.

Play and leisure refers to solitary or interactive games or activities engaged in for enjoyment, including play with objects, social play, pretend play and imaginative play.

**7. Learning & applying knowledge and skills** refers to the child's ability to gain knowledge or skills by experience, practice or teaching and the ability to retain and access this information when required.

**8. Eyesight and Hearing**

Hearing refers to the ability to perceive sound and involves the detection, recognition, discrimination, comprehension and perception of auditory information.

Eyesight refers to four levels of visual functioning according to the International Classification of Diseases

1. Normal vision.
2. Moderate visual impairment.
3. Severe visual impairment.
4. Blindness.

Moderate visual impairment and severe visual impairment are grouped under the term low vision. Low vision together with blindness represents all visual impairment.

**9. Sensory Processing** refers to the process of taking in information from the world and from within our own bodies, making sense of that information, thus making it possible to use the body effectively within the environment.

**10. Medical need** refers to an impairment or limiting condition that requires medical or nursing management and/or use of specialised services. The condition may be congenital, developmental or acquired through disease or trauma and places restrictions in daily living.

**Definitions for Levels of Difficulty**

**No difficulty**

Within the domain under consideration the child is able to participate and function within a typical / age appropriate range.

**Some difficulties**

This refers to functional difficulties which:

- Result in restrictions in participation in one or more settings (home, school and community).
- Likely to be mitigated by short-term intervention and/or ongoing low level support or strategies.

The child:-

- Experiences mild difficulties in participating in social, educational, family daily activities.
- Needs little assistance to choose, initiate and engage in activities.

**Significant difficulties**

This refers to functional difficulties which:

- result in the child's ability to perform in this area being delayed or different from peers and
- result in restrictions in participation in most settings (home, school and community) and
- negatively impact performance across some other areas of function and participation.

The child:-

- Experiences moderate difficulties in participating in social, educational, family and daily activities.
- Needs moderate assistance to choose, initiate and engage in activities.

**Highly significant difficulties**

This refers to functional difficulties which:

- result in the child's ability to perform in this area being markedly delayed or markedly different from peers and
- result in restrictions in participation in all settings (home, school and community) and
- negatively impact performance across multiple other areas of function and participation.

The child:-

- Experiences severe difficulties in participating in social, educational, family and daily activities.
- Requires maximum assistance to choose, initiate and engage in activities.

***7.5 Children's Services Referral Form and Additional Information Forms***

***These forms are available in two formats - editable PDF for completing on a computer and read only Word for completing by hand. They are reproduced in this document for information purposes only.***

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Health Service Executive

## CHILDREN'S SERVICES REFERRAL FORM

| | |
|---|---|
| **Date of Referral** | **Referrer** |

**SERVICE YOU WISH TO REFER TO (Please see attached sheet for addresses of local services)**

| | |
|---|---|
| **Primary Care Services**<br>**Children with non-complex needs arising from a disabilityshould be referred to Primary Care. Copies of referral forms will be forwarded to all selected disciplines.**<br>Dietetics ☐ Physiotherapy ☐ Speech & Language Therapy ☐<br>Occupational Therapy ☐ Social Work ☐ Psychology ☐Community Medicine Service ☐ Nursing ☐<br>Other ☐ (specify) ____________________ | **Children's Disability Services**<br>**Children with complex needs arising from a disabilityshould be referred to Children's Disability Services**<br>A child has complex needs arising from a disabilityif he or she has a range of significant difficulties that require the services and support of a disability team.<br>**Children's Disability Network Team** ☐ |

**CHILD'S PERSONAL DETAILS**

| | | | |
|---|---|---|---|
| **Surname** | | **First name** | |
| **Gender** | **Date of Birth** | **Child's Age Years** | **Months** |
| **Address** | | | **Eircode** |

| | | | | | |
|---|---|---|---|---|---|
| **Parent/Guardian 1 Name** | | | **Parent/Guardian 2 Name** | | |
| **Relationship to child** | | | **Relationship to child** | | |
| **Telephone** | **Mobile** | **Email** | **Telephone** | **Mobile** | **Email** |
| **Address** (If different from the child's) | | | **Address** (If different from the child's) | | |

| | | |
|---|---|---|
| **Country of Birth** | **First Language**<br>**Other languages spoken at home** | **Interpreter required**<br>YES ☐ NO☐ |

**Number of siblings, their ages and details of any services they are attending**

## REASONS FOR REFERRAL

| | |
|---|---|
| **What are the main concerns and priorities for the child and their family?** | 1. |
| | 2. |
| | 3. |

## GENERAL PRACTITIONER DETAILS

| | | |
|---|---|---|
| **GP Name/Practice** | **GP Telephone** | **Email** |
| **GP Address** | | |

## OTHER COMMUNITY HEALTHCARE SERVICES List all other services currently involved or waitlisted

| | |
|---|---|
| **Children's Disability Network Team** ☐ | **Primary Care:** Speech and language therapy ☐<br>Occupational therapy ☐ Physiotherapy ☐ Psychology ☐<br>Other (please give details) ☐ |
| **Child & Adolescent Mental Health Service** ☐ | **Tusla** ☐ |
| **Other (Please give details)** ☐ | |

## CRECHE, PRE-SCHOOL OR SCHOOL DETAILS ( Attach any Preschool or School Reports)

| | | | |
|---|---|---|---|
| **Creche** | **Preschool** | **School** | Child's Class |
| **Address** | | **Address** | |
| **Manager/Contact Person** | | **Principal's Name** | |

| | |
|---|---|
| **Telephone** **Email** | **Telephone** **Email** |

| |
|---|
| **MEDICAL HISTORY (Attach any relevant Medical Reports)** |
| **Relevant Medical History & Birth History** |
| **Any diagnosis e.g. medical condition, learning disability, developmental disorder, hearing impairment. There may be more than one. Who made the diagnosis and date?** |
| **If the child is currently in hospital what date is he/she expected to be discharged?** |
| **Current medications** |
| **Allergies/Adverse medication events** |
| **Current investigations e.g. blood tests, scans, hearing tests** |
| **SOCIAL CIRCUMSTANCES** |
| **Relevant family and social history**<br>For example family health or housing difficulties, financial or employment problems, bereavement or other stresses. |
| **ANY OTHER RELEVANT INFORMATION** |
| |
| **Please indicate whether referrer should be contacted prior to the initial appointment YES** ☐ **NO** ☐ |

**Are there any relevant risk factors in relation to this referral?**

**CONSENT: Referrals without signed consent of parent(s) / guardian(s) will not be accepted.**

**It is required by law that at least one of the child's legal guardians consents to the referral and signs this form. It is advisable that both parents/legal guardians are aware of this referral.**

**Definition of a Legal Guardian**
All mothers, whether they are married or unmarried, have automatic guardianship status in relation to their children, unless they give the child up for adoption. A father who is married to the mother of his child also has automatic guardianship rights in relation to that child. This applies even if the couple married after the birth of the child.

A father who is not married to the mother of his child does not have automatic guardianship rights in relation to that child. If the mother agrees for him to be legally appointed guardian, they must sign a joint statutory declaration. However an unmarried father is automatically a guardian if he has lived with the child's mother for 12 consecutive months after 18/1/2016, including at least 3 months with the mother and child following the child's birth.

**Children in Care**
For children in voluntary care or on an interim order, the parents must sign the consent. For children on a care order the consent is signed by a Tusla Child and Family Agency social worker.

**Child's Name** **Date of Birth**

- **I give permission for my child to be referred to Primary Care Services /Children's Disability Services** YES ☐ NO ☐
- **I give permission for information about my child to be held by Primary Care Services/Children's Disability Services in accordance with obligations under the Data Protection Acts 1988, 2003 and 2018** YES ☐ NO ☐
- **I give permission that in the event that this referral is not appropriate it may be shared with other relevant services to facilitate an onward referral. I will be contacted in advance of this information being forwarded on to another service.** YES ☐ NO ☐
- **I give permission to Primary Care Services/ Children's Disability Services to contact and obtain relevant information in order to understand and address my child's needs from the professionals and services listed below, such as a hospital consultant, psychologist, speech & language therapist, teacher etc. Only those listed below will be contacted.** YES ☐ NO ☐

| Name (if available) | Service | Contact Details |
|---|---|---|
| | | |
| | | |
| | | |

**Name of Parent 1/Guardian**

**Signature** **Date:**

| | |
|---|---|
| **Name of Parent 2/Guardian**<br>**Signature** | **Date** |

**REFERRERS DETAILS**

| | | |
|---|---|---|
| **Name:**<br>**Role (Parent/ Legal guardian, professional):** | **Date:** | |
| **Address:** | **Telephone:** | **Mobile:** |
| | **Email:** | |
| **Signature:** | | |

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Health Service Executive

# ADDITIONAL INFORMATION FORM TO ACCOMPANY CHILDREN'S SERVICES REFERRAL FORM

## Baby aged from birth to 11 months

| | |
|---|---|
| **Date of Referral** | **Referrer** |

**In order to help services appropriately accept and prioritize referrals, this form should be completed by the baby's parents or in consultation with them, and sent with the Children's Services Referral Form.**

**Please also attach any health or other reports you have on your child**

| | | |
|---|---|---|
| **Child's Surname** | **Child's First Name** | **Date of Birth** |
| **Parents' names and contact details** | | |

BIRTH HISTORY

| | | | | |
|---|---|---|---|---|
| Length of Pregnancy | Weeks/days | Place of Birth | Birth Weight | Birth Length |

Was your baby admitted to the neonatal unit? Yes ☐ No ☐

Has your baby been in hospital at any time since they were born? Yes ☐ No ☐

If Yes, for what reason?

Please give details of medications, hospital and nursing needs, breathing and feeding supports

Please provide your baby's up to date length, weight and head size centile scores from their growth chart if available.

TELL US ABOUT YOUR BABY'S DEVELOPMENT

**Can your baby….**

| | |
|---|---|
| Grab a toy with either hand? | Left ☐ Right ☐ Not yet ☐ |
| Grab both feet when lying on his or her back? | Yes ☐ Not yet ☐ |
| Roll over… | On to tummy ☐ On to back ☐ Neither yet ☐ |
| Tolerate lying on his or her tummy? | Yes ☐ Not yet ☐ |
| Sit…. | On his or her own ☐ Only with support ☐ Not yet ☐ |
| Crawl… | On tummy ☐ On hands and knees ☐ Not yet ☐ |
| Does your baby pull to standing? | Yes ☐ Not yet ☐ |
| Stand…. | Without support ☐ Only with support ☐ Not yet ☐ |
| Do you have any other concerns about your baby's movement such as being floppy or tense when you lift him or her?<br>If so please give details: | |
| Is your baby able to fully open his or her hands including thumb? Yes ☐ Not yet ☐ | |
| Is your baby able to grasp and release a toy? Yes ☐ Not yet ☐ | |
| Does your baby use one hand more than the other? Yes ☐ Not yet ☐ | |
| Can your baby pass toys from one hand to the other? Yes ☐ Not yet ☐ | |
| If you have concerns about your baby's hand movements please give details: | |
| Do you have any concerns about your baby's weight or growth? Yes ☐ No ☐<br>If Yes please describe<br>Please enclose any growth and weight charts. | |
| Describe your baby's daily feeding routine, times and size of feeds. How does your baby feed? How long does a breast or bottle feed take? If your baby has started spoon feeding, is it going well? | |

Do you find feeding stressful? Yes ☐ No ☐

If Yes please describe

Is your baby taking any specialised feeds, drinks or foods? Yes ☐ No ☐

Please give details

Do you have concerns about your baby’s sleep? Yes ☐ No ☐

If Yes please describe

How do you know what your baby wants? e.g. does he or she look at you, cry when hungry, smile, reach out?

Can your baby look at an object and follow it when it moves? Yes ☐ Not yet ☐

What kind of sounds does your baby make? e.g. happy sounds, sad sounds, types of cries, sounds like aah, babble such as bada, gaga

Do you have concerns about how your baby’s behaves? e.g. excessive crying, irritable, too quiet Yes ☐ No ☐

If Yes please describe your concerns

Do you have concerns about your baby’s ability to play and respond to play? Yes ☐ No ☐

Please describe your concerns:

Do you think your baby is over-sensitive to noise, textures, movements or smells? Yes ☐ No ☐

If Yes please give details

Do you have concerns about your baby’s eye sight? Yes ☐ No ☐

If Yes, give details of your concerns and result of any tests undertaken

Has your baby had a hearing test? Yes ☐ No ☐

Please give details

Do you have any concerns about your baby’s hearing now? Yes ☐ No ☐

If Yes, give details of your concerns

Has anyone else expressed concern about any aspect of your baby's development? e.g. Doctor, Public Health Nurse, family members, childminder Yes ☐ No ☐

If Yes please give details including who expressed the concern:

**Is there anything else you would like to tell us about your baby?**

Tell us about what he or she enjoys and can do, along with any concerns you have

What is your main concern and priority for your baby?

**Safety and Risk** Please give details of any issues which pose a significant risk to the health and wellbeing of your baby or of others.

**Please give details of who completed this form**

Form completed by:

Relationship to child:

Contact details:

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

# ADDITIONAL INFORMATION FORM TO ACCOMPANY CHILDREN'S SERVICES REFERRAL FORM

## Child aged from 12 months to 2 years11 months

| | |
|---|---|
| **Date of Referral** | **Referrer** |

**In order to help services appropriately accept and prioritize referrals, this form should be completed by the parents or in consultation with them, and sent with the Children's Services Referral Form.**

**Please also attach any health or other reports you have on your child**

| | | |
|---|---|---|
| **Surname** | **First Name** | **Date of Birth** |

**Parents' names and contact details**

## BIRTH HISTORY (Please attach any relevant reports)

| | | |
|---|---|---|
| Length of Pregnancy: Weeks/days | Place of Birth | Birth Weight |

Was your child admitted to the neonatal unit? Yes☐ No ☐

Has your child ever been in hospital since they were born? Yes ☐ No ☐

If Yes, for what reason?

Please give details of any medications, hospital and nursing needs, breathing and feeding supports

## YOUR CHILD'S DEVELOPMENT Please note some questions may not be relevant for your child

### 1. Movement and Gross Motor Skills

**Has your child achieved the following?**

| | | | |
|---|---|---|---|
| Rolling from back to tummy | Yes ☐ | At what age | Not yet ☐ |
| Sitting | Yes ☐ | At what age | Not yet ☐ |
| Crawling | Yes ☐ | At what age | Not yet ☐ |
| Walking independently | Yes ☐ | At what age | Not yet ☐ |
| Running | Yes ☐ | At what age | Not yet ☐ |

If your child is walking do they tend to walk on tiptoes? Yes ☐ No ☐

Is your child clumsier than other children their age? Yes ☐ No ☐

Describe any concerns you have about your child's movement and gross motor skills:

| |
|---|
| **2. Fine Motor Skills and Hand Movement** |
| **Which of the following can your child do?** |
| Pick up small objects such as raisins Yes ☐ Not yet ☐ |
| Play with construction games e.g. building blocks or Duplo Yes ☐ Not yet ☐ |
| Use a pencil or crayon to scribble or draw Yes ☐ Not yet ☐ |
| Describe any concerns you have about your child's ability to use their hands |

| |
|---|
| **3. Communication, Speech and Language** |
| Please explain how your child lets you know they want something? (e.g. crying, pulling, pointing, sounds, gestures, uses signs, uses pictures, words, sentences or a combination of these?) |
| **Has your child achieved the following?** |
| Babbling (e.g. gaga bada) Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| Gestures such as wave "bye bye" and point? Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| First word such as 'cat' 'more'? Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| Putting two words together? Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| How many words can your child put together now in a sentence? |
| Give an example of the kind of things your child says now: |
| Does your child have difficulty understanding what you say? Yes ☐ No ☐ |
| Please give details of any concerns you have about your child's speech, language, communication and voice: |
| **4. Social Interaction, Relationships, Play and Leisure** |
| When playing does your child allow you or other adults to join in? Always ☐ Sometimes ☐ Never ☐<br>When playing does your child allow other children to join in? Always ☐ Sometimes ☐ Never ☐<br>Describe how your child plays with others: |
| Describe what toys your child plays with and how they play with them: |
| What activity does your child like to do? |
| Does your child engage in pretend play and make believe games? Yes ☐ No ☐ |
| Is there anything you would like us to know about your child's play, friendships and activities? |

## 5. Daily Living Skills

### 5A Food and Drink

Do you have any concerns about your child's weight or growth? Yes ☐ No ☐

If Yes, give details

Do you have any concerns about your child's nutrition or the range of foods they eat? Yes ☐ No ☐

If Yes, give details

Describe your child's usual food, drinks and mealtime routine?

Can your child use a spoon to feed him or herself? Yes ☐ Not yet ☐

Can your child drink from a beaker with a spout or a cup by themselves? Yes ☐ Not yet ☐

Give details of any concerns about your child's ability to feed themselves

Do you have any concerns about ***how*** your child is chewing, swallowing or drinking? Yes ☐ No ☐

If Yes please describe

Are mealtimes stressful? Yes ☐ No ☐

If Yes please describe

Is your child on specialised feeds, drinks or foods? Yes ☐ No ☐

If Yes, give details

### 5B. Urinary and Bowel Habits

Please describe what stage your child has reached with toilet training

Are there any issues around toileting? Yes ☐ No ☐

If Yes, describe

## 5C. Sleep and Rest

Do you have concerns about your child's sleeping routine? Yes ☐ No ☐

If Yes, describe:

Do you have any concerns about your child's level of energy? Yes ☐ No ☐

If Yes, describe

## 6. Behaviour and Emotions

Have you any concerns about your child's emotional wellbeing and behaviour? At home ☐ Out and about ☐

Describe any concerns

**Do the following statements describe your child? (Please tick the appropriate boxes)**

| | | | | |
|---|---|---|---|---|
| Frequent prolonged tantrums ☐ | Aggressive ☐ | Irritable ☐ | Excessive Crying ☐ | Clingy ☐ |
| Upset for seemingly minor things ☐ | Withdrawn or too quiet ☐ | Doesn't like change☐ | Frustrated ☐ | Worries a lot☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's ability to learn new skills? Yes ☐ No ☐

If Yes, describe

Has anyone else expressed any concern about your child's ability to learn, such as the creche, a family member?

Yes ☐ No ☐

If Yes, give details of the concern and who expressed it

**8. Vision and Hearing**

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details

Does your child attend a specialist service for their vision or for their hearing? Yes ☐ No ☐

If Yes, give details

**9. Sensory Processing**

If you have concerns about your child's sensitivity to any of the following, either avoiding them or seeking them out, please tick:

Noise ☐ Touch ☐ Textures (such as fabrics) ☐ Movements ☐ Smells ☐ Food ☐ Lights ☐

If you have ticked any of the above, please give details and describe how this impacts on everyday life

10. **Is there anything else you would like to tell us about your child?**

Tell us what your child enjoys and is good at as well as the things they find difficult:

What is your main concern and priority for your child?

**Safety and Risk**

Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?

**Please give details of who completed this form**

**Form completed by**:

**Relationship to child:**

**Contact details**:

**Date:**

**N.B. Please attach copies of any health or pre-school reports that you have.**

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

# ADDITIONAL INFORMATION FORM TO ACCOMPANY CHILDRE SERVICES REFERRAL FORM

## Child aged from 3 years to 5 years 11 months

**Date of Referral:** **Referrer:**

**In order to help services appropriately accept and prioritize referrals, this form should be completed by the parents or in consultation with them, and sent with the Children's Services Referral Form.**

**Please also attach any health or school or pre-school reports you have on your child**

| | | |
|---|---|---|
| **Child's Surname** | **Child's First Name** | **Date of Birth** |

**Parents' names and contact details:**

**BIRTH HISTORY (Please attach any relevant reports)**

| | | |
|---|---|---|
| Length of Pregnancy weeks/days | Place of Birth | Birth Weight |

Was your child admitted to the neonatal unit? Yes ☐ No ☐

Has your child ever been in hospital since they were born? Yes ☐ No ☐

If Yes, for what reason?

Please give details of any medications, hospital and nursing needs, breathing and feeding supports:

**YOUR CHILD'S DEVELOPMENT Please note some questions may not be relevant for your child**

### 1. Movement and Gross Motor Skills

**Has your child achieved the following?**

| | | | |
|---|---|---|---|
| Walking independently | Yes ☐ | At what age | Not yet ☐ |
| Running | Yes ☐ | At what age | Not yet ☐ |
| Jumping | Yes ☐ | At what age | Not yet ☐ |
| Climbing up and down stairs | Yes ☐ | At what age | Not yet ☐ |
| Throwing a ball | Yes ☐ | At what age | Not yet ☐ |
| Catching a ball | Yes ☐ | At what age | Not yet ☐ |
| Kicking a ball | Yes ☐ | At what age | Not yet ☐ |

|  |
|---|
| **Please tick if any of the following describe your child's movements** |
| Trips more than other children their age ☐ |
| Falls more than other children their age ☐ |
| Bumps into other things more than other children their age ☐ |
| Tends to walk on tiptoes ☐ |
| Clumsier than other children their age ☐ |
| My child is losing skills they did have ☐ |
| My child's posture looks different from other children ☐ |
| If you have ticked any of these, give details: |
| Is your child keeping up with other children of their age in physical development and activity? Yes ☐ No ☐<br>If No, give examples |
| Describe any other concerns you have about your child's movement and gross motor skills |
| **2. Fine Motor Skills and Hand Movement** |
| **Which of the following can your child do if they have had a chance to try it?** |
| Pick up small objects such as raisins or beads Yes ☐ No ☐ |
| Play with construction toys such as building blocks or Lego Yes ☐ No ☐ |
| Use a pencil or crayon to scribble or draw Yes ☐ No ☐ |
| Use a child's scissors to cut paper Yes ☐ No ☐ |
| Open their lunchbox Yes ☐ No ☐ |
| Describe any concerns you have about your child's fine motor and hand movements |
| **3. Communication, Speech and Language** |
| Please explain how your child communicates ***most*** of their messages ***now***? (e.g. crying, pulling, pointing, sounds, gestures, uses signs, uses pictures, words, sentences or a combination of these?) |
| **Has your child achieved the following?** |
| First words, such as 'cat' 'more'? Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| Putting two words together? Yes ☐ At what age ☐ Not yet ☐ Skill achieved but since lost ☐ |
| How many words can your child put together now in a sentence? |
| Give an example of the kind of things your child says now |
| **Do any of the following describe your child's speech, language, and communication abilities?** |

My child has difficulty understanding what I say Yes ☐ No ☐

If yes, please give examples

My child has difficulty telling a story, such as telling me about something that happened during their day
Yes ☐ No ☐

My child finds it hard to pronounce/say certain sounds, for example says “tup” for “cup Yes ☐ No ☐

Please give details of a

ny concerns you have about your child’s speech, language, communication and voice

## 4. Social Interaction, Relationships, Play and Leisure

When playing does your child allow you or other adults to join in? Always ☐ Sometimes ☐ Never ☐

When playing does your child allow other children to join in? Always ☐ Sometimes ☐ Never ☐

Describe how your child plays with others

Does your child show an interest in other children? Yes ☐ No ☐

Does your child take turns with other children? Yes ☐ No ☐

Does your child share toys with other children? Yes ☐ No ☐

What toys does your child like to play with and how do they play with them?

Does your child engage in imaginative play e.g. pretend and make believe games?

What activities do your child like to do?

Please give any further comments about your child’s play, friendships and activities:

## 5. Daily Living Skills

### 5A. Food and Drink.

Do you have any concerns about your child's weight or growth? Yes ☐ No ☐

If yes, give details

**Please enclose any growth or weight charts available**

Do you have any concerns about how much your child eats and drinks, or the range of foods they eat? Yes ☐ No ☐

If yes, give details

Describe your child's usual food, drinks and mealtime routine?

Can your child use a spoon to feed themselves? Yes ☐ No ☐

Can your child drink from a cup by themselves? Yes ☐ No ☐

If No, give details:

Do you have any concerns about ***how*** your child is eating, swallowing and drinking? Yes ☐ No ☐

If Yes please describe:

Are mealtimes stressful? Yes ☐ No ☐

If Yes please describe

Is your child on any specialised feeds, drinks or food? Yes ☐ No ☐

If Yes, give details

### 5B. Urinary and Bowel Habits

Please describe what stage your child has reached with toilet training

Are there any issues around toileting? Yes ☐ No ☐

If Yes, describe

## 5C. Personal Care, Dressing and Independence

Does your child dress themselves? Yes ☐ No ☐ With some help ☐

Does your child undress themselves? Yes ☐ No ☐ With some help ☐

Describe what your child can do for themselves

Have you any concerns about your child's safety awareness in the home or out and about? Yes ☐ No ☐

If Yes, describe

## 6. Behaviour and Emotions

**Do you have concerns about your child's emotional wellbeing and behaviour**?

At home ☐ At crèche, pre-school or school ☐ Out and about ☐

Please describe any concerns

**Do the following statements describe your child's behaviour? (Please tick the appropriate boxes)**

| | | | | |
|---|---|---|---|---|
| Frequent prolonged tantrums ☐ | Aggressive ☐ | Irritable ☐ | Excessive Crying ☐ | Clingy ☐ |
| Upset for seemingly minor | Withdrawn/too quiet ☐ | Doesn't like change ☐ | Frustrated ☐ | Worries a lot ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems

## 7. Learning

Do you have any concerns about your child's ability to learn new skills? Yes ☐ No ☐

If yes please describe

Has anyone else expressed any concern about your child's ability to learn such as a teacher, psychologist, family member?

Yes ☐ No ☐

If Yes give details of the concern and who expressed it

Do you have any concerns about your child's ability to concentrate? Yes ☐ No ☐

Is your child having any difficulties keeping up with learning or school work? Yes ☐ No ☐

If Yes give details

**8. Vision and Hearing**

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details

Does your child attend a specialist service for their vision or hearing? Yes ☐ No ☐

If Yes, give details

**9. Sensory Processing**

**If you have concerns about your child's sensitivity to any of the following, either avoiding them, getting annoyed with them or seeking them out, please tick:**

Noise ☐ Touch ☐ Textures (such as fabrics) ☐ Movements ☐ Smells ☐ Food ☐ Lights ☐

If you have ticked any of the above, describe how this impacts on everyday life for your child and for you

10. **Is there anything else you would like to tell us about your child?**

**Tell us what your child enjoys and is good at as well as the things they find difficult**

**What is your main concern and priority for your child?**

**Safety and Risk**

**Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?**

**Please give details of who completed this form**

**Form completed by:**

**Relationship to child:**

**Contact details:**

**Date:**

**Please attach copies of any health, school or pre-school reports that you have.**

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

# ADDITIONAL INFORMATION FORM TO ACCOMPANY CHILDREN'S SERVICES REFERRAL FORM

## Child aged from 6 years to 11 years 11 months

**Date of Referral:** **Referrer:**

**In order to help services appropriately accept and prioritise referrals, this form should be completed by the child's parents or in consultation with them, and sent with the Children's Services Referral Form.**
**Please also enclose copies of any health or school reports you have on your child**

| | | |
|---|---|---|
| **Child's Surname** | **Child's First Name** | **Date of Birth** |

**Parents' names and contact details**

**YOUR CHILD'S DEVELOPMENT *Please note some questions may not be relevant for your child***

### 1. Movement and gross motor skills

**Do you have any concerns about your child's ability to move around such as walking, running, jumping, balancing compared to other children their age?** Yes ☐ No ☐

If Yes please give details, including any assistance required such as crutches, wheelchair for distance

How does your child's difficulty with moving impact on their ability to do everyday activities? e.g. washing, dressing, play

Have you noticed any recent changes in your child's ability to move or their level of fatigue? Yes ☐ No ☐
If Yes, please give details

Do you have any other concerns about your child's movement or gross motor skills?

### 2. Hand Movement and Fine Motor Skills

**In comparison with other children their age can your child do the following?**

| | | |
|---|---|---|
| Pick up small objects with finger and thumb | Yes ☐ | No ☐ |
| Play with construction toys such as building blocks or Lego | Yes ☐ | No ☐ |
| Use a pencil or pen to write | Yes ☐ | No ☐ |
| Use a scissors to cut paper | Yes ☐ | No ☐ |
| Open their lunchbox | Yes ☐ | No ☐ |

If you answered No to any of the above questions or you have other concerns about your child's hand movement please give details

| | |
|---|---|
| **3. Communication, Speech and Language** | |
| **Do any of the following describe your child? Please tick if Yes** | |
| My child has difficulty telling a story e.g. telling me about something that happened at school | ☐ |
| My child gets confused when I give them long instructions | ☐ |
| My child has difficulty holding a conversation with other children | ☐ |
| My child has difficulty holding a conversation with adults | ☐ |
| My child's speech is difficult to understand compared to other children | ☐ |
| My child likes to talk about particular topics to the exclusion of others | ☐ |
| My child has difficulty holding eye contact | ☐ |
| My child has difficulty understanding what is said to them | ☐ |
| My child does not consistently respond to their name | ☐ |
| My child has issues with their voice e.g. prolonged hoarseness | ☐ |
| My child has a stammer | ☐ |
| **If you have ticked any of the above please give further details:** | |
| Does your child use technology or a computer to communicate? Yes ☐ No ☐<br>If yes please give further information on technology or computer use: | |
| Please give details of any other concerns about your child's speech, language, communication and voice: | |

| | |
|---|---|
| **4. Social Interaction, Relationships, Play and Leisure** | |
| When playing does your child allow you or other adults to join in? | Always ☐ Sometimes ☐ Never ☐ |
| When playing does your child allow other children to join in? | Always ☐ Sometimes ☐ Never ☐ |
| Give details of any concerns about how your child plays with others | |
| What toys and games does your child like to play with and how do they play with them? | |
| Does your child engage in imaginative play e.g. pretend and make believe games? | |
| What activities does your child like to do? | |
| What activities in the community does your child take part in? | |
| Does your child need extra help to play with others and if so what kind of help? | |
| Please give any further comments about your child's play, friendships and activities: | |

## 5. Daily Living Skills

### 5A. Food and Drink

Do you have any concerns about your child's weight or growth? Yes ☐ No ☐

If Yes, give details

Please describe your child's usual meal, food and drink routine:

Do you have any concerns about how much your child eats or the range of foods they eat? Yes ☐ No ☐

If Yes, describe

Does your child have special feeding requirements? Yes ☐ No ☐

If Yes, describe

Do you have any concerns about ***how*** your child is eating, swallowing and drinking? Yes ☐ No ☐

If Yes, describe

Are mealtimes stressful? Yes ☐ No ☐

If Yes, describe

### 5B. Urinary and Bowel Habits

Does your child have any issues with toileting? Yes ☐ No ☐

If Yes please describe

### 5C. Personal Care, Dressing and Independence

**Do you have concerns about your child's ability to manage the following compared with other children their age?**

| | | | |
|---|---|---|---|
| Dressing | Yes ☐ No ☐ | Undressing | Yes ☐ No ☐ |
| Washing | Yes ☐ No ☐ | Brushing teeth | Yes ☐ No ☐ |
| Organising belongings | Yes ☐ No ☐ | Getting ready for school | Yes ☐ No ☐ |
| Getting ready for bed | Yes ☐ No ☐ | | |

If Yes to any of the above please describe your concerns

### 5D. Sleep and Rest

Do you have concerns about your child's sleeping routine? Yes ☐ No ☐

Do you have any concerns about your child's level of energy? Yes ☐ No ☐

If Yes to either of these questions give details

## 6. Behaviour and Emotions

**Do you have concerns about your child's emotional wellbeing and behaviour?**

At home ☐ At school ☐ Out and about ☐

Please describe any concerns

**Do any of the following describe your child's behaviour? (Please tick if Yes)**

| | | | | |
|---|---|---|---|---|
| Frequent prolonged outbursts or meltdowns ☐ | Aggressive ☐ | Avoids certain activities or people ☐ | Excessive crying ☐ | Clingy ☐ |
| Upset for seemingly minor things ☐ | Withdrawn or too quiet ☐ | Doesn't like change ☐ | Frustrated ☐ | Worries a lot ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's ability to learn? Yes ☐ No ☐

If Yes please describe

Has anyone expressed any concern about your child's ability to learn such as a teacher, psychologist or family member?

Yes ☐ No ☐

If Yes, give details of the concern and who expressed it

Is your child having any difficulties keeping up with learning and schoolwork? Yes ☐ No ☐

If Yes, give details:

Has your child had any assessments of their learning? e.g. NEPS

**Please enclose with this form copies of any school or psychology reports you have on your child.**

Does your child have any additional support in school, such as SNA, Special Education teaching? Yes ☐ No ☐

If Yes, give details :

## 8. Vision and Hearing

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details:

Does your child attend a specialist service for their vision or for their hearing? Yes ☐ No ☐

If Yes, give details:

**9. Sensory Processing**

If you have concerns about your child's sensitivity to any of the following, either avoiding them, getting annoyed with them or seeking them out, please tick:

Noise ☐ Touch ☐ Textures(such as fabrics) ☐ Movements ☐ Smells ☐ Food ☐ Lights ☐

If you have ticked any of the above, describe how this impacts on everyday life for your child and for you:

**Is there anything else you would like to tell us about your child?**

**Tell us what your child enjoys and can do well, as well as the things they find difficult**

**What is your main concern and priority for your child?**

**Safety and Risk**

**Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?**

**Please give details of who completed this form**

**Form completed by:**

**Relationship to child:**

**Contact details:**

**Date:**

**Please attach copies of any health or school reports**

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

# ADDITIONAL INFORMATION FORM TO ACCOMPANY CHILDREN'S SERVICES REFERRAL FORM

## Child/young person aged from 12 years to 17 years 11 months

| | |
|---|---|
| **Date of Referral:** | **Referrer:** |

**In order to help services appropriately accept and prioritize referrals, this form should be completed by the child's parents or in consultation with them, and sent with the Children's Services Referral Form.**
**Please also enclose copies of any health or school reports you have**

| | | |
|---|---|---|
| **Child's or Young Person's Surname** | **First Name** | **Date of Birth** |

**Parents' names and contact details**

**YOUR CHILD'S OR YOUNG PERSON'S DEVELOPMENT** **Please note some questions may not be relevant**

### 1. Movement (Gross Motor Skills)

Do you have any concerns about your child's or young person's ability to move around such as walking, running, jumping, and balancing? Yes ☐ No ☐

If Yes give details including any assistance required such as crutches, wheelchair for distance

How does their difficulty with moving impact on their ability to do everyday tasks e.g. leisure and social activities, washing, dressing?

Have you noticed any recent changes in their ability to move or their level of fatigue? Yes ☐ No ☐
If Yes, please give details

Do you have any other concerns about their movement or gross motor skills?

### 2. Fine Motor and Hand Skills

Does your child or young person have difficulty using their hands such as handwriting, using scissors, picking up small items, using computers? Yes ☐ No ☐
If yes, give details

| |
|---|
| **3. Communication** |
| Does your child or young person have difficulty expressing themselves e.g. asking for help, describing events?<br>Yes ☐ No ☐ |
| Do they have difficulty understanding people? Yes ☐ No ☐ |
| Is it difficult to understand what they are saying? Yes ☐ No ☐ |
| Do they have difficulty going along with a conversation if the other person changes the topic? Yes ☐ No ☐ |
| Do they have any difficulty with understanding jokes or phrases such as 'I'm only pulling your leg'? Yes ☐ No ☐ |
| **If Yes to any of the above questions please describe:** |
| Do they use technology or a computer to communicate? Yes ☐ No ☐<br>If yes please give further information on technology or computer use: |
| Do they have any issues with their voice e.g. prolonged hoarseness? |
| Do you have any other concerns about their speech, language, communication and voice? |
| **4. Social Interaction, Relationships and Leisure** |
| Do you have concerns about your child's or young person's ability to form and keep up relationships with others?<br>Yes ☐ No ☐<br>Please describe your concerns |
| Please describe any leisure or sport activities they take part in |

| |
|---|
| **5. Daily Living Skills** |
| **5A. Food and Drink** |
| Do you have any concerns about your child's or young person's weight or growth? Yes ☐ No ☐<br>If Yes, give details |
| Do you have any concerns about how much food they eat or the range of foods they eat? Yes ☐ No ☐<br>If Yes, give details |
| Describe their daily food, drinks and mealtime routine |
| Do you have any concerns about *how* they are eating drinking or swallowing?<br>If yes please describe |
| Are mealtimes stressful? Yes ☐ No ☐<br>If Yes, describe |
| Are they on specialised drinks or foods? Yes ☐ No ☐<br>If Yes, give details |

## 5B. Bowel and Urinary Habits

Are there any difficulties with toileting? Yes ☐ No ☐

If Yes, give details:

## 5C. Personal Care, Dressing and Independence

Do you have concerns about your child's or young person's ability to manage the following compared with others their age?

Dressing Yes ☐ No ☐ Undressing Yes ☐ No ☐
Washing Yes ☐ No ☐ Brushing teeth Yes ☐ No ☐
Organising belongings Yes ☐ No ☐ Getting ready for bed Yes ☐ No ☐
Getting ready for school Yes ☐ No ☐

If Yes to any of the above give details

## 5D. Sleep and Rest

Do you have concerns about their sleep or ability to rest or relax? Yes ☐ No ☐

Do they have difficulty initiating activities or appear lethargic or tire easily? Yes ☐ No ☐

If Yes to either of these questions, give details

## 6. Behaviour and Emotions.

Have you concerns about your child's or young person's emotional wellbeing and behaviour?

At home ☐ At school ☐ Out and about ☐

Please describe any concerns

**Do the following statements describe their behaviour and emotions? (Please tick the appropriate boxes)**

| | | | | |
|---|---|---|---|---|
| Frequent prolonged outbursts or meltdowns ☐ | Aggressive ☐ | Avoids certain activities or people ☐ | Low mood ☐ | Clingy ☐ |
| Upset for seemingly minor things ☐ | Withdrawn/too quiet ☐ | Doesn't like change ☐ | Frustrated ☐ | Worries a lot ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on them and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's or young person's ability to learn? Yes ☐ No ☐

If Yes give details

Has anyone expressed any concern about their ability to learn such as a teacher, psychologist or family member?

Yes ☐ No ☐

If Yes give details of the concern and who expressed it

Are they having any difficulties keeping up with learning and school work? Yes ☐ No ☐

If yes please give details

Have they had any assessments e.g. NEPS?

***Please enclose with this form copies of any school or psychology reports you have on your child.***

Do they have extra learning support in school such as SNA, Special Education teaching? Yes ☐ No ☐

If Yes give details

## 8. Vision and Hearing

Does your child or young person have problems with eyesight or vision which cannot be corrected with glasses?

Yes ☐ No ☐

If Yes, give details

Do they attend a specialist service for their vision or hearing? Yes ☐ No ☐

If Yes, give details

## 9. Sensory Processing

If you have concerns about your child's or young person's sensitivity to any of the following, either avoiding, getting annoyed with or seeking out, please tick

Noise ☐ Touch ☐ Textures (such as fabrics) ☐ Movements ☐ Smells ☐ Food ☐ Lights ☐

If you have ticked any of the above, please describe how this impacts on everyday life for your child and for you

| Is there anything else you would like to tell us? |
|---|
| **Tell us what your child or young person enjoys and can do well as well as those things they find difficult** |
| **What is your main concern and priority?** |

| Safety and Risk |
|---|
| **Are there any issues which are a significant risk to their health and wellbeing or that of others, such as physical injury to self or others, refusal to eat?** |
| **Please give details of who completed this form** |
| **Form completed by:**<br>**Relationship to child:**<br>**Contact details:**<br>**Date:** |

**The following forms are available in two formats – an 'editable PDF' for completing on a computer and 'read only' version in Word for completing by hand.**

**They are reproduced in this document for information purposes only.**

Children's Disability Network Team

**Primary Care**

# Children's Services Referral Form

## Who should use this form?

Referral can be made by the child's parents or legal guardian, health and social care professionals or education professionals **either** to a Children's Disability Network Team **or** to Primary Care Services. The completed Children's Services Referral Form should be sent with the Additional Information Form for the child's age group, completed by the child's parents.

| | | | |
|---|---|---|---|
| Date of Referral | | Referrer | |

Please also attach any health or other reports you have on your child.

## Which service do you wish to refer to?

Select either Children's Disability Services or Primary Care Services. Please do not send the referral to both services. We will send your referral to the appropriate service if needed.

### Children's Disability Services

**Children with complex needs arising from a disability should be referred to their local Children's Disability Network Team.** A child has complex needs if they have a range of significant difficulties that require the services and support of a disability team.

To find your local Children's Disability Network Team please see the list **here**.

Children's Disability Network Team ☐

**Or**

### Primary Care Services

**Children with non-complex needs should be referred to Primary Care services.**

| | | | |
|---|---|---|---|
| Dietetics | ☐ | Physiotherapy | ☐ |
| Speech & Language Therapy | ☐ | Occupational Therapy | ☐ |
| Social Work | ☐ | Psychology | ☐ |
| Community Medicine Service | ☐ | Nursing | ☐ |

Other ☐ (specify)

Page 1

## Child’s personal details

| | | | |
|---|---|---|---|
| Surname | | First Name | |
| Gender | | Date of Birth | / / |
| Child’s Age | Years | Months | |

Address

PPSN

---

Parent/Guardian 1 Name

Relationship to child

| | | | |
|---|---|---|---|
| Telephone | | Mobile | |

Email

Address (If different from the child’s)

---

Parent/Guardian 2 Name

Relationship to child

| | | | |
|---|---|---|---|
| Telephone | | Mobile | |

Email

Address (If different from the child’s)

---

| | |
|---|---|
| Country of Birth | |
| First Language | |
| Other languages spoken at home | |

Interpreter required Yes ☐ No ☐

Number of siblings, their ages and details of any services they are attending.

## Reasons for referral

What are the main concerns and priorities for the child and their family?

**1**

**2**

**3**

## General practitioner details

GP Name/Practice

GP Telephone

Email

GP Address

## Other community healthcare services currently involved or waitlisted

**List all other services currently involved or waitlisted.**

**Children's Disability Network Team** ☐

**Primary Care**

Speech and language therapy ☐ Occupational therapy ☐

Physiotherapy ☐ Psychology ☐

Other ☐ (please give details)

**Child & Adolescent Mental Health Service** ☐

**Tusla** ☐

**Other** ☐ (please give details)

## Creche, pre-school or school details

**(Attach any Preschool or School Reports)**

Creche

Preschool

Address

Manager/Contact Person

Telephone

Email

---

School

Child’s Class

Address

Principal’s Name

Telephone

Email

## Medical history

**(Attach any relevant Medical Reports)**

Relevant Medical History & Birth History.

Any diagnosis e.g. medical condition, learning disability, developmental disorder, hearing impairment. There may be more than one. Who made the diagnosis and date?

If the child is currently in hospital what date is he/she expected to be discharged?

Current medications.

Allergies/Adverse medication events.

Current investigations e.g. blood tests, scans, hearing tests.

## Social circumstances

**Relevant family and social history**

For example family health or housing difficulties, financial or employment problems, bereavement or other stresses.

## Any other relevant information

Please indicate whether referrer should be contacted prior to the initial appointment Yes ☐ No ☐

Are there any relevant risk factors in relation to this referral?

## Consent

**Referrals without signed consent of parent(s) / guardian(s) will not be accepted.**

It is required by law that at least one of the child's legal guardians consents to the referral and signs this form. It is advisable that both parents/legal guardians are aware of this referral.

## Definition of a Legal Guardian

All mothers, whether they are married or unmarried, have automatic guardianship status in relation to their children, unless they give the child up for adoption. A father who is married to the mother of his child also has automatic guardianship rights in relation to that child. This applies even if the couple married after the birth of the child.

A father who is not married to the mother of his child does not have automatic guardianship rights in relation to that child. If the mother agrees for him to be legally appointed guardian, they must sign a joint statutory declaration. However an unmarried father is automatically a guardian if he has lived with the child's mother for 12 consecutive months after 18/1/2016, including at least 3 months with the mother and child following the child's birth.

### Children in Care

For children in voluntary care or on an interim order, the parents must sign the consent. For children on a care order the consent is signed by a Tusla Child and Family Agency social worker.

Child's Name

Date of Birth  /  /

| | | | | |
|---|---|---|---|---|
| I give permission for my child to be referred to Primary Care Services / Children's Disability Services. | Yes | ☐ | No | ☐ |
| I give permission for information about my child to be held by Primary Care Services/Children's Disability Services in accordance with obligations under the Data Protection Acts 1988, 2003 and 2018. | Yes | ☐ | No | ☐ |
| I give permission that in the event that this referral is not appropriate it may be shared with other relevant services to facilitate an onward referral. I will be contacted in advance of this information being forwarded on to another service. | Yes | ☐ | No | ☐ |
| I give permission to Primary Care Services/ Children's Disability Services to contact and obtain relevant information in order to understand and address my child's needs from the professionals and services listed below, such as a hospital consultant, psychologist, speech & language therapist, teacher etc. Only those listed overleaf will be contacted. | Yes | ☐ | No | ☐ |

### Professionals and services your child has attended

| Name (if available) | Service | Contact Details |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

Name of Parent 1/ Guardian

Signature

Date

---

Name of Parent 2/ Guardian

Signature

Date

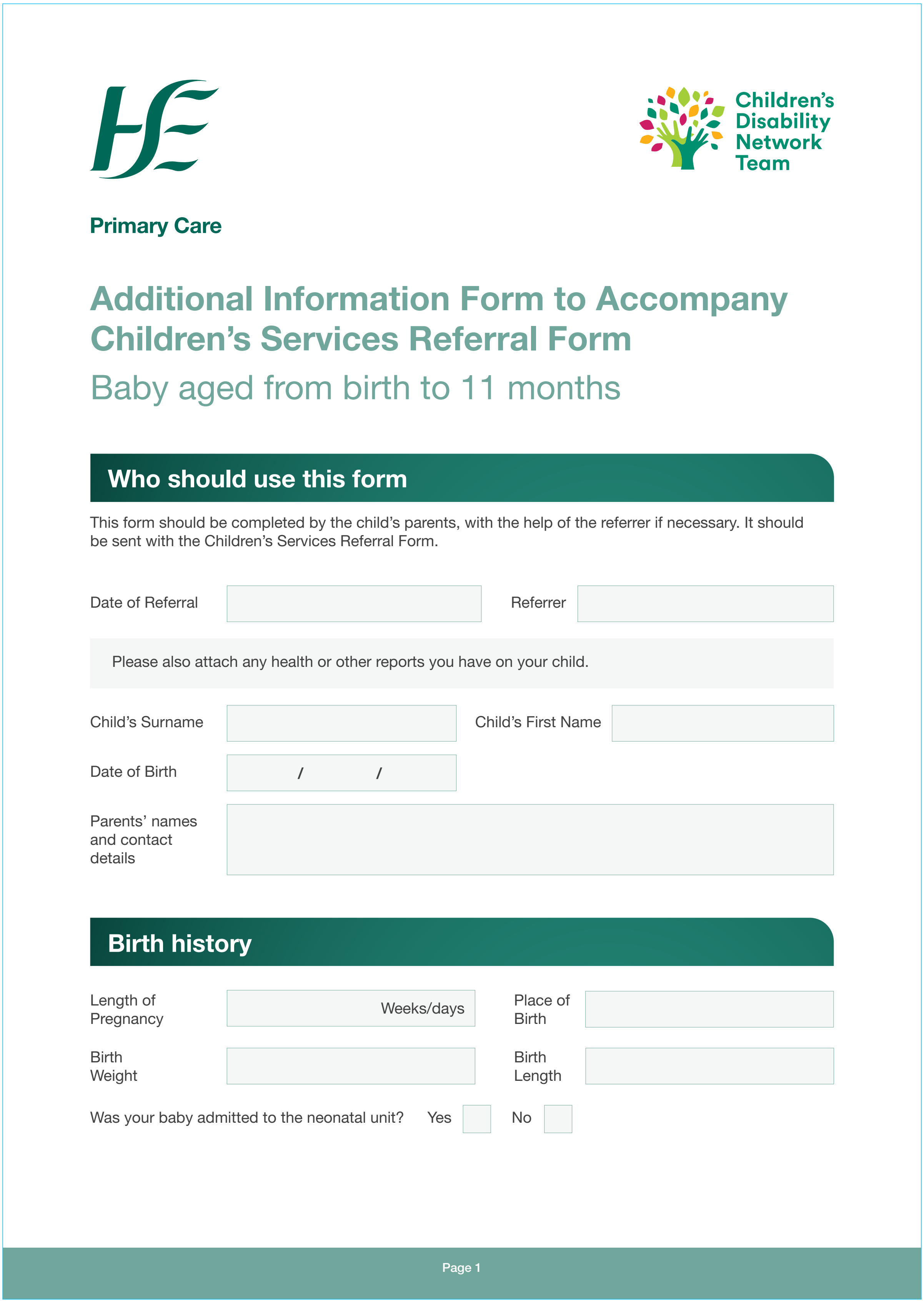
## Referrers details

| | | | |
|---|---|---|---|
| Name | | | |
| Role (Parent/ Legal guardian, professional) | | | |
| Date | | | |
| Address | | | |
| Telephone | | Mobile | |
| Email | | | |
| Signature | | | |

## Any other information you want to give us

# Additional information form to accompany children's services referral form

## Baby aged from birth to 11 months



Children's Disability Network Team

Primary Care

# Additional Information Form to Accompany Children's Services Referral Form

## Baby aged from birth to 11 months

### Who should use this form

This form should be completed by the child's parents, with the help of the referrer if necessary. It should be sent with the Children's Services Referral Form.

| | | | |
|---|---|---|---|
| Date of Referral | | Referrer | |

Please also attach any health or other reports you have on your child.

| | | | |
|---|---|---|---|
| Child's Surname | | Child's First Name | |
| Date of Birth | / / | | |
| Parents' names and contact details | | | |

### Birth history

| | | | |
|---|---|---|---|
| Length of Pregnancy | Weeks/days | Place of Birth | |
| Birth Weight | | Birth Length | |

Was your baby admitted to the neonatal unit? Yes ☐ No ☐

Page 1

Has your baby been in hospital at any time since they were born? Yes ☐ No ☐

If Yes, for what reason?

Please give details of medications, hospital and nursing needs, breathing and feeding supports.

Please provide your baby's up to date length, weight and head size centile scores from their growth chart if available.

## Tell us about your baby's development

### Can your baby...

Grab a toy with either hand? Left ☐ Right ☐ Not yet ☐

Grab both feet when lying on his or her back? Yes ☐ Not yet ☐

Roll over… On to tummy ☐ On to back ☐ Neither yet ☐

Tolerate lying on his or her tummy? Yes ☐ Not yet ☐

Sit... On his or her own ☐ Only with support ☐ Not yet ☐

Crawl... On tummy ☐ On hands and knees ☐ Not yet ☐

Does your baby pull to standing? Yes ☐ Not yet ☐

Stand... Without support ☐ Only with support ☐ Not yet ☐

Do you have any other concerns about your baby's movement such as being floppy or tense when you lift him or her? Yes ☐ No ☐

If so please give details.

Is your baby able to fully open his or her hands including thumb? Yes ☐ Not yet ☐

Is your baby able to grasp and release a toy? Yes ☐ Not yet ☐

Does your baby use one hand more than the other? Yes ☐ Not yet ☐

Can your baby pass toys from one hand to the other? Yes ☐ Not yet ☐

If you have concerns about your baby’s hand movements please give details.

Do you have any concerns about your baby’s weight or growth? Yes ☐ No ☐

If Yes please describe.

Please enclose any growth and weight charts.

Describe your baby’s daily feeding routine, times and size of feeds. How does your baby feed? How long does a breast or bottle feed take? If your baby has started spoon feeding, is it going well?

Do you find feeding stressful? Yes ☐ No ☐

If Yes please describe.

Is your baby taking any specialised feeds, drinks or foods? Yes ☐ No ☐

Please give details.

Do you have concerns about your baby's sleep? Yes ☐ No ☐

If Yes please describe.

How do you know what your baby wants? e.g. does he or she look at you, cry when hungry, smile, reach out?

Can your baby look at an object and follow it when it moves? Yes ☐ No ☐

What kind of sounds does your baby make? e.g. happy sounds, sad sounds, types of cries, sounds like aah, babble such as bada, gaga.

Do you have concerns about how your baby's behaves? e.g. excessive crying, irritable, too quiet. Yes ☐ No ☐

If Yes please describe your concerns.

Do you have concerns about your baby's ability to play and respond to play? Yes ☐ No ☐

Please describe your concerns.

Do you think your baby is over-sensitive to noise, textures, movements or smells? Yes ☐ No ☐

If Yes please give details.

Do you have concerns about your baby's eye sight? Yes ☐ No ☐

If Yes, give details of your concerns and result of any tests undertaken.

Has your baby had a hearing test? Yes ☐ No ☐

Please give details.

Do you have any concerns about your baby's hearing now? Yes ☐ No ☐

If Yes, give details of your concerns.

Has anyone else expressed concern about any aspect of your baby's development? e.g. Doctor, Public Health Nurse, family members, childminder. Yes ☐ No ☐

If Yes please give details including who expressed the concern.

## Is there anything else you would like to tell us about your baby?

Tell us about what he or she enjoys and can do, along with any concerns you have.

What is your main concern and priority for your baby?

## Safety and Risk

Please give details of any issues which pose a significant risk to the health and wellbeing of your baby or of others.

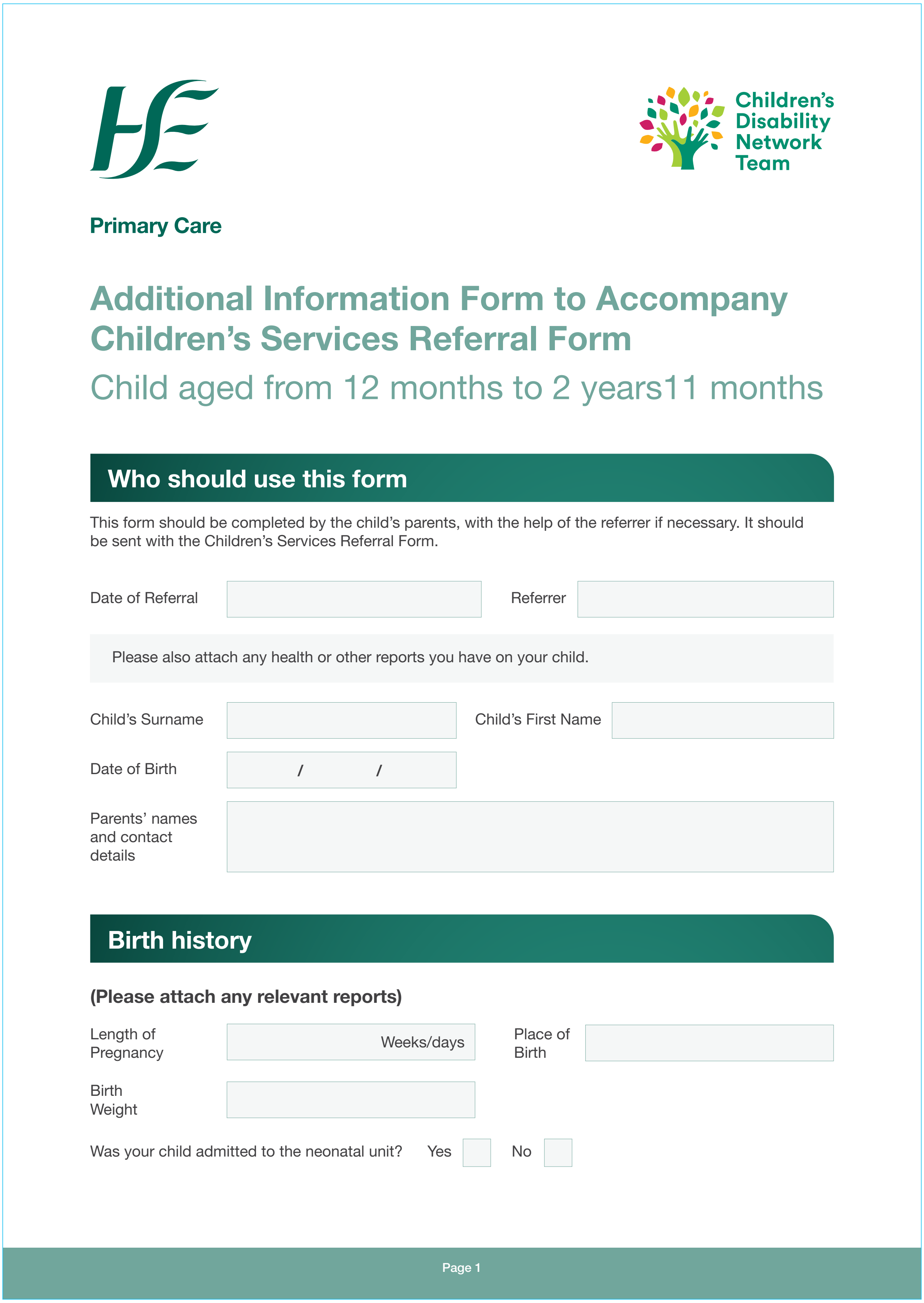
## Please give details of who completed this form

| | |
|---|---|
| Form completed by | |
| Relationship to child | |
| Contact details | |
| Date | / / |

## Any other information you want to give us

# Additional information form to accompany children's services referral form

## Child aged from 12 months to 2 years 11 months



Primary Care

Children's Disability Network Team

# Additional Information Form to Accompany Children's Services Referral Form

## Child aged from 12 months to 2 years11 months

## Who should use this form

This form should be completed by the child's parents, with the help of the referrer if necessary. It should be sent with the Children's Services Referral Form.

| | | | |
|---|---|---|---|
| Date of Referral | | Referrer | |

Please also attach any health or other reports you have on your child.

| | | | |
|---|---|---|---|
| Child's Surname | | Child's First Name | |
| Date of Birth | / / | | |
| Parents' names and contact details | | | |

## Birth history

**(Please attach any relevant reports)**

| | | | |
|---|---|---|---|
| Length of Pregnancy | Weeks/days | Place of Birth | |
| Birth Weight | | | |

Was your child admitted to the neonatal unit? Yes ☐ No ☐

Has your child ever been in hospital since they were born? Yes ☐ No ☐

If Yes, for what reason?

☐

Please give details of medications, hospital and nursing needs, breathing and feeding supports.

☐

## Your child's development

**Please note some questions may not be relevant for your child.**

### 1. Movement and Gross Motor Skills

**Has your child achieved the following?**

| | | | | | | |
|---|---|---|---|---|---|---|
| Rolling from back to tummy | Yes | ☐ | At what age | | Not yet | ☐ |
| Sitting | Yes | ☐ | At what age | | Not yet | ☐ |
| Crawling | Yes | ☐ | At what age | | Not yet | ☐ |
| Walking independently | Yes | ☐ | At what age | | Not yet | ☐ |
| Running | Yes | ☐ | At what age | | Not yet | ☐ |

If your child is walking do they tend to walk on tiptoes? Yes ☐ No ☐

Is your child clumsier than other children their age? Yes ☐ No ☐

Describe any concerns you have about your child's movement and gross motor skills.

## 2. Fine Motor Skills and Hand Movement

### Which of the following can your child do?

Pick up small objects such as raisins Yes ☐ Not yet ☐

Play with construction games e.g. building blocks or Duplo Yes ☐ Not yet ☐

Use a pencil or crayon to scribble or draw Yes ☐ Not yet ☐

Describe any concerns you have about your child's ability to use their hands.

## 3. Communication, Speech and Language

### How does your child let you know they want something?

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Crying | Yes | ☐ | Not yet | ☐ | Pulling | Yes | ☐ | Not yet | ☐ |
| Pointing | Yes | ☐ | Not yet | ☐ | Sounds | Yes | ☐ | Not yet | ☐ |
| Gestures | Yes | ☐ | Not yet | ☐ | Uses signs | Yes | ☐ | Not yet | ☐ |
| Uses pictures | Yes | ☐ | Not yet | ☐ | Words | Yes | ☐ | Not yet | ☐ |
| Sentences | Yes | ☐ | Not yet | ☐ | Or a combination of these<br>Yes ☐ Not yet ☐ | | | | |

## Has your child achieved the following?

| | | | | |
|---|---|---|---|---|
| Babbling (e.g. gaga bada) | Yes ☐ | At what age | | |
| | Not yet ☐ | Skill achieved but since lost ☐ | | |
| Gestures such as wave "bye bye" and point? | Yes ☐ | At what age | | |
| | Not yet ☐ | Skill achieved but since lost ☐ | | |
| First word such as 'cat' 'more'? | Yes ☐ | At what age | | |
| | Not yet ☐ | Skill achieved but since lost ☐ | | |
| Putting two words together? | Yes ☐ | At what age | | |
| | Not yet ☐ | Skill achieved but since lost ☐ | | |

How many words can your child put together now in a sentence?

Give an example of the kind of things your child says now.

Does your child have difficulty understanding what you say? Yes ☐ No ☐

Please give details of any concerns you have about your child's speech, language, communication and voice.

## 4. Social Interaction, Relationships, Play and Leisure

| | | | |
|---|---|---|---|
| When playing does your child allow you or other adults to join in? | Always ☐ | Sometimes ☐ | Never ☐ |
| When playing does your child allow other children to join in? | Always ☐ | Sometimes ☐ | Never ☐ |

Describe how your child plays with others.

Describe what toys your child plays with and how they play with them.

What activity does your child like to do?

Does your child engage in pretend play and make believe games? Yes ☐ No ☐

Is there anything you would like us to know about your child's play, friendships and activities?

## 5. Daily Living Skills

### 5A. Food and Drink

Do you have any concerns about your child's weight or growth? Yes ☐ No ☐

If Yes, give details.

Do you have any concerns about your child's nutrition or the range of foods they eat? Yes ☐ No ☐

If Yes, give details.

Describe your child's usual food, drinks and mealtime routine?

Can your child use a spoon to feed him or herself? Yes ☐ Not yet ☐

Can your child drink from a beaker with a spout or a cup by themselves? Yes ☐ Not yet ☐

Give details of any concerns about your child's ability to feed themselves.

Do you have any concerns about **how** your child is chewing, swallowing or drinking? Yes ☐ No ☐

If Yes please describe.

Are mealtimes stressful? Yes ☐ No ☐

If Yes please describe.

Is your child on specialised feeds, drinks or foods? Yes ☐ No ☐

If Yes, give details.

## 5B. Urinary and Bowel Habits

Please describe what stage your child has reached with toilet training.

Are there any issues around toileting? Yes ☐ No ☐

If Yes, describe.

### 5C. Sleep and Rest

Do you have concerns about your child's sleeping routine? Yes ☐ No ☐

If Yes, describe.

Do you have any concerns about your child's level of energy? Yes ☐ No ☐

If Yes, describe.

## 6. Behaviour and Emotions

Have you any concerns about your child's emotional wellbeing and behaviour? At home ☐ Out and about ☐

Describe any concerns.

### Do the following statements describe your child? (Please tick the appropriate boxes)

| | | | |
|---|---|---|---|
| Frequent prolonged tantrums | ☐ | Aggressive | ☐ |
| Irritable | ☐ | Excessive Crying | ☐ |
| Clingy | ☐ | Upset for seemingly minor things | ☐ |
| Withdrawn or too quiet | ☐ | Doesn't like change | ☐ |
| Frustrated | ☐ | Worries a lot | ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's level of energy? Yes ☐ No ☐

If Yes, describe.

Has anyone else expressed any concern about your child's ability to learn, such as the creche, a family member? Yes ☐ No ☐

If Yes, give details of the concern and who expressed it.

## 8. Vision and Hearing

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details.

Does your child attend a specialist service for their vision or for their hearing? Yes ☐ No ☐

If Yes, give details.

## 9. Sensory Processing

If you have concerns about your child's sensitivity to any of the following, either avoiding them or seeking them out, please tick:

| | | | |
|---|---|---|---|
| Noise ☐ | Touch ☐ | Textures (such as fabrics) ☐ | Movements ☐ |
| Smells ☐ | Food ☐ | Lights ☐ | |

If you have ticked any of the above, please give details and describe how this impacts on everyday life.

## 10. Is there anything else you would like to tell us about your child?

Tell us what your child enjoys and is good at as well as the things they find difficult.

What is your main concern and priority for your child?

## Safety and Risk

Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?

## Please give details of who completed this form

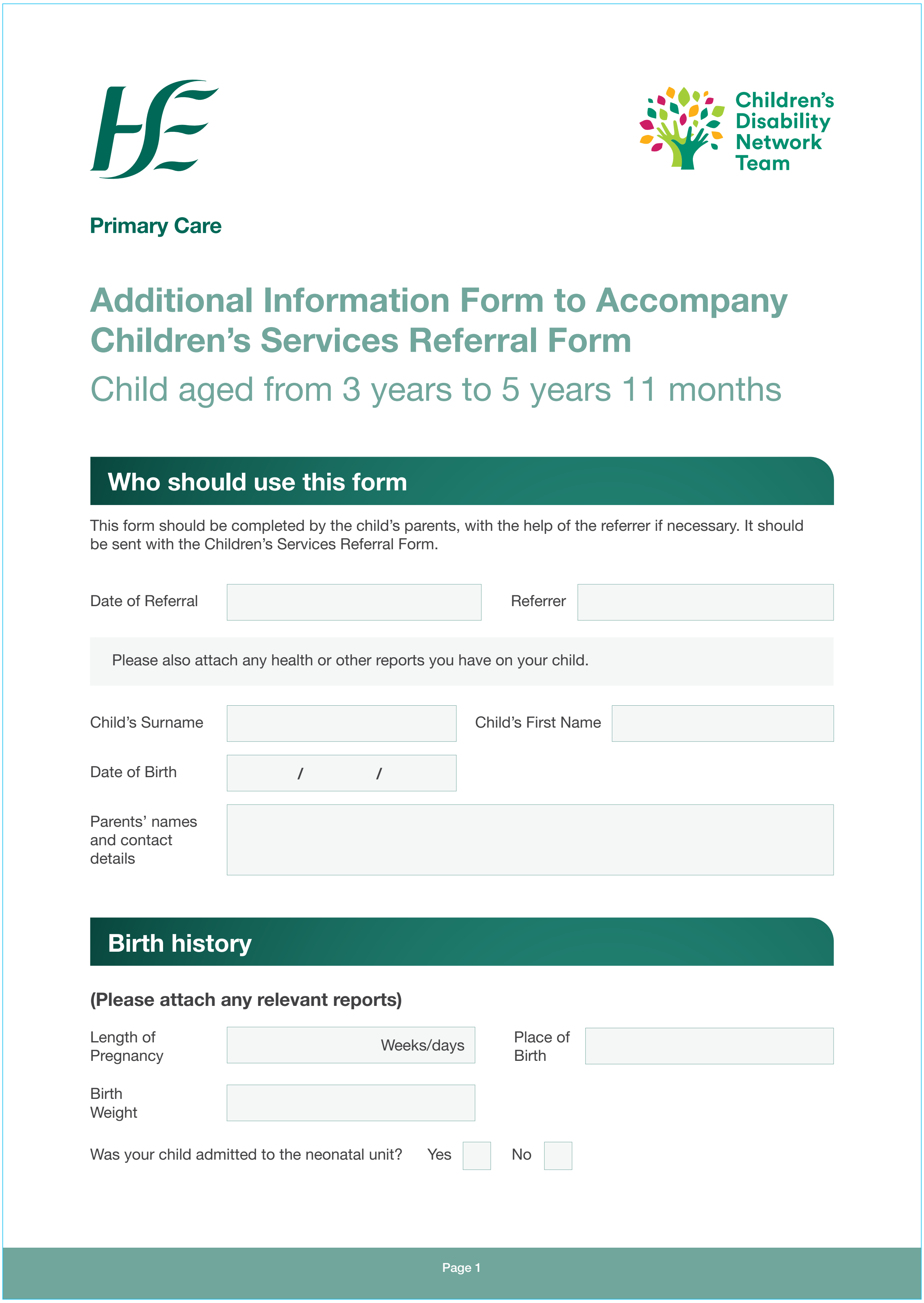
| | |
|---|---|
| Form completed by | |
| Relationship to child | |
| Contact details | |
| Date | / / |

**N.B. Please attach copies of any health or pre-school reports that you have.**

## Any other information you want to give us

# Additional information form to accompany children's services referral form

## Child aged from 3 years to 5 years 11 months



**Primary Care**

Children's Disability Network Team

# Additional Information Form to Accompany Children's Services Referral Form

## Child aged from 3 years to 5 years 11 months

## Who should use this form

This form should be completed by the child's parents, with the help of the referrer if necessary. It should be sent with the Children's Services Referral Form.

Date of Referral ______ Referrer ______

Please also attach any health or other reports you have on your child.

Child's Surname ______ Child's First Name ______

Date of Birth / /

Parents' names and contact details ______

## Birth history

**(Please attach any relevant reports)**

Length of Pregnancy Weeks/days

Place of Birth ______

Birth Weight ______

Was your child admitted to the neonatal unit? Yes ☐ No ☐

Page 1

Has your child ever been in hospital since they were born? Yes ☐ No ☐

If Yes, for what reason?

Please give details of medications, hospital and nursing needs, breathing and feeding supports.

## Your child's development

**Please note some questions may not be relevant for your child.**

### 1. Movement and Gross Motor Skills

**Has your child achieved the following?**

| | | | | | | |
|---|---|---|---|---|---|---|
| Walking independently | Yes | ☐ | At what age | | Not yet | ☐ |
| Running | Yes | ☐ | At what age | | Not yet | ☐ |
| Jumping | Yes | ☐ | At what age | | Not yet | ☐ |
| Climbing up and down stairs | Yes | ☐ | At what age | | Not yet | ☐ |
| Throwing a ball | Yes | ☐ | At what age | | Not yet | ☐ |
| Catching a ball | Yes | ☐ | At what age | | Not yet | ☐ |
| Kicking a ball | Yes | ☐ | At what age | | Not yet | ☐ |

**Please tick if any of the following describe your child's movements.**

| | | | |
|---|---|---|---|
| Trips more than other children their age | ☐ | Falls more than other children their age | ☐ |
| Bumps into other things more than other children their age | ☐ | Tends to walk on tiptoes | ☐ |
| Clumsier than other children their age | ☐ | My child is losing skills they did have | ☐ |
| My child's posture looks different from other children | ☐ | | |

If you have ticked any of these, give details.

Is your child keeping up with other children of their age in physical development and activity? Yes ☐ No ☐

If No, give examples.

Describe any other concerns you have about your child's movement and gross motor skills.

## 2. Fine Motor Skills and Hand Movement

**Which of the following can your child do if they have had a chance to try it?**

| | | |
|---|---|---|
| Pick up small objects such as raisins or beads | Yes ☐ | No ☐ |
| Play with construction toys such as building blocks or Lego | Yes ☐ | No ☐ |
| Use a pencil or crayon to scribble or draw | Yes ☐ | No ☐ |
| Use a child's scissors to cut paper | Yes ☐ | No ☐ |
| Open their lunchbox | Yes ☐ | No ☐ |

Describe any concerns you have about your child's fine motor and hand movements.

## 3. Communication, Speech and Language

Please explain how your child communicates most of their messages now? (e.g. crying, pulling, pointing, sounds, gestures, uses signs, uses pictures, words, sentences or a combination of these?)

### Has your child achieved the following?

First words, such as ‘cat’ ‘more’?
Yes ☐ At what age
Not yet ☐ Skill achieved but since lost ☐

Putting two words together?
Yes ☐ At what age
Not yet ☐ Skill achieved but since lost ☐

How many words can your child put together now in a sentence?

Give an example of the kind of things your child says now.

### Do any of the following describe your child’s speech, language, and communication abilities?

My child has difficulty understanding what I say Yes ☐ No ☐

If yes, please give examples.

My child has difficulty telling a story, such as telling me about something that happened during their day Yes ☐ No ☐

My child finds it hard to pronounce/say certain sounds, for example says “tup” for “cup Yes ☐ No ☐

Please give details of any concerns you have about your child’s speech, language, communication and voice.

## 4. Social Interaction, Relationships, Play and Leisure

| | | | |
|---|---|---|---|
| When playing does your child allow you or other adults to join in? | Always ☐ | Sometimes ☐ | Never ☐ |
| When playing does your child allow other children to join in? | Always ☐ | Sometimes ☐ | Never ☐ |

Describe how your child plays with others.

| | | |
|---|---|---|
| Does your child show an interest in other children? | Yes ☐ | No ☐ |
| Does your child take turns with other children? | Yes ☐ | No ☐ |
| Does your child share toys with other children? | Yes ☐ | No ☐ |

What toys does your child like to play with and how do they play with them?

Does your child engage in imaginative play e.g. pretend and make believe games?

What activities do your child like to do?

Please give any further comments about your child's play, friendships and activities.

## 5. Daily Living Skills

### 5A. Food and Drink

| | | |
|---|---|---|
| Do you have any concerns about your child's weight or growth? | Yes ☐ | No ☐ |

If Yes, give details.

Please enclose any growth or weight charts available.

| | | |
|---|---|---|
| Do you have any concerns about how much your child eats and drinks, or the range of foods they eat? | Yes ☐ | No ☐ |

If Yes, give details.

Describe your child's usual food, drinks and mealtime routine?

| | | |
|---|---|---|
| Can your child use a spoon to feed themselves? | Yes ☐ | No ☐ |
| Can your child drink from a cup by themselves? | Yes ☐ | No ☐ |

If No, give details.

| | | |
|---|---|---|
| Do you have any concerns about **how** your child is eating, swallowing and drinking? | Yes ☐ | No ☐ |

If Yes please describe.

Are mealtimes stressful? Yes ☐ No ☐

If Yes please describe.

Is your child on any specialised feeds, drinks or food? Yes ☐ No ☐

If Yes, give details.

## 5B. Urinary and Bowel Habits

Please describe what stage your child has reached with toilet training.

Are there any issues around toileting? Yes ☐ No ☐

If Yes, describe.

## 5C. Personal Care, Dressing and Independence

Does your child dress themselves? Yes ☐ No ☐ With some help ☐

Does your child undress themselves? Yes ☐ No ☐ With some help ☐

Describe what your child can do for themselves.

Have you any concerns about your child's safety awareness in the home or out and about? Yes ☐ No ☐

If Yes, describe.

### 5D. Sleep

Do you have any concerns about your child's sleep routine? Yes ☐ No ☐

If Yes, describe.

Have you any concerns about your child's level of energy? Yes ☐ No ☐

If Yes, describe.

## 6. Behaviour and Emotions

Have you any concerns about your child's emotional wellbeing and behaviour?

At home ☐ At crèche, pre-school or school ☐ Out and about ☐

Please describe any concerns.

**Do the following statements describe your child? (Please tick the appropriate boxes)**

| | | | |
|---|---|---|---|
| Frequent prolonged tantrums | ☐ | Aggressive | ☐ |
| Irritable | ☐ | Excessive Crying | ☐ |
| Clingy | ☐ | Upset for seemingly minor things | ☐ |
| Withdrawn/too quiet | ☐ | Doesn't like change | ☐ |
| Frustrated | ☐ | Worries a lot | ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's ability to learn new skills? Yes ☐ No ☐

If Yes, describe.

Has anyone else expressed any concern about your child's ability to learn such as a teacher, psychologist, family member? Yes ☐ No ☐

If Yes, give details of the concern and who expressed it.

Do you have any concerns about your child's ability to concentrate? Yes ☐ No ☐

Is your child having any difficulties keeping up with learning or school work? Yes ☐ No ☐

If Yes give details.

## 8. Vision and Hearing

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details.

Does your child attend a specialist service for their vision or hearing? Yes ☐ No ☐

If Yes, give details.

## 9. Sensory Processing

If you have concerns about your child's sensitivity to any of the following, either avoiding them, getting annoyed with them or seeking them out, please tick:

| | | | |
|---|---|---|---|
| Noise ☐ | Touch ☐ | Textures (such as fabrics) ☐ | Movements ☐ |
| Smells ☐ | Food ☐ | Lights ☐ | |

If you have ticked any of the above, describe how this impacts on everyday life for your child and for you.

## 10. Is there anything else you would like to tell us about your child?

Tell us what your child enjoys and is good at as well as the things they find difficult.

What is your main concern and priority for your child?

## Safety and Risk

Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?

## Please give details of who completed this form

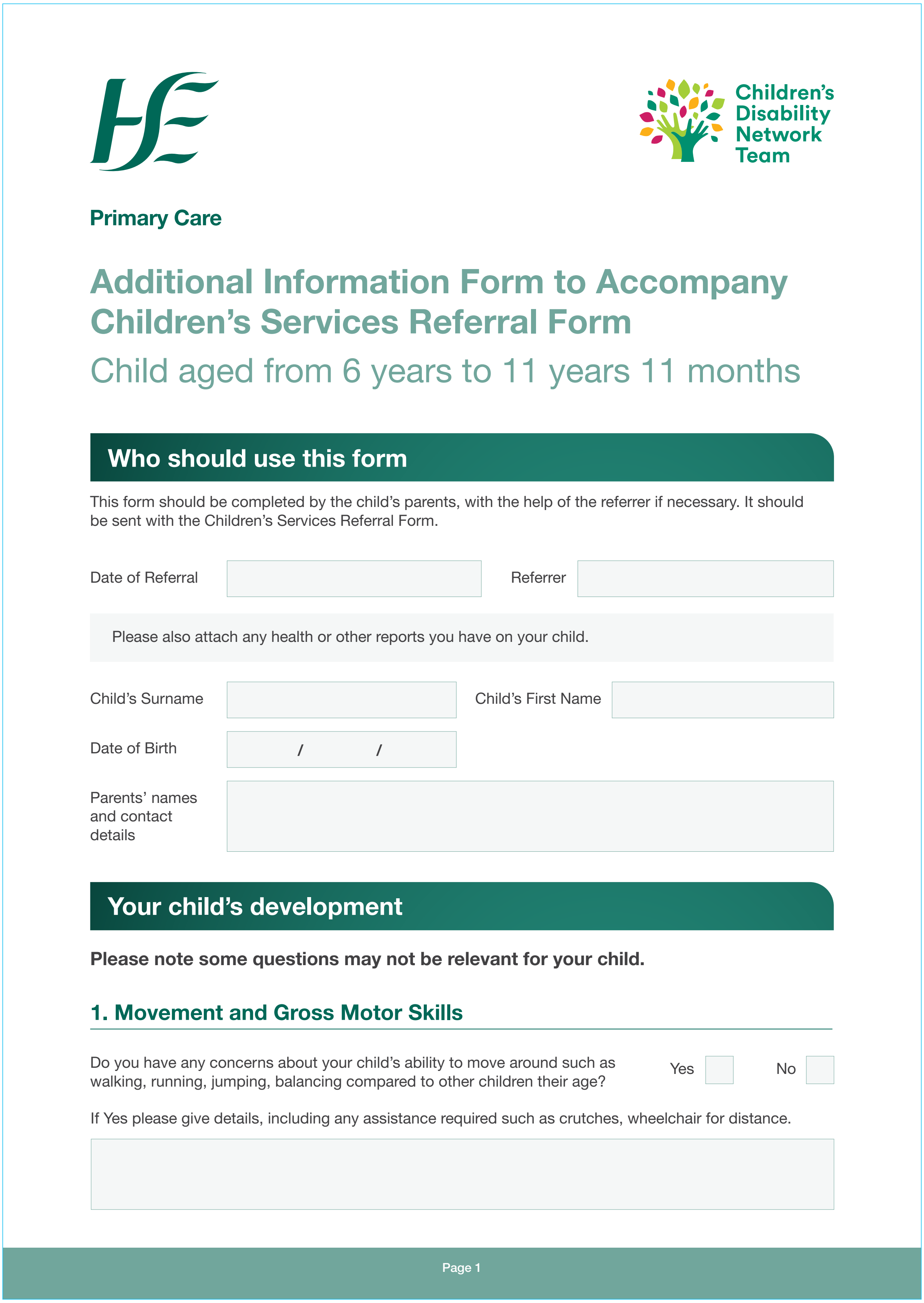
| | |
|---|---|
| Form completed by | |
| Relationship to child | |
| Contact details | |
| Date | / / |

**N.B. Please attach copies of any health, school or pre-school reports that you have.**

## Any other information you want to give us

# Additional information form to accompany children's services referral form

## Child aged from 6 years to 11 years 11 months



Primary Care

Children's Disability Network Team

# Additional Information Form to Accompany Children's Services Referral Form

## Child aged from 6 years to 11 years 11 months

## Who should use this form

This form should be completed by the child's parents, with the help of the referrer if necessary. It should be sent with the Children's Services Referral Form.

| | | | |
|---|---|---|---|
| Date of Referral | | Referrer | |

Please also attach any health or other reports you have on your child.

| | | | |
|---|---|---|---|
| Child's Surname | | Child's First Name | |
| Date of Birth | / / | | |
| Parents' names and contact details | | | |

## Your child's development

**Please note some questions may not be relevant for your child.**

### 1. Movement and Gross Motor Skills

Do you have any concerns about your child's ability to move around such as walking, running, jumping, balancing compared to other children their age? Yes ☐ No ☐

If Yes please give details, including any assistance required such as crutches, wheelchair for distance.

Page 1

How does your child's difficulty with moving impact on their ability to do everyday activities?
e.g. washing, dressing, play.

Have you noticed any recent changes in your child's ability to move or their level of fatigue? Yes ☐ No ☐

If Yes, please give details.

Do you have any other concerns about your child's movement or gross motor skills?

## 2. Hand Movement and Fine Motor Skills

### In comparison with other children their age can your child do the following?

| | | |
|---|---|---|
| Pick up small objects with finger and thumb | Yes ☐ | No ☐ |
| Play with construction toys such as building blocks or Lego | Yes ☐ | No ☐ |
| Use a pencil or pen to write | Yes ☐ | No ☐ |
| Use a scissors to cut paper | Yes ☐ | No ☐ |
| Open their lunchbox | Yes ☐ | No ☐ |

If you answered No to any of the above questions or you have other concerns about your child's hand movement please give details.

## 3. Communication, Speech and Language

**Do any of the following describe your child? Please tick if Yes.**

| | |
|---|---|
| My child has difficulty telling a story e.g. telling me about something that happened at school | ☐ |
| My child gets confused when I give them long instructions | ☐ |
| My child has difficulty holding a conversation with other children | ☐ |
| My child has difficulty holding a conversation with adults | ☐ |
| My child's speech is difficult to understand compared to other children | ☐ |
| My child likes to talk about particular topics to the exclusion of others | ☐ |
| My child has difficulty holding eye contact | ☐ |
| My child has difficulty understanding what is said to them | ☐ |
| My child does not consistently respond to their name | ☐ |
| My child has issues with their voice e.g. prolonged hoarseness | ☐ |
| My child has a stammer | ☐ |

If you have ticked any of the above please give further details.

Does your child use technology or a computer to communicate? Yes ☐ No ☐

If yes please give further information on technology or computer use.

Please give details of any other concerns about your child's speech, language, communication and voice.

## 4. Social Interaction, Relationships, Play and Leisure

| | | | |
|---|---|---|---|
| When playing does your child allow you or other adults to join in? | Always ☐ | Sometimes ☐ | Never ☐ |
| When playing does your child allow other children to join in? | Always ☐ | Sometimes ☐ | Never ☐ |

Give details of any concerns about how your child plays with others.

What toys and games does your child like to play with and how do they play with them?

Does your child engage in imaginative play e.g. pretend and make believe games?

What activities does your child like to do?

What activities in the community does your child take part in?

Does your child need extra help to play with others and if so what kind of help?

Please give any further comments about your child's play, friendships and activities.

## 5. Daily Living Skills

### 5A. Food and Drink

Do you have any concerns about your child's weight or growth? Yes ☐ No ☐

If Yes, give details.

Please describe your child's usual meal, food and drink routine.

Do you have any concerns about how much your child eats or the range of foods they eat? Yes ☐ No ☐

If Yes, describe.

Does your child have special feeding requirements? Yes ☐ No ☐

If Yes, describe.

Do you have any concerns about **how** your child is eating, swallowing and drinking? Yes ☐ No ☐

If Yes please describe.

Are mealtimes stressful? Yes ☐ No ☐

If Yes please describe.

### 5B. Urinary and Bowel Habits

Does your child have any issues with toileting? Yes ☐ No ☐

If Yes please describe.

### 5C. Personal Care, Dressing and Independence

**Do you have concerns about your child's ability to manage the following compared with other children their age?**

| | | | | | | |
|---|---|---|---|---|---|---|
| Dressing | Yes ☐ | No ☐ | | Undressing | Yes ☐ | No ☐ |
| Washing | Yes ☐ | No ☐ | | Brushing teeth | Yes ☐ | No ☐ |
| Organising belongings | Yes ☐ | No ☐ | | Getting ready for school | Yes ☐ | No ☐ |
| Getting ready for bed | Yes ☐ | No ☐ | | | | |

If Yes to any of the above please describe your concerns.

### 5D. Sleep and Rest

Do you have any concerns about your child's sleep routine? Yes ☐ No ☐

Have you any concerns about your child's level of energy? Yes ☐ No ☐

If Yes to either of these questions give details.

## 6. Behaviour and Emotions

Do you have concerns about your child's emotional wellbeing and behaviour?

At home ☐ At school ☐ Out and about ☐

Please describe any concerns.

**Do any of the following describe your child's behaviour? (Please tick if Yes)**

| | | | |
|---|---|---|---|
| Frequent prolonged outbursts or meltdowns | ☐ | Aggressive | ☐ |
| Avoids certain activities or people | ☐ | Excessive Crying | ☐ |
| Clingy | ☐ | Upset for seemingly minor things | ☐ |
| Withdrawn or too quiet | ☐ | Doesn't like change | ☐ |
| Frustrated | ☐ | Worries a lot | ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on your child and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child's ability to learn? Yes ☐ No ☐

If Yes please describe.

Has anyone expressed any concern about your child's ability to learn such as a teacher, psychologist or family member? Yes ☐ No ☐

If Yes, give details of the concern and who expressed it.

Is your child having any difficulties keeping up with learning and schoolwork? Yes ☐ No ☐

If Yes give details.

Has your child had any assessments of their learning? e.g. NEPS.

Please enclose with this form copies of any school or psychology reports you have on your child.

Does your child have any additional support in school, such as SNA, Special Education teaching? Yes ☐ No ☐

If Yes, give details.

## 8. Vision and Hearing

Does your child have vision problems which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details.

Does your child attend a specialist service for their vision or for their hearing? Yes ☐ No ☐

If Yes, give details.

## 9. Sensory Processing

If you have concerns about your child's sensitivity to any of the following, either avoiding them, getting annoyed with them or seeking them out, please tick:

| | | | |
|---|---|---|---|
| Noise ☐ | Touch ☐ | Textures (such as fabrics) ☐ | Movements ☐ |
| Smells ☐ | Food ☐ | Lights ☐ | |

If you have ticked any of the above, describe how this impacts on everyday life for your child and for you.

## 10. Is there anything else you would like to tell us about your child?

Tell us what your child enjoys and can do well, as well as the things they find difficult.

What is your main concern and priority for your child?

## Safety and Risk

Are there any issues which are a significant risk to the health and wellbeing of your child or others, such as physical injury to self or others, refusal to eat?

## Please give details of who completed this form

| | |
|---|---|
| Form completed by | |
| Relationship to child | |
| Contact details | |
| Date | / / |

**N.B. Please attach copies of any health or school reports.**

## Any other information you want to give us

# Additional information form to accompany Children’s services referral form

## Child/young person aged from 12 years to 17 years 11 months

**Primary Care**

Children’s Disability Network Team

# Additional Information Form to Accompany Children’s Services Referral Form

## Child/young person aged from 12 years to 17 years 11 months

## Who should use this form

This form should be completed by the child’s parents, with the help of the referrer if necessary. It should be sent with the Children’s Services Referral Form.

| | | | |
|---|---|---|---|
| Date of Referral | | Referrer | |

Please also attach any health or other reports you have on your child.

| | | | |
|---|---|---|---|
| Child’s or Young Person’s Surname | | First Name | |
| Date of Birth | / / | | |
| Parents’ names and contact details | | | |

## Your child’s or young person’s development

**Please note some questions may not be relevant.**

### 1. Movement (Gross Motor Skills)

Do you have any concerns about your child’s or young person’s ability to move around such as walking, running, jumping, and balancing? Yes ☐ No ☐

If Yes give details including any assistance required such as crutches, wheelchair for distance.

How does their difficulty with moving impact on their ability to do everyday tasks e.g. leisure and social activities, washing, dressing?

| |
|---|
| |

Have you noticed any recent changes in their ability to move or their level of fatigue? Yes ☐ No ☐

If Yes, please give details.

| |
|---|
| |

Do you have any other concerns about their movement or gross motor skills?

| |
|---|
| |

## 2. Fine Motor and Hand Skills

Does your child or young person have difficulty using their hands such as handwriting, using scissors, picking up small items, using computers? Yes ☐ No ☐

If yes, give details.

| |
|---|
| |

## 3. Communication

Does your child or young person have difficulty expressing themselves e.g. asking for help, describing events? Yes ☐ No ☐

Do they have difficulty understanding people? Yes ☐ No ☐

Is it difficult to understand what they are saying? Yes ☐ No ☐

Do they have difficulty going along with a conversation if the other person changes the topic? Yes ☐ No ☐

Do they have any difficulty with understanding jokes or phrases such as ‘I’m only pulling your leg’? Yes ☐ No ☐

If Yes to any of the above questions please describe.

| |
|---|
| |

Do they use technology or a computer to communicate? Yes ☐ No ☐

If yes please give further information on technology or computer use.

Do they have any issues with their voice e.g. prolonged hoarseness?

Do you have any other concerns about their speech, language, communication and voice?

## 4. Social Interaction, Relationships and Leisure

Do you have concerns about your child's or young person's ability to form and keep up relationships with others? Yes ☐ No ☐

Please describe your concerns.

Please describe any leisure or sport activities they take part in.

## 5. Daily Living Skills

### 5A. Food and Drink

Do you have any concerns about your child's or young person's weight or growth? Yes ☐ No ☐

If Yes, give details.

### 5C. Personal Care, Dressing and Independence

**Do you have concerns about your child's or young person's ability to manage the following compared with others their age?**

| | | | | |
|---|---|---|---|---|
| Dressing | Yes ☐ | No ☐ | Undressing | Yes ☐ | No ☐ |
| Washing | Yes ☐ | No ☐ | Brushing teeth | Yes ☐ | No ☐ |
| Organising belongings | Yes ☐ | No ☐ | Getting ready for bed | Yes ☐ | No ☐ |
| Getting ready for school | Yes ☐ | No ☐ | | | |

If Yes to any of the above give details.

### 5D. Sleep and Rest

| | | |
|---|---|---|
| Do you have concerns about their sleep or ability to rest or relax? | Yes ☐ | No ☐ |
| Do they have difficulty initiating activities or appear lethargic or tire easily? | Yes ☐ | No ☐ |

If Yes to either of these questions, give details.

## 6. Behaviour and Emotions

Have you concerns about your child's or young person's emotional wellbeing and behaviour?

At home ☐ At school ☐ Out and about ☐

Please describe any concerns.

**Do the following statements describe their behaviour and emotions? (Please tick the appropriate boxes)**

| | | | |
|---|---|---|---|
| Frequent prolonged outbursts or meltdowns | ☐ | Aggressive | ☐ |
| Avoids certain activities or people | ☐ | Low mood | ☐ |
| Clingy | ☐ | Upset for seemingly minor things | ☐ |
| Withdrawn/too quiet | ☐ | Doesn’t like change | ☐ |
| Frustrated | ☐ | Worries a lot | ☐ |

If Yes to any of the above, how often does this occur? Daily ☐ Weekly ☐ Monthly ☐ Less often ☐

What impact does this have on them and on your family and what helps to prevent problems?

## 7. Learning

Do you have any concerns about your child’s or young person’s ability to learn? Yes ☐ No ☐

If Yes give details.

Has anyone expressed any concern about their ability to learn such as a teacher, psychologist or family member? Yes ☐ No ☐

If Yes give details of the concern and who expressed it.

Are they having any difficulties keeping up with learning and school work? Yes ☐ No ☐

If yes please give details.

Have they had any assessments e.g. NEPS?

Please enclose with this form copies of any school or psychology reports you have on your child.

Do they have extra learning support in school such as SNA, Special Education teaching? Yes ☐ No ☐

If Yes give details.

## 8. Vision and Hearing

Does your child or young person have problems with eyesight or vision which cannot be corrected with glasses? Yes ☐ No ☐

If Yes, give details.

Do they attend a specialist service for their vision or hearing? Yes ☐ No ☐

If Yes, give details.

## 9. Sensory Processing

If you have concerns about your child's or young person's sensitivity to any of the following, either avoiding, getting annoyed with or seeking out, please tick:

| | | | |
|---|---|---|---|
| Noise ☐ | Touch ☐ | Textures (such as fabrics) ☐ | Movements ☐ |
| Smells ☐ | Food ☐ | Lights ☐ | |

If you have ticked any of the above, please describe how this impacts on everyday life for your child and for you.

## 10. Is there anything else you would like to tell us?

Tell us what your child or young person enjoys and can do well, as well as those things they find difficult.

What is your main concern and priority?

## Safety and Risk

Are there any issues which are a significant risk to their health and wellbeing or that of others, such as physical injury to self or others, refusal to eat?

## Please give details of who completed this form

| | |
|---|---|
| Form completed by | |
| Relationship to child | |
| Contact details | |
| Date | / / |

## Any other information you want to give us

# Appendix 9:
# Recommendations of the review report

## Recommendations of the review report specific to the role and remit of the Operational Model Working Group

**NOTE: For accuracy and fidelity to the 2017 review report the original terminology is retained. This means, for instance, that the term “ASD” is used. However, it should be noted that the suggestion that autistic experience necessarily reflects a “disorder” is not consistent with the neuropositive framing of autism promoted in this protocol. This is a reminder of the rapidly changing views regarding autism.**

### Recommendation 1

### Engagement and collaborative working where all services work together with service users to meet their needs

In order to meet their changing needs, people with ASD and their families need easy, typically simultaneous, access to various parts of the health and wider services (e.g., education, social welfare). However, as supported by consultation feedback, their experience is often characterised by fragmented and sometimes duplicated care, partially due to different services working in silos. The Sláintecare health service reform blueprint and the new HSE governance structures around the advancement of community healthcare create an opportunity for more joined up service provision. The HSE needs to ensure that people with ASD and their families have easy access to various health care providers so that they get the right service at the right time. As highlighted by the academic literature (NICE, 2014) and consultation feedback, the voice of people with ASD and their family members must be heard. They must be consulted in a meaningful way about the design of ASD services.

**RECOMMENDATIONS**

1.1 Each Community Healthcare Organisation (CHO) will ensure an integrated service delivery model has been identified. This process will involve engagement with individuals with ASD, their family members, voluntary service providers and advocacy groups to ensure they are fully engaged in the development and implementation of services for those with ASD in their community.

1.2 Each CHO will identify a lead manager who will work with key stakeholders to ensure an integrated service delivery model has been identified and an action plan for implementation put in place.

1.3 A national oversight group will be established with a lead manager identified to ensure consistency of approach across all CHO and the actions identified in this report are being prioritised. This group will provide an bi-yearly update of operational effectiveness of services and the implementation of the actions of this report.

1.4 An ongoing process will be established in each CHO with all key stakeholders to ensure consultation is carried out regularly with service users as part of the ongoing evaluation of the effectiveness of services. This process of consultation will also be central to any design of services.

1.5 Policies and reports involving those with ASD and their families will be published in straightforward language with visual aids to make them easier to understand.

### Recommendation 2
### Clear and functioning pathways to services

There is a need to facilitate timely access to services. There is also a need delineate clear pathways to services so that there is universal understanding of the most appropriate care pathway for children and their families. This is particularly important for young children and later for those in transition.

#### RECOMMENDATIONS

2.1 There is a need to introduce/embed ‘Stepped care models’ whereby Primary Care services are the first point of contact with access to “step up” to secondary care services for further assessment and intervention; and these can in turn be ‘stepped down’. Additionally, there is a need for simultaneous service delivery e.g. continued OT in the community with input from a mental health team at a particular point in time.

2.2 An Assessment protocol which links with the model of care and clinical pathways described above should be developed.

2.3 There is a need for effective and timely communication between HSE-funded and other services so that individuals with ASD can transition between services and interact with them fluidly.

2.4 There is a need to provide families with a named healthcare individual who can remain available to them for support, particularly in transition.

2.5 There is a need for metrics on ASD. This should be considered by the implementation group.

### Recommendation 3
### Tiered approach to assessment

Timely access to diagnostic assessment can be promoted yet diagnostic accuracy retained by shifting away from highly intensive ASD assessments towards a tiered approach to assessing ASD. Assessments can take place in primary care with the facility to access more specialist services dependent on presentation.

#### RECOMMENDATIONS

3.1 Introduce an assessment pathway where all referrals to Primary Care services with query ASD are triaged, resulting either in determining whether ASD is present or absent (as supported by consultation with secondary care colleagues) or onward referral to secondary care services.

3.2 Introduce a tiered approach to assessment in secondary care services whereby the required intensity of a diagnostic process is determined by the complexity of presenting symptoms and clinicians’ judgement of these symptoms.

3.3 For co-morbid presentations (e.g., query ASD with moderate-to-severe mental health issues) different secondary care services (e.g., Children’s Disability Teams, CAMHS) will undertake conjoint assessments.

3.4 Formulate evidence-based guidelines for how privately sourced ASD diagnostic assessments are conducted, and evaluate whether these are adhered to and whether such outsourcing provides value for money.

### Recommendation 4
### Performance management / governance structures

ASD services need to have a strong emphasis on performance management at all levels within the organisation. Areas of underperformance in services must be highlighted and addressed. As ASD services are often delivered by multidisciplinary teams, it is essential to have clarity on the roles and responsibilities of various team members and indeed various services within the stepped care model.

Governance structures need to include provision of clinical supervision and performance appraisal that includes a focus on individualised objectives and personal development plans that will help chart future professional and personal development consistent with organisational goals and strategy and service user needs. In addition, the HSE need to provide training to staff and managers on the value of complaints and on its complaints procedures, thereby ensuring that complaints are welcomed and are used to improve services.

#### RECOMMENDATIONS

4.1 Conduct monthly performance and accountability review meetings that are chaired by managers within the organisation at various levels. Standard agenda items will include caseload management, performance reports, quality and safety and workforce and efficiency reports.

4.2 Apply appropriate Human Resource practices to ensure that effective appraisal systems are in place for all grades of staff. These will include a focus on individualised objectives and personal development plans which will help chart future professional and personal development consistent with the organisational goals and strategy and patient needs.

4.3 Implement team building measures including clarifying the roles and responsibilities of individual members of specific service provision teams as well as the work of these teams and indeed the broader services in which they are embedded.

4.4 Ensure there is formal regular clinical supervision by appropriately experienced and competent supervisors.

4.5 Complete a training needs analysis of all staff who work with individuals with ASD.

## Recommendation 5
## Adult services

Services for adults with ASD are minimal to non-existent in many countries (Ministries of Health and Education, 2016; The National Autistic Society, 2009). Consultation respondents, including parents, professionals, and Community Healthcare Organisations, highlighted how Ireland was also devoid of such services, despite there being approximately 16,379–23,079 adults living with ASD in Ireland, with many of these remaining undiagnosed (NDA, in press). Hence, there is need to provide both a diagnostic service for adults with query ASD; and to provide basic supports (e.g., help to secure employment, link them with mainstream services) that may sustain independent living and obviate the need for referral to specialist services.

Regarding other interventions, services need to ensure that adults and their families are involved in making decisions about their care and determining what interventions may be effective (e.g., social skills training, social groups, befriending, vocational opportunities; e.g., SIGN, 2016).

### RECOMMENDATIONS

5.1 Provide timely diagnostic assessments to adults with query ASD.

5.2 Provide a menu of choices of interventions to adults with ASD (e.g., social skills training) that can be accessed when required to meet their needs.

5.3 An inter-departmental working group will establish what the needs of adults with ASD are, and will identify clear pathways regarding accessing services and how these services will work in a co-ordinated manner to offer interventions that will best meet the needs of adults with ASD.

## Recommendation 6
## ASD Specific Training

This review has found that healthcare and other professionals need to improve their competencies to work with individuals with ASD. Training is necessary to address this. Additionally, training for family members should also be available.

### RECOMMENDATIONS

6.1 Use multiple platforms (e.g. online, workshops) to provide training to staff working in Primary Care and similar settings to identify the behavioural indicators of ASD as early as possible. These may include General Practitioners, Public Health Nurses, Psychologists, Speech and Language Therapists, Occupational Therapists, Teachers and employers.

6.2 Provide training and ongoing supervision to Primary Care staff to undertake triage/ preliminary / screening assessments where there is a query of ASD.

6.3 Profile the diagnostic assessment training that secondary care staff (e.g. Children's Disability Teams, CAMHS) would require and provide them with this training and ongoing supervision to enable them to undertake, when required, more comprehensive diagnostic assessments.

6.4 Profile the range of episodic interventions that Primary Care and secondary care staff need to deliver to meet the needs of individuals with ASD; and provide them with the appropriate training/supervision to deliver these interventions.

6.5 There is a need for links with the colleges to ensure that the professional training programmes are facilitating adequate clinical competencies in graduates to work with individuals with ASD across the lifespan. This should involve communication around the model of care and clinical pathways recommended above.

6.6 There is a need for a profiling of local services (in each Community Healthcare Organisation) to ensure that they have both a sufficient skill-mix and a continuum of services (e.g. therapeutic, behavioural support, respite care) to respond to the multiple needs of individuals with ASD. This may have a local and national component.

6.7 Provide parents of children with ASD with training as per the model of care.

## Recommendation 7
## Communication, Information, and Awareness

Many parents noted significant frustration with the lack of communication from HSE-funded and other services about what supports/services they could access, what services they might need to access, and about their child's (current and anticipated) clinical progress (e.g., assessment findings). While often a result of poor inter-agency working, such communication deficits partially reflected a lack of knowledge among service providers as to what supports/services are available, and/or their not having adequate time to sufficiently communicate with parents. There was also frustration regarding a lack of information about vocational opportunities.

Consultation feedback also highlighted the need for information about clinical aspects of ASD and how to manage these (e.g., what a diagnosis of ASD means; ASD and behaviour that challenges; ASD and anxiety; how to promote language development; ASD and sensory processing; ASD and socialising); and what are evidence-based interventions for ASD (i.e. what works). The latter will also promote high quality and evidence-based interventions.

### RECOMMENDATIONS

7.1 Formulate a compendium of ASD-specific information leaflets for parents (and staff/employers) on various topics including what local supports/services are available; how to access these; clinical aspects of ASD and how to manage these; and what are evidence-based interventions for ASD. These will be made available as information packs and/or online (e.g., HSE website).

7.2 The HSE, Voluntary Service Providers and Advocacy Groups will jointly develop a calendar of workshops, training and information about ASD for individuals (with or without an ASD diagnosis), families, schools, professionals and employers.

7.3 Audit annually whether services are adequately communicating with parents (e.g., conduct satisfaction surveys).

## Recommendation 8
## Evidence-based interventions

It is critical that service users and their families are provided with evidence-based assessments and interventions or those that have been shown to be effective. While the evidence base for both assessment practices and interventions for children is relatively well-established (e.g., parent-mediated; communication; behavioural / psychological; e.g., NICE, 2011), that for adults is less so (e.g., Ministries of Health and Education, 2016; The National Autistic Society, 2009). As profiled by respondents, some parents have accessed both public and/or private interventions (at considerable expense) that have yielded minimal improvements, if any at all. Hence, it is important to establish that assessment practices are evidence-based, and accurately profile the needs of individuals with ASD; and likewise, that interventions are evidence-based, implemented in the manner that they were designed to be implemented, and prove to be effective.

### RECOMMENDATIONS

8.1 Audit how services are currently assessing ASD.

8.2 Further to introducing a tiered approach to assessing ASD, audit the outcomes of this approach across selected multiple sites.

8.3 Audit the intervention services currently being provided to individuals with ASD and their families.

## Recommendation 9
## Supporting service users / families

Given that the ability of parents of a child with ASD to cope is related to the resources and supports available to them, every effort needs to be made to support parents/families who have a child with ASD. Hence, in addition to the training noted in recommendation 5.7 above, and given the disproportionate stress on such families and associated mental health concerns (e.g., Hamlyn-Wright et al., 2007), services need to provide access to respite care (Doig et al., 2009), residential or otherwise; independent living facilities and employment facilities for adults with autism (Peeters, 2000); and individual and/or family counselling to help sustain families.

### RECOMMENDATIONS

9.1 Provide families with, where requested, individual and/or family counselling.

9.2 Provide families with supports such as home help; respite care; and independent living facilities and employment facilities for adults with autism.

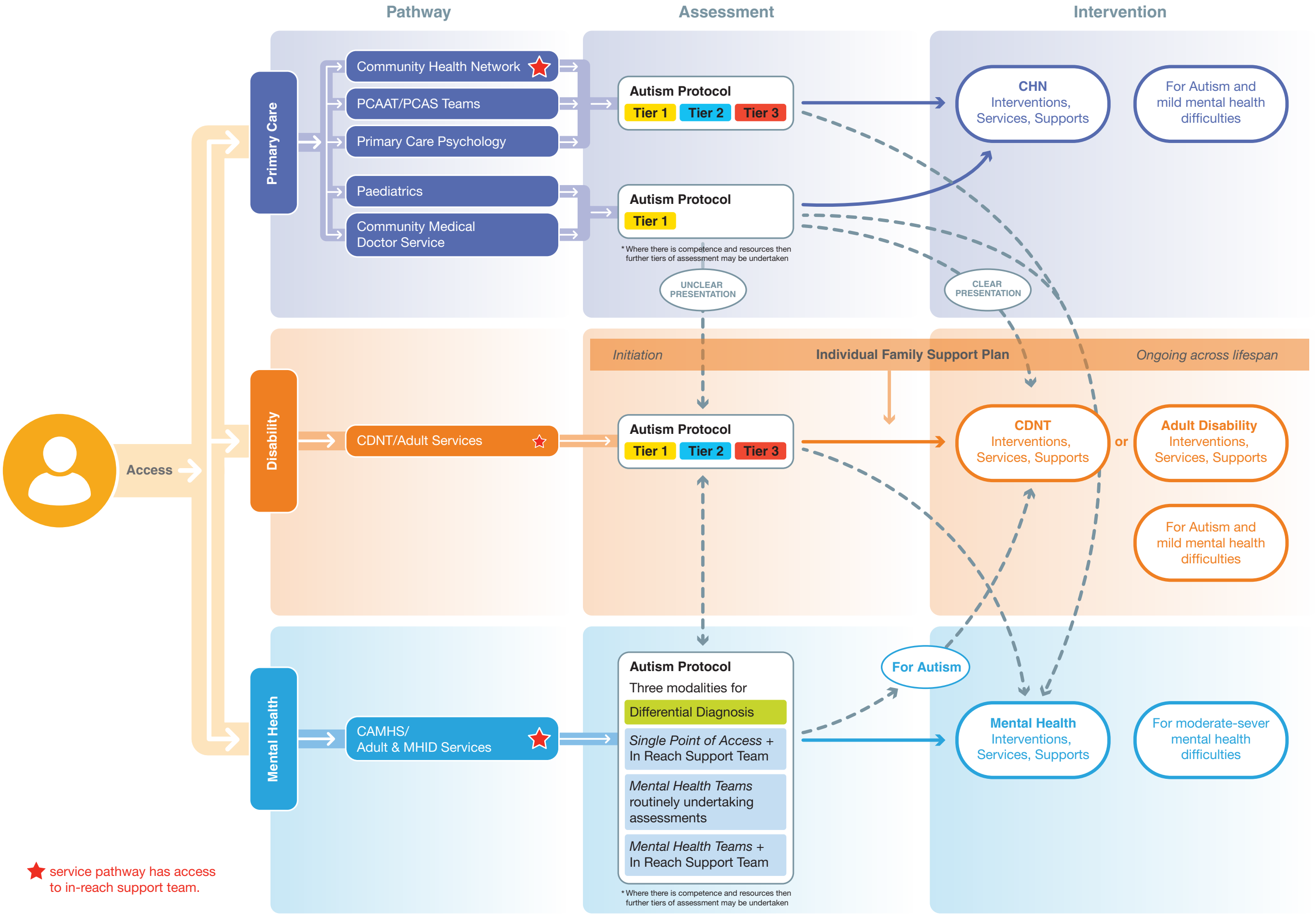
9.3 Provide peer support groups with access to local HSE-funded premises to facilitate meetings.

# Appendix 10:

# Assessment summary report for ongoing but incomplete assessments

| | | | |
|---|---|---|---|
| Name: | | Address: | |
| Date of birth: | | | |
| Date of Report: | | | |
| Notes: | | | |
| Clinician(s): | | | |
| Reports reviewed: | | | |
| Assessment Tools: | | | |
| Formulation and conclusion: | | | |
| Recommendations: | | | |

# Appendix 11:
# Service Users Pathway Diagram



** See appendix 18 for description of indicative profiles

# Appendix 12:
# Autism Pathway Information Document

| | | |
|---|---|---|
| HOW | **How do I get a referral for an Autism assessment?** | You can refer yourself or be referred by another person, such as your GP or Public Health Nurse, other health or social care practitioners, teachers, school head teachers, or community group facilitators. |
| Where | **Where do assessments take place?** | Assessments take place in your area and may be provided by<br>- Primary Care Services (Community Healthcare Networks)<br>- Children's Disability Network Teams (CDNTs), ***and where necessary,***<br>- Mental Health Services (where they can work alongside these other services to address mental health conditions). |
| WHAT | **What type of assessment is carried out?** | There are three types of assessment and the assessing clinician will decide how long the assessment needs to be carried out.<br>**Autism assessment** – used to identify the needs of people who clearly present with Autism.<br>**Autism extended assessment** – assessment to establish if a person is presenting with Autism and another different condition(s).<br>**Autism continuing assessment** – assessment may need to be extended where a person's presentation remains unclear and it is not yet apparent how to begin to address their needs. |
|  | **What happens once an assessment has been completed?** | A 'Link Worker' will be appointed so that a person has an immediate point of contact for support and to ensure that the relevant information and services are provided based on the person's needs. |
| | **How long will a person be able to access services for, once help is obtained?** | A person will have regular reviews with the Link Worker and this may include other health or social care workers who may be part of the team.<br>Services will continue to be provided based on individual needs. |

# Appendix 13:
# ‘Frank Autism Presentations’

The concept of ‘Frank Presentations’ refers to the idea that some presentations of autism are easier to identify than are others. However, this view has been contested by one of the professional bodies. The guidance note on features of such presentations has therefore been withdrawn. Practitioners interested in this issue are referred to the following literature if they wish to find out more about the topic.

Bishop, S. L., & Lord, C. (2023). Commentary: Best practices and processes for assessment of autism spectrum disorder–the intended role of standardized diagnostic instruments. *Journal of Child Psychology and Psychiatry, 64*(5), 834-838.

de Marchena, A. and Miller, J. (2017). ‘Frank’ presentations as a novel research construct and element of diagnostic decision-making in Autism spectrum disorder. *Autism Research*, 10(4), pp.653–662).

Gabrielsen, T. P., Farley, M., Speer, L., Villalobos, M., Baker, C. N., & Miller, J. (2015). Identifying autism in a brief observation. Pediatrics, 135(2), e330-e338.

Wieckowski, et al (2021). The first five minutes: Initial impressions during autism spectrum disorder diagnostic evaluations in young children. *Autism Research,* 14(9), 1923-1934.

Wieckowski, et al (2022). Addressing current barriers to Autism diagnoses through a tiered diagnostic approach involving paediatric primary care providers. *Autism Research,* 15(12), pp.2216–2222.)

# Appendix 14:
# About Masking/Camouflaging in Autism

## Service Improvement Programme for the Autistic Community
## Autism Assessment and Intervention Pathways Protocol

### What is it?

‘Although definitions of camouflaging are still evolving, here we define camouflaging (also variously referred to in the literature as compensation, masking and adaptive morphing) as the **employment of specific behavioural and cognitive strategies by Autistic people to adapt to or cope within the predominately non-Autistic social world’.**

(P. 1, emphasis added, Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in Autism: A systematic review. Clinical Psychology Review, 89, 102080)

Masking can also occur in neurotypical individuals but it may persist to a greater extent in adults who are Autistic compared to neurotypical peers.

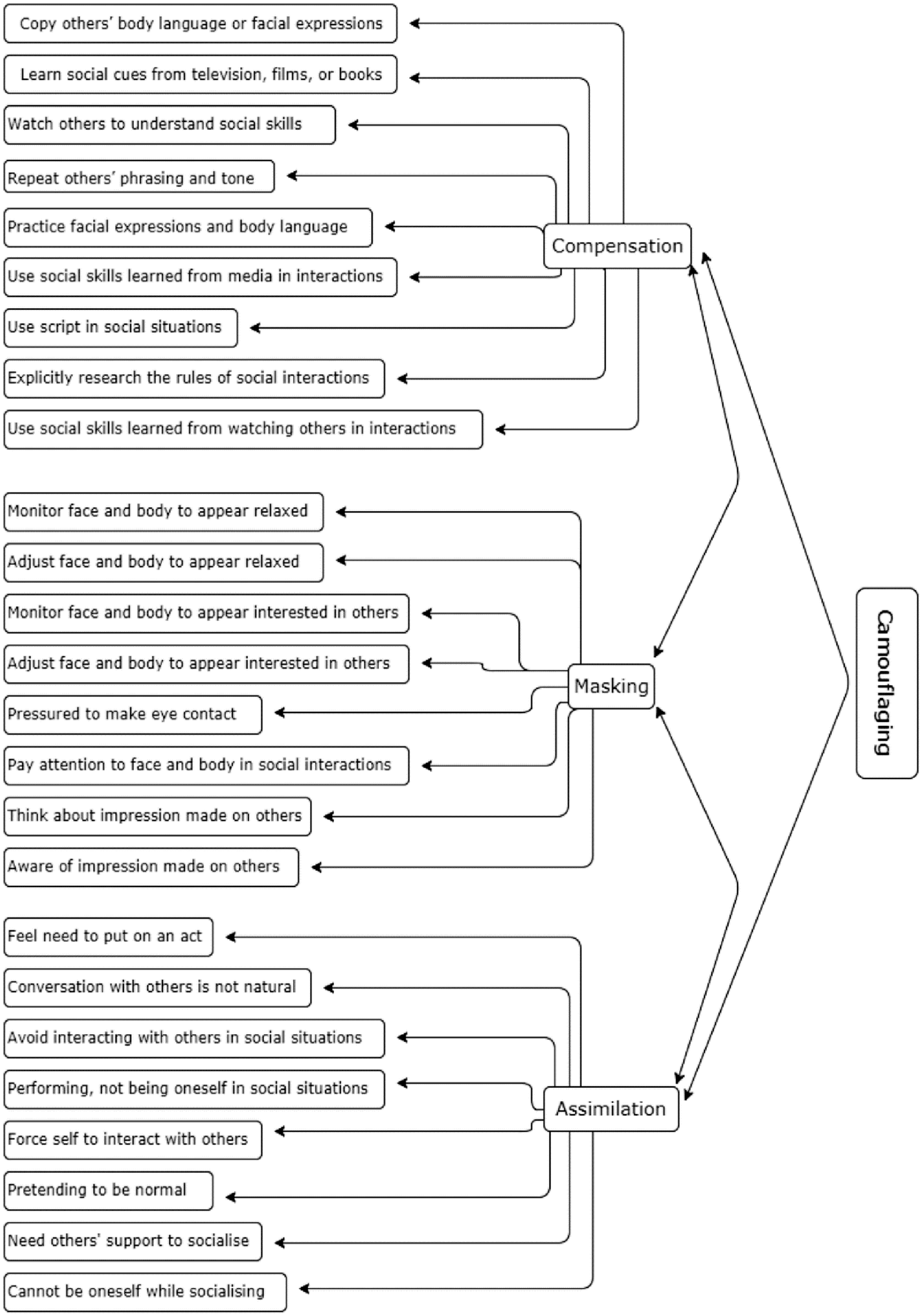
### What does the research indicate?

1. **adults with more self-reported Autistic traits also report more attempts to mask/camouflage** their Autism
2. across the lifespan **girls/ women mask/camouflage more than boys/men** – who also mask/camouflage
3. **more self-reported masking/camouflaging is associated with more mental health difficulties.** This may be related more to the felt need to camouflage rather than their ability to do so. (Cook et al, 2021)

### What are some examples of masking/camouflaging?

As the felt need to mask/camouflage may reflect **experiences of or expectations of marginalisation,** it is important to consider other factors that might interact with Autism to also marginalise; such as race/ethnicity, gender identity, sexual orientation and social economic status.

The Camouflaging Autistic Trait Questionnaire (CAT-Q) has been developed to help identify camouflaging in people with Autistic traits. It is a self-administered questionnaire and its psychometric properties and the appropriateness of some questions may vary across cultures or subgroups. The diagram below illustrates the different issues and related themes that may be relevant for exploring a person’s possible masking/camouflaging.



Issues and themes in the Camouflaging Autistic Traits Questionnaire (CAT-Q)

Hull, L., Mandy, W., Lai, MC. et al. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *J Autism Dev Disord* 49, 819–833 (2019). https://doi.org/10.1007/s10803-018-3792-6

Further research is needed on how factors such as age, context and culture impact on the presentation of masking behaviour and strategies. The usefulness of the CAT-Q items in younger people requires more investigation, as does the role of parental reports in exploring masking of younger children.

### Additional points to consider

Compared to males, females may mask to a greater degree in **formal contexts**.

Observation/information on presentation **across contexts** is important. Where there is report of different presentation across contexts (such as ‘perfect’ in school but difficult/meltdowns at home) it is especially important to explore the possibility of masking.

Masking is reported by Autistic people to be effortful and exhausting. The link between masking and mental health difficulties has implications for intervention/ support offered post-assessment and for **avoiding an over-emphasis on ‘fitting in’** as opposed to providing reasonable accommodations and support to the person as an Autistic individual.

# Appendix 15:
# Brief psychometric instruments that could be used as part of a Tier 1 assessment by Community Medical Doctors

### Service Improvement Programme for the Autistic Community

### Autism Assessment and Intervention Pathways Protocol

## What we were asked to do

Following a meeting with Community Medical Doctors involved in Pilot Phase 2 we agreed to ask clinicians with expertise in Autism assessment to advice on which brief psychometric measures could be used by Community Medical Doctors as part of their Tier 1 assessments.

It is important to stress that each of the experts expressed some reluctance to do this due to concerns that assessors may be overly reliant on numerical cut-offs, rather than simply **using scores to contribute to forming their clinical impression, which should also be based on discussions with parents/care givers and on observation, and review of case notes**. One of our advisers also notes that according to Bishop & Lord (2023, p.836) ‘There are many situations in which the use of any given tool might not be possible. As such, requiring the use of specific tools, without exception, is discriminatory and damaging’.

## Age 4+

Nonetheless, the **Social Communication Questionnaire (SCQ)** for use with children from age 4 upward was among the instruments recommended by all three advisers.

See https://www.carepatron.com/files/social-communication-questionnaire.pdf

This questionnaire can be completed by the parent/primary care giver of the child concerned, as part of the practitioner’s overall assessment.

According to one of our advisers ‘The SCQ is a screener often used in research and clinical settings. It was created by the authors of the ADI-R [Autism Diagnostic Interview – Revised] and designed as a questionnaire with both current and lifetime forms’. Early studies of the SCQ reported good sensitivity and specificity with school-age children.

### Under age 16 months to 4 years

Two of our three advisors also recommended the **Modified Checklist for Autism in Toddlers (M-CHAT)** for children from 16months up to 4 years. The most recent version of this instrument is a Revised, with Follow-Up version (referred to as M-CHAT-R/F), where a follow up interview allows more probing (Robins, Fein, & Barton , 2009 with 2018 revision below). See https://www.mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F_Rev_Aug2018.pdf

This questionnaire can be completed by the parent/primary care giver of the child concerned, as part of the practitioner's overall assessment.

The M-CHAT-R is intended to maximize sensitivity (not miss true presentations of Autism) but in so doing it also has a relatively high false positives rate – however many children who are 'false positive' for Autism, are subsequently found to have other developmental difficulties, delays or differences.

### Under 16 months

While there are also instruments to assess children younger than 16 months we recommend that such children are referred to a community team which includes a psychologist, if assessment seems warranted.

### Things to consider during observation

Two of our advisors also stressed the importance of considering the range of experiences that are incorporated in DSM/ICD diagnostic criteria for Autism spectrum disorder (whilst being sensitive to the fact that many people in the Autistic community refute the legitimacy of a 'disorder' label). Primary Care Services in CHO9 have kindly shared the below sheet which they use to guide clinicians in observation.

**Cúram Príomhúil & Sóisialta**
ECSP9, Áras Nexus, Páirc Chorparáideach
Bhaile Bhlainséir, D15 CF9K

**Primary & Social Care**
CHO9, Nexus Building, Blanchardstown
Corporate Park, D15 CF9K

**www.hse.ie**
**@hselive**
t
e

Location: Date/time: Client: Rater:

S = Similar to peers or expected level LD = a little different to peers or expected level D = different II = insufficient info

| Observation item | Rating | Observed behaviour | Comment |
|---|---|---|---|
| **Social approach/initiation** (only for help/limited or unusual – intrusive touching, licking/sniffing, use of others/hand as tool) | | | |
| **Pragmatics/back-and-forth conversation** (also note failure to respond to name, initiate conversation, one-sided conversations/ monologues/tangents) | | | |
| **Sharing of interests** (doesn't share, lack of showing/bringing/ pointing out, poor joint attention) | | | |
| **Sharing of emotions** (joy/excitement/achievement shared, social smile as a response, pleasure in praise/interaction, comforts others, indifference/aversion to physical contact/affection) | | | |
| **Social imitation** (engages in simple social games – depends on age) | | | |
| **Nonverbal communication** (eye contact, gestures, speech/ accent, body orientation to others) | | | |
| **Nonverbal affect** (flat/limited/exaggerated facial expressions, lack of warmth, affected not coordinated with eye contact etc, limited recognition of others' affect) | | | |
| **Relationship skills** (understands/adjusts to social/context cues & conventions e.g. picks up on distress/disinterest of others/not welcome in play or conversation/teasing, inappropriate questions/ statements, appropriate expression of emotion) | | | |
| **Imaginative social play** (>4yrs) | | | |
| **Friendship skills** (initiation of play, preferred friend(s), cooperative play, group play, same age friends, overly passive/ directing, unresponsive, naïve) | | | |
| **Interest in others** (prefers solitary, limited interactions, aloof/ withdrawn/in own world, does not try to attract others attention) | | | |
| **Repetitive or stereotyped speech, movements, or use of objects** | | | |
| **Strong need for routine, verbal/nonverbal rituals, struggles with change/transitions, or rigid thinking** | | | |
| **Restricted interests abnormal in intensity or focus** | | | |
| **Over/under-reactive to sensation or unusual sensory interests** | | | |

According to the Autism Assessment and Intervention Pathways Protocol, following referral for services and supports which seek to address difficulties/needs arising from or associated with Autistic behaviours, the team providing these interventions should continually reformulate their understanding of the person, based on the impact of the actions taken.

Such reformulation may support or question the categorisation/diagnosis of Autism. A Tier 1 assessment does not therefore represent a definitive end of an assessment process, but rather the beginning of engagement with services which prioritise intervention, allowing such interventions to further inform the understanding of the person's difficulties and/or needs.

# Appendix 16:
# Sources suggested by Lived Experience Members who have contributed to the development of the protocol

I am Special: A workbook to help children, teens and adults with Autism Spectrum Disorders to understand their diagnosis, gain confidence and thrive
https://amzn.eu/d/9XHI2UE

https://www.cdc.gov/cbddd/Autism/index.html

A discussion of the challenges and value around a diagnosis of Autism can be seen here: https://youtu.be/HIrxgD3oqYc

Assisted decision-making information can be accessed through the decisions support website:

https://www.decisionsupportservice.ie/

**This list is non exhaustive, and a number of other resources are available on HSE and Civil Society Websites**

# Appendix 17:
# Autism Protocol Competency Statement

All practitioners involved in conducting assessments using the Autism Protocol (whether in public, independent or private settings) must comply with the requirements of the protocol for their assessment to be recognised at fulfilling the requirements for Autism assessment regarding access to social welfare, education or health benefits or services.

All practitioners should be registered with CORU, NMBI, IMC or PSI.

In addition (during transitional arrangements for psychologists' registration with CURO) all psychologists involved in Autism assessments must have completed a recognised practitioner training (to Masters or Doctorate level) in clinical, counselling or educational psychology, and be recognised by the Psychological Society of Ireland as fulfilling the requirements to practise in those roles; or must be under the supervision of such a person.

All practitioners should also be familiar with assessments for reaching expected developmental milestones. See here – https://www2.hse.ie/babies-children/checks-milestones/developmental-milestones/

In addition to these general requirements practitioners should fulfil the following requirements for competence for undertaking assessments at each of the Tiers of assessment.

## Tier 1 Competence

This tier may be undertaken by individual practitioners or those working in teams with other disciplines.

This assessment requires at least one practitioner to have prior experience of undertaking Autism assessments within the context of a multi or interdisciplinary team, so that they are familiar not only with different types of Autistic presentation but also under what circumstances it is necessary to have different disciplines involved in the assessment.

At least one practitioner should also be experienced in making differential assessments and diagnosis related to Autism and possible co-occurring conditions; and to have gained such experience from having undertaken at least twenty assessments.

Conventionally differential diagnosis requires a professional training in psychology (clinical, counselling or educational), paediatrics, psychiatry, or in some cases, is also held by community medical doctors. Where other professions have undertaken specific certified further training to acquire this competence, this may also be considered.

## Tier 2 Competence

As this level requires the use of formal psychometric instruments, such training should have been undertaken within professional training, or completed as a specific certified training to acquire competence in the use of specific assessment instruments used in Autism assessment (such as ADOS or ADIR).

Tier 1 requirements also apply.

## Tier 3 Competence

As this tier may require more intensive and broader assessment with a range of standardised psychometric instruments (including possibly tests of neuropsychological and cognitive functioning) a significant level of experience and advanced training in assessment is required.

It may also be necessary to integrate a broad range of information across disciplines outside the usual assessment team.

## Team constitution and competencies[1]

Both the shared clinical skills and unique professional contributions of team members are acknowledged and respected.

By virtue of their clinical training and experience, shared competencies must include:

Knowledge of Autism, Autism assessment and neurodiversity

- Conducting comprehensive clinical interviews with families, professionals and young people
- Conducting clinically-informed observations and interactions with children and young people
- Using clinical information to inform and contribute to formulation
- Providing person-centred feedback to families and young people on the outcome of assessments
- Providing information and guidance to families regarding Autism, neurodiversity and supportive approaches
- Providing training as appropriate

It is acknowledged that team members may vary in the development of the above competencies, and so could be considered to demonstrate these skills on a scale ranging from introductory to advanced levels. Where a team member would like support to enhance their competency in any of the above levels, a professional development plan may be developed with the relevant discipline manager, supported as appropriate by team colleagues – such as CPD, enhanced supervision, shadowing, co-working etc., to promote further competency development.

In addition to the above, there are clinical skills that are unique to different disciplines, and therefore requests for completion of specific assessments will be directed to the discipline with the appropriate training.

e.g. Psychology – cognitive or other psychological assessments; mental health screening or differential assessment; assessment of impact of trauma

Occupational Therapy – specific OT standardised assessments

SLT – specific SLT standardised assessments

1. Adopted from Three Rivers PCAAT

## Autism Protocol Competency Declaration

Each practitioners is required to make a brief statement asserting:

1) Their claimed competence level(s) in terms of tiers of assessment

2) How they comply with the competency requirements,

3) Indicate how the above can be verified (professional body, professional qualification, specific training certificates, etc.)

4) Indicate supervision relationships supporting their practice.

# Appendix 18:
# Indicative profiles for different assessment pathways

**See Appendix 11 for Service User Pathways Diagram*

## Indicative profiles for different assessment pathways

The NHS Confederation (2023) published its report *No wrong door: a vision for mental health, learning disabilities and Autism services.* The report, calling for 'Access to quality, compassionate care' asserts that 'there will be no wrong door for anyone seeking support for mental health, Autism and learning disability needs. People will be able to present at any point in the system – from pharmacies, advisory services and community groups to education, social services, the criminal justice system and primary care – and get the right support'. (p.5). A key driver of this is that a person is 'immediately "in" the system and able to access the care they need, no matter where their first point of contact is'.

The protocol seeks to achieve a similar ethos within the context of the Irish health and social service system, accessing assessment across primary care, disability and mental health services. Autism interventions will usually be accessed in either primary care or disability services, and Autistic people experiencing moderate-severe mental health difficulties (see later) should access interventions from mental health services.

To illustrate the sort of presentations that may be encountered through different pathways, a range of hypothetical scenarios are described below. In reality a range of presentations may be encountered through any single pathway for assessment.

## A possible presentation to a Community Health Network

A possibly Autistic child who has been referred by a GP presents with sensory sensitivities (for example aversive to strong lights, loud noises, etc.) and demonstrating some inflexibility and frustration with how they prefer things to be arranged. However they appear socially skilled when required to be, but seek to exit such social situations as soon as possible. These problems are also associated with difficulties concentrating and sometimes impulsivity. While focusing on the child's difficulties and the services which may help them address such difficulties, the assessor(s) seeking to classify the child's problems may, for instance, be considering social anxiety, Autism, ADHD or a combination of these – the lower level of these difficulties may make them much more difficult to identify conclusively.

### A possible presentation to Primary Care Psychology

A child (or their parent) may be self-referred or referred from a GP or school as possibly Autistic but also with a mild-moderate mental health condition, such as irritability, low-mood, withdrawn, low self-esteem, low motivation and loss of interest in activities and in associating with others, as well as sensory sensitivities and restricted or repetitive behaviours.

### A possible presentation to a Primary Care Autism Assessment Team/Primary Care Autism Service (PCAAT/PCAS)

This could incorporate either of the above, several of the below, or presentations of Autism which are anticipated to be less challenging to manage. However, the often high level of expertise in these teams is justified on the basis that more subtle and less clear presentations of Autism are more difficult to identify and may therefore require more intensive assessment to ensure that the person is receiving the appropriate services. These services have been established to address the sheer volume of self or other referrals and to allow for community teams to focus on providing interventions (services and supports) required to help people cope with these difficulties.

### A possible presentation to a paediatrician

A child may be referred by a GP, Community Healthcare Network (CHN) or school, with gastrointestinal problems, apparent epilepsy, developmental delay, or eating problems (such as ARFID – avoidant and restrictive food intact disorder). The sometimes co-occurrence of these conditions with Autism will mandate an exploration of Autistic experiences and behaviours. The child will usually be referred to PC or disability services for Autism-related interventions, but may continue to see the paediatrician for other problems, often working in conjunction with community teams.

### A possible presentation to a CMD (community medical doctor)

As part of a vaccination programme or though attendance at a Child Health Clinic a child who is failing to reach expected milestones may be identified or brought to the attention of a CMD. As many CMDs are experienced in identifying Autism, then such as assessment with onward referral to a CHN, CDNT or paediatrician would be expeditious, rather than referral for a further assessment before interventions could be provided.

### A possible presentation to a CDNT

According to the National Access Policy CDNTs work with complex cases, and this often means multiple co-occurring disabilities and difficulties. For instance, a child with sensory sensitivities and restrictive and repetitive behaviours, may also demonstrate difficulties with a range of executive functions associated with intellectual disability, and/or other co-occurring physical disabilities related to sleep, eating or mobility problems. They may also experience mild to moderate mental health problems. Following assessment, children will be referred for interventions based on their needs, although individual-level interventions are often associated with lengthy waiting lists.

### A possible presentation to adult disability services

International studies have estimated that the majority of Autistic adults have not been assessed or identified as being Autistic. It is also believed that while girls may effectively mask their difficulties when younger, women may have greater difficulty doing this as they experience more demanding and less controlled environments when they are older. Presentations amongst adults may be more subtle as they have developed coping strategies over time, but the evidence indicates very high associated levels of distress (see below). It will be important for services to develop a competency at Autism assessment Tier 1 for adults. However, there are currently very few assessment or intervention services for adults and these are often private.

### Emergency departments

The most common reasons why Autistic people attend emergency departments are for respiratory and gastrointestinal problems. Mental health presentations for Autistic people are less common but may be difficult for staff to manage (Bilginer et al, 2021). Given that Autism assessment involves case history-taking, file review, interviews with the person and family members, and observation in non-stressful environments; emergency departments (Eds) are not recommended for Autism assessment, but rather referral into one of the pathways mentioned above.

Many of the difficulties that Autistic people experience attending EDs are related to environmental overstimulation (such as lighting, noise and space) and/or staff unawareness of Autistic difficulties. A new module on Autism Awareness Training has been developed by the Service Improvement Programme for the Autistic Community and this is now available on HSeLanD. This training provides staff guidance on communicating with Autistic people, making reasonable accommodations and understanding Autistic experience, including distress (‘meltdowns’ etc). We hope this will help staff in EDs and elsewhere in our services to respond to the needs of Autistic people more effectively.

# Appendix 19:
# Annual Review Process of the Autism Assessment and Intervention Pathways Protocol – Factors to be considered for inclusion

The Autism Assessment and Pathways Protocol should be assessed on an annual basis for the first three years of operation and then every second year after that.

The review should be a structured process. Matters within scope of the annual review could include – over the previous twelve months – data collection that would facilitate evidence on the following:

Protocol process data – (Tracker to be provided)

*Assessment outcomes from the past year:*

Assessment pathways used

Tier of assessment

Number of assessments

Number of formulations

Number and categories of diagnoses (ICD 11)

Age at referral

Age at diagnosis and/or formulation

Age at first type of intervention services/supports other than assessment.

Rates of false positives/negatives for any existing diagnosis

Demographics (race, gender, socioeconomic status, disability).

Assessment tools used

Speaking/non-speaking

Waiting time for first assessment

Length of time assessment took

Waiting time for first intervention (services or supports)

Number and type of interventions (services and supports).

Number and range of disciplines involved in assessment, according to tier

Provision of information or data across sectors (such as health, education, justice, Tusla)

## Stakeholders

Identify stakeholders (any new?) service users, civil society, advocacy groups, service provider organisations (HSE, 38s, 39s, private), professional bodies, clinical leads, policymakers, educators.

Invite stakeholders to the annual Conference on Autism Assessment and Pathways Protocol (CAAPP).

Clinician input: usability, clarity, workload, use of psychometric instruments (sensitivity, specificity, reliability and validity in relation to construct or specified criterion) and the legitimacy of difficulties with a tiered approach to assessment.

Family and client feedback: clarity, comfort, perceived fairness, utility, access to services.

Therapist feedback: downstream impacts on care planning and cross-sectoral working.

## Literature update

Review latest research and clinical guidelines (such as ICD updates, NICE guidelines).

Identify new evidence that may impact the protocol (such as recognition of masking behaviours, alexithymia, late-identified Autism, neurodiversity-informed practices).

Training and competency review

Did those administering the protocol received adequate training?

Did those administering the protocol maintain competencies?

Do those administering the protocol need refreshers or additional education (for example on cultural sensitivity, trauma-informed care)?

## Equity and accessibility

Is the protocol equally effective across different ethnic groups, genders, language groups, and socio-economic statuses?

Is the protocol accessible to non-verbal individuals or those with co-occurring disabilities?

What cultural variations in communication and behaviour have been observed? .

How has use of the protocol been adapted to specific needs on an individual basis?

## Operational review

Are the teams using the protocol adequately resourced in terms of number of staff required to undertake assessments and to provide subsequent interventions, if required?

Is the composition of disciplines appropriate within the teams to undertake assessments and to provide subsequent interventions, if required

Number of assessments done in-person

Number of assessments done virtually

Number of blended assessments

Efficiency: time and cost per assessment.

Workflow integration: ease of integration into existing system.

Barriers: tools, technologies, premises

## Compliance, competence and ethical considerations

Adherence to privacy laws ( such as GDPR).

Informed consent procedures.

Use of results (such as how data is shared or used in service settings)

Completion of competency self-assessment

Access to clinical supervision

Provision of appropriate clinical governance structures

Provision of sufficient clinical staff to implement effective clinical governance

## Open response format allowing unprompted comments on protocol experience

## Recommendations for improvement

Propose refinements or adaptations.

Set goals for next year’s review (e.g., increase access for underserved groups).

## Documentation and reporting

Summarise findings in a formal review report.

Include metrics, key feedback points, action items, and responsible parties.

Distribute to stakeholders.

# Appendix 20:

## Form for Sharing with HSE or HSE-funded services Psychologist Assessments of Possibly Autistic Children undertaken in Other Service Sectors

*This form may be used by psychologists who wish the results of any assessments undertaken by them in another sector to be considered by other practitioners working with the same child*

| |
|---|
| 1. Has consent by child's parents to share this information been received? |
| 2. Reason for Assessment of Child |
| 3. Instruments and/or Methods used for assessment (with results, as relevant) |
| 4. Formulation, identified strengths, differences, difficulties, development supports and services needed. |
| 5. Are required services or supports currently being provided or have they been requested? (If so, when and from whom?) |
| 6. While we appreciate that some assessors do not adopt a diagnostic approach to assessment, the findings from the above assessment **may/may not** (select) be consistent with a diagnostic approach attributing such experiences to autism. |
| 7. If you believe that the child may be described within a diagnostic approach as autistic - how confident are you that a clinician (s) in a service that uses diagnosis would determine this child to be autistic (not withstanding any other co-occurring conditions or difficulties)?<br>On a scale of 1-5:<br>1 being *not very confident,* 3 being *confident,* and 5 being *extremely confident.*<br>1 2 3 4 5 (please circle s appropriate) |
| Any other comments that may be helpful?<br>Name and contact details of Psychologist and service undertaking assessment: |

# Appendix 21:

# Possible Assessment Instruments in Tier 2 Assessments

| Potential Element | Suggested Modality |
|---|---|
| **Review of the three referral forms** | Email / Desktop |
| **Review of any available previous reports** | Desktop |
| **Interview with parent(s) / caregiver / individual**<br>• Considering current presentation, context and the individual's personal development and history. | Video call / face to face |
| **Screening measures** – such as<br>• 40-item *Social Communication Questionnaire* (SCQ; Rutter et al., 2003);<br>• 20-item Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F; Robins et al., 2014; for ages 16-30-months;<br>• 25-item Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001); | Email / Desktop |
| **Behavioural observation** – such as<br>• 15-item *Childhood Autism Rating Scale* – Second Edition Questionnaire for Parents or Caregivers (CARS-2 QPC; Schopler et al., 2010) | Email |
| • 15-item CARS2-ST (or Standard version; Schopler et al., 2010; for ages 2-6-yrs; 5-10 minutes to administer);<br>• Naturalistic Observation Diagnostic Assessment (NODA; Author, Yr) for parent-collected in-home video evidence;<br>• TELE-ASD-PEDS; SORF (Corona et al., 2020a) in lieu of ADOS-2 for ages up to 36-months; Unstructured video clips of child behaviour/interaction (e.g., ADOS-2 modules for qualitative data;<br>• 12-item Screening Tool for Autism in Toddlers [STAT]; Stone & Ousley, 1997) for ages 24-35-months | Video call / face to face |
| • **Face to face feedback** to person/family may be provided by one (or sometimes more) clinician(s). | Video call / face to face |

# Appendix 22:

## Possible Instruments that can contribute to the assessment of autism in adults

**All of these tools are to assist clinical judgement, none are valid as stand-alone diagnostic instruments, and some of the information elicited may contribute to development of a clinical formulation.**

**As with all assessment instruments clinicians should always ascertain the relevance and generalisability of any norms associated with the tool to the person being assessed.**

**Autism Clinical Interview Adults Training (ACIA) | Neurodevelopment and Disability | Newcastle University**

This is a short professional course designed to teach clinicians and researchers how to use the *Autism Clinical Interview for Adults (ACIA)* — a structured diagnostic interview for assessing autism in people aged 16 years and older.  A two-hour on-line live course provides instruction on the use, structure, and administration of the ACIA, for clinicians mandated to undertake such assessments.

**ndpsig-autism-diagnostic-interview-guide-2.pdf**

Royal College of Psychiatrists Autism Diagnostic Interview Guide is a structured clinical interview to help clinicians gather diagnostic information and make clinical judgments about "autism spectrum disorder" (ASD). It is intended for adults with average or above-average cognitive ability (i.e. without intellectual disability).  The Guide is not a scoring algorithm, it suggests probes and topic areas to elicit relevant history and behavioural information.

**RAADS-R Test - Ritvo Autism Asperger Diagnostic Scale Revised**

The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS 80) is an 80-item self-report questionnaire  to assist clinicians in identifying autistic traits in adults. It is not a definitive diagnostic instrument and is aimed at younger adults with average or above average intelligence.

**The Camouflaging Autistic Traits Questionnaire (CAT-Q) | Embrace Autism**

- see appendix 14 for a description of the use and limitations of this questionnaire.

**The Ritvo Autism & Asperger Diagnostic Scale (RAADS-14)**

is a shorter version of the RAADS 80 and intended more for screening in primary care or mental health settings.

**The Autism Spectrum Quotient – 10 items (AQ-10) (Adult) - Autism Research Centre**

is a 10 items screening questionnaire designed to indicate if an adult should be considered for a more in-depth assessment. It is the short version of the AQ50.