“We were happy to just get an autism diagnosis”: a mixed-methods study of parents’ experience with the autism assessment protocol

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Abstract

Purpose – *Despite increasing autism prevalence, delays in diagnostic assessments persist, likely impeding access to effective early interventions. In 2022, Ireland’s Health Service Executive piloted new, three-tiered Autism Assessment and Pathways Protocol in the Republic of Ireland.*

Design/methodology/approach – *An online survey was completed by six parents of autistic children assessed through the novel, Tier 1 Assessment Pathway Protocol, and 25 parents of autistic children assessed through the standard Assessment of Need Pathway participated in this study. All respondents provided quantitative and qualitative data on their experience of the diagnostic assessment pathway, including satisfaction, self-reported stress and perceived child stress. Parental satisfaction and stress were compared between pathways.*

Findings – *Some 65% of parents were satisfied with the diagnostic process overall. The process was stressful for both parents and children. There were no significant differences in parents’ satisfaction, stress levels or participant characteristics between the diagnostic assessment pathways. Time to assessment displayed negative correlations with parents’ satisfaction with the overall diagnostic process and self-reported stress. Four themes were identified: falling through the cracks, accessing effective supports, the emotional and psychological impact of the assessment experience and being seen, heard and understood.*

Research limitations/implications – *Parents’ experiences did not differ between the pathways, suggesting the viability of the Assessment Protocol Tier 1 pathway. Reducing waiting times and increasing post-diagnostic support to facilitate early intervention should be emphasised.*

Originality/value – *To the best of the authors’ knowledge, this mixed-methods study was the first to explore parents’ experience and satisfaction with Tier 1 of this protocol.*

Keywords *Autism, Early intervention, Autism assessment*

Paper type *Research paper*

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Introduction

In Northern Ireland, 1 in 20 school-aged children are autistic, a three-fold increase in the past decade (Pham, 2025; Maenner, 2023). Services have been unable to meet the demands of the increasing prevalence of autism, creating delays that heighten parental stress and dissatisfaction during the diagnostic process (Argumedes *et al.*, 2018; Hanley, 2025; Murray and Berwick, 2003). Positive diagnostic experiences, however, support parental coping and acceptance (Small and Belluigi, 2024), making parents’ perspectives vital for evaluating service feasibility (Templeman, 2019).

The autism diagnostic process encompasses initial concerns, assessment and post-diagnostic supports (Health Service Executive, 2022). While no universal method exists, assessments should follow recognised systems such as the DSM-5 (American Psychiatric

Association, 2013; Hyman, *et al.*, 2020; Psychological Society of Ireland [PSI], 2022). Waiting times vary internationally, with a median of nine months in the UK and four to six months in the USA (Kraft *et al.*, 2022; Morris, 2024). However, on average, children in Ireland receive a diagnosis 3.7 years later than their global peers (Houses of the Oireachtas, 2023).

Delayed diagnosis impedes access to early intervention, defined as before age three years, though research indicates autism can be identified from 18 months (Dawson *et al.*, 2010; Guthrie *et al.*, 2013). The Early Intervention Model (EIM) involves the identification and provision of effective early support, asserting early diagnosis and targeted intervention indicate the greatest capacity to influence behavioural and neurodevelopmental processes, as neurodevelopmental plasticity is most pronounced in early childhood (Dawson and Zanolli, 2003). World Health Organisation (WHO) guidelines posit specific empirically supported interventions implemented throughout early childhood can improve outcomes and nurture resilience, recommending regular monitoring of child development within standard maternal and child health care (Langford *et al.*, 2007; Lord *et al.*, 2022). Parent-mediated early interventions have been linked to more efficacious outcomes for children than direct interventions (Dawson-Squibb *et al.*, 2019; Rogers *et al.*, 2012).

Family-centred care (FCC) is an approach to early intervention and is internationally recognised as best practice in autism assessment and intervention. The FCC asserts children's development and well-being are situated within family participation and relationships, stressing parents be empowered to deliver evidenced supports tailored to family needs (Dunst and Espe-Sherwindt, 2016; Health Service Executive, 2023; McCarthy and Guerin, 2022; McConachie *et al.*, 2015).

Naturalistic Developmental Behavioural Interventions (NDBIs) illustrate the significant efficacy of early intervention that is primarily parent-mediated. NDBIs combine developmental and behavioural techniques in natural settings to nurture and accelerate social communication skills (Schreibman *et al.*, 2015). Parent-mediated NDBIs, including the Early Start Denver Model (ESDM) and Joint Attention, Symbolic Play, Engagement, Regulation (JASPER), have shown improvements in social communication, language and parent–child interactions compared with controls (Schreibman *et al.*, 2015; Song *et al.*, 2025). Early diagnosis and effective intervention are associated with higher parental satisfaction with the diagnostic process (Crane *et al.*, 2016; Hennel *et al.*, 2016; HSE, 2013).

Parents' satisfaction with the autism diagnostic process varies internationally, with broad dissatisfaction reported in Canada, the USA and the UK and satisfaction in Australia, New Zealand, Denmark and Ireland (Legg and Tickle, 2019; Makino *et al.*, 2021). Satisfaction reflects whether parents' needs are met (Cottrell and Summers, 1990) and is influenced by diagnostic practices such as waiting times, number of referrals and clinicians seen, clarity of information, professionals' interpersonal manner and provision of post-diagnostic support (Brogan and Knussen, 2003; Crane *et al.*, 2016; Martyn and Brereton, 2024; Siklos and Kerns, 2007). Inadequate post-diagnostic support remains common (Legg and Tickle, 2019; Rasmussen *et al.*, 2020), with 80 Irish parents (37.9%) reporting none in O'Brien and colleagues' study (2024).

Ireland's autism assessment system has been criticised as "broken", requiring a "major culture shift" (O'Flanagan *et al.*, 2021, p.2), despite policy emphasis on early intervention and assessment service development (Department of Children, Equality, Disability, Integration and Youth, 2024). In Ireland, autism assessments conducted in the public health system are implemented by the HSE within the following services: Primary Care comprising community health and social services; Children's Disability Network Teams (CDNT) comprising an interdisciplinary team supporting children with complex needs and Assessment of Need (AON), a specialist team which assesses for the presence of a disability (HSE, 2022). The Disability Act affirms the right of individuals with disabilities to an

AON within three months of referral/application. Waiting times are routinely exceeded because of resource constraints, costing the HSE tens of thousands of euros in legal fees (Coyne, 2025) and contributing to stakeholder dissatisfaction with AON (Houses of the Oireachtas, 2023).

The HSE's 2022 Autism Assessment and Pathways Protocol (Assessment Protocol) piloted a three-tiered model, although the Psychological Society of Ireland (PSI), the professional organisation for Irish psychologists, raised concerns regarding alignment with international standards and reliance on screening tools (2024). The only evaluation of the Assessment Protocol to date reported high parental satisfaction, linked to confidence in outcomes, shorter wait times and link-worker support, but satisfaction was pooled across tiers, limiting conclusions on Tier 1 (Martyn and Brereton, 2024; O'Brien *et al.*, 2024).

Given recommendations to improve the diagnostic process, exploring parents' experiences is essential to inform services (Whelan *et al.*, 2025). This mixed-methods study examined parental satisfaction with the Tier 1 component of the Assessment Protocol through an online questionnaire with parents of autistic children from one Dublin-based CDNT who accessed Tier 1 or AON pathways (Crane *et al.*, 2016).

Methodology

Participants

In all, 31 participants identifying as parents of autistic children provided quantitative data and 18 provided qualitative data. Most parents (97%) were female, with 74.3% identifying as Irish/White Irish/Caucasian, all residing in one Irish postal code area. In all, 30 children (96.8%) had a positive autism diagnosis; their mean age was 7.16 years (SD = 2.22; range 4–13), with a gender ratio of 81% male (n = 25) to 19% female (n = 6). Six children (19%) accessed the Assessment Protocol Tier 1 pathway and 25 (81%) the AON pathway. On average, children waited 805 days (SD = 529.5) between first seeing a professional and accessing an autism assessment and were 3.27 years old (SD = 2.03 years) at assessment. Of the AON group, 68% were assessed directly, 20% via private companies validated by an Assessment Officer (AO) and 12% via AO-commissioned companies. Table 1 presents the child characteristics for the Assessment Protocol Tier 1 (upper panel) and AON (lower panel) pathways.

Procedure

Quantitative and qualitative data were collected concurrently via a 20-min anonymous parent-report survey on Qualtrics. All eligible participants (n = 56) were contacted by phone, and, if interested, received an information and consent leaflet and the survey link by email with weekly reminders. Individuals were eligible for participation if they, had a child who accessed an autism assessment through the Assessment Protocol Tier 1 (unstandardised local assessment) or AON pathway (standardised specialist assessment), the parent was over 18 years-old and the child was under 18 years-old. Parents were excluded if they had already participated in a previous research programme that evaluated the Assessment Protocol. Data were collected over 11.5 weeks (February to May, 2025). Upon completion, the debriefing sheet alongside support details were provided. Ten parents declined participation because of literacy or family circumstances. In all, 31 parents (Assessment Protocol Tier 1 pathway; n = 6, AON pathway; n = 25) consented to participate.

Materials

Survey. An adapted version of Crane and colleagues' (2016) "Questionnaire Used to Survey Parents about their Experiences of Receiving a Diagnosis of Autism Spectrum Disorder for Their Children" (Howlin and Moore, 1997; Siklos and Kerns, 2007) was used, which has

Table 1 Child demographics and characteristics for assessment protocol Tier 1 ($n = 6$) and AON pathways ($n = 25$)

Participant characteristics		n *(%)*	*M (SD)*
Assessment protocol Tier 1 (n = *6)*			
Autism diagnosis	Yes	6 (100)	
	No		
Gender	Male	3 (50)	
	Female	3 (50)	
Age (years)			7 (3.23)
Age at diagnosis (years)			5 (3.63)
Age when first professional attended (years)			2.17 (1.33)
Time to assessment (days)			791.67 (591.64)
AON (n = *25)*			
Autism diagnosis	Yes	24 (96)	
	No	1 (4)	
Gender	Male	22 (88)	
	Female	3 (12)	
Age (years)			7.2 (2)
Age at diagnosis (years)			5.92 (2.28)
Age when first professional attended (years)			3.54 (2.11)
Time to assessment (days)			807.92 (526.65)

Note(s): IQR = Interquartile range; SD = standard deviation; M = Mean; MD = median; Time to Assessment = time from first professional seen to accessing an autism assessment
Source(s): Authors' own work

shown good reliability ($\alpha = 0.74$; O'Brien *et al.*, 2024). The 57-item survey comprised seven sections using Likert scales, dichotomous, multiple-choice and open-ended items. Section 1, About You, obtained parents' demographics and characteristics. Section 2, About Your Child, collected information on children's demographics and characteristics. Section 3, The Diagnostic Process, comprised closed questions concerning age when first seeing a professional, who this was and what recommendation or diagnosis was provided. Section 4–6 First/Second/Third Referral mirrored Section 3, exploring the referrals before an autism assessment was accessed.

Participants only answered Sections 4–6 if applicable. Section 7, Provision of Diagnosis and Your Experience, comprised open and closed questions, covering assessment measures used, diagnostic feedback session, provision of information and supports, perception of manner of professionals, self-reported parent stress and parent-reported child stress.

Study variables. Outcome variables. All items concerning parental satisfaction were measured on five-point Likert scales ranging from "very dissatisfied" (0) to "very satisfied" (4). All items concerning stress levels were measured using a five-point Likert scale ranging from "not at all stressful" (0) to "very stressful" (4) (Crane *et al.*, 2016).

Parental satisfaction with the process overall. Parental satisfaction with the diagnostic process, from first clinician visit to provision of post-diagnostic support, was measured by self-rating scores on one item "Overall, how satisfied were you with the diagnostic process as a whole".

Number of referrals made. The number of subsequent referrals after the initial visit to a professional before diagnosis was attained. This number was created based on how many referrals (questionnaire sections four to six) parents reported.

Co-occurring diagnoses identified. The number of diagnoses held simultaneously with autism. The items "If a diagnosis was provided for your child, please specify what this was" in Sections 3–5 and "What happened at this referral" in Section 6 were compiled to measure the number of co-occurring diagnoses.

Time to assessment.

The length of time between first contact with a professional and accessing an autism assessment was measured in days on a sliding scale with a minimum value of 0 and a maximum of 1,825 (5 years).

Child's age at diagnosis. The age of the child upon receiving an autism diagnosis was measured in years.

Number of tools used. Parents responded to a multiple-choice item that presented a comprehensive list of possible assessment tools used in their child's evaluation. The number of instruments was measured numerically by summing the number of tools selected.

Parental satisfaction with the professionals conducting the assessment. The level of parental satisfaction with the communication and collaboration provided by the professionals conducting the assessment and providing the diagnostic outcome was measured by self-rating scores on one item "How satisfied were you with the professional way the diagnosis was given, considering their communication and collaboration".

Parental satisfaction with the perceived quality of information received at diagnosis. The level of parental satisfaction with the information and its quality received at diagnosis was measured by self-rating scores on one item "How satisfied were you with the information given at diagnosis".

Parental satisfaction with the perception of link-worker role. The level of parental satisfaction with the assistance and resources provided by the family's designated support person was measured by self-rating scores on the item "How satisfied were you with the support offered during the assessment process?". This question was only displayed if families answered yes to the item querying if they were allocated a link-worker.

Parental satisfaction with the support offered post-diagnosis. The level of parental satisfaction with the assistance and resources provided after the diagnostic outcome. Support encompassed universal, targeted and specialist supports. Universal support involved generalised assistance offered to all families of autistic children, such as parenting groups. Targeted supports included clinician-led, collaborative interventions, such as a specific occupational therapy intervention. Specialist, individualised supports included 1.1 therapy provided directly by clinicians (Martyn and Brereton, 2024). Satisfaction was measured by the item "How satisfied were you with the help/support offered after you received the diagnostic outcome for your child?".

Parental stress levels during the process. Stress was operationalised as the psychological or physiological response to a stressor, negatively impacting physical and/or mental health (VandenBos, 2007). This was measured by self-rating scores on one item "Overall, how stressful did you find the diagnostic process?".

Perceived child stress level during the assessment process. Children's stress levels during the diagnostic process were measured by parent-rated scores on one item "Overall, how stressful was the diagnostic process for your child?".

Autism assessment pathways (independent variable)

The assessment protocol – Tier 1. The Autism Assessment Pathways Protocol (Assessment Protocol) is a novel pathway to autism assessments within the HSE, encompassing a three-tiered approach where the assessment intensity and presentation complexity increase across the tiers. Thus, children are referred to an assessment appropriate to their presentation complexity. Tier 1 involves low intensity, nonstandardised assessments for children with distinct autism presentations or where needs are not yet known. They are conducted by local clinicians in Primary Care, CDNT or acute services. An interview, brief

assessment (screening measures), informal observation and clinical judgement are used. Tier 2 assessments are conducted by a specialist autism team for children with more complicated presentations and use standardised instruments. Tier 3 involves an extended assessment using additional instruments alongside differential assessment, for more complex presentations (HSE, 2021). Children with non-complex needs access a Tier 1 assessment; children may be escalated to a Tier 2 assessment where further differential assessment is needed; and further escalation to Tier 3 may be necessitated where inconclusive evidence or additional contributors (e.g. trauma) persist.

The Assessment Protocol aims to provide timely, efficient and equitable access to supports – moving away from intensive assessments (Martyn and Brereton, 2024). It was piloted between April and September 2022 within two Community Health Organisation areas (CHO) and again, between November 2022 and April 2024 within four CHOs (Martyn and Brereton, 2024). Ireland was divided into nine CHOs, each responsible for delivering health and social care services in their area.

Assessment of need (AON). In Ireland, public autism assessments are primarily conducted by the Assessment of Need (AON) service, established by the DA. The AON service comprises a multidisciplinary team employed by the HSE. AONs are conducted by a team of HSE specialists, private providers commissioned by the HSE or private providers with validation by AON. AON evaluates the presence of a disability using standardised measures (Martyn and Brereton, 2024).

Data analysis

Missing data. Of 43 survey responses, 12 recorded no data for all measures and were removed manually. In all, 19 participants provided partial responses but were included because of the limited sample size and value of their insights (Osborne, 2012). The inclusion criteria for partial responses involved the provision of demographics and information on the diagnostic process, which were central to the study's objectives. Little's Missing Completely at Random test showed data were missing at random [$\chi 2\,(63) = 66.91$ and $p = 0.344$]; thus, pairwise deletion was used (Marsh, 1998).

Quantitative data analysis. Quantitative data were analysed by IBM Statistical Package for Social Sciences (SPSS; IBM Corp, 2021) version 30.0.0. Ethnicity was transformed into a nominal variable with four levels (Irish, White Irish, Caucasian and other) to enhance statistical power. Other included Asian, Bangladeshi and Black African, as only one to two people reported these ethnicities (Ross *et al.*, 2020). Nonparametric tests were used, as they are robust to uneven sample sizes and violations of normality and homogeneity of variance. A Mann–Whitney U Test tested for differences in participant characteristics and levels of satisfaction and stress between the Assessment Protocol Tier 1 and AON pathways. A Chi-Square Test of Independence investigated the association between the assessment pathway accessed (Assessment Protocol Tier 1 or AON) and the categorical participant characteristics (Pallant, 2020). Because of cell count violation, Fisher's exact test was used. The relationships between assessment pathway (Assessment Protocol Tier 1 and AON), participant characteristics, satisfaction levels and stress levels were analysed using a nonparametric Spearman Rank-Order Correlation.

Qualitative data analysis. Qualitative data were analysed in Microsoft Word using Braun and Clarke (2006) six-step reflexive thematic analysis. An inductive, latent, essentialist/realist approach was applied to allow for broad, flexible observations to understand parents' experiences (Maxwell, 2013). A guideline of two to six themes was followed were developed to ensure meaningful representation of the data (Ayton *et al.*, 2024). To enhance credibility and reduce bias, an independent Senior Clinical Psychologist reviewed the themes (Hurst, 2023).

Results

Participant characteristics

Table 1 presents the parent and child characteristics for the entire sample (upper panel), Assessment Protocol Tier 1 (middle panel) and AON (lower panel) pathways. Social development difficulties (88%), delay in starting to talk (73.3%), rituals/obsessions/dislike of change/object attachments (66.7%) and behavioural problems (60%) were the most frequently noted initial concerns. After their first visit to a professional, some 77.4% ($n = 24$) of families were referred to another discipline or for an autism assessment. Some families received second (61.3%; $n = 19$) and third (45.2%; $n = 14$) referrals to additional disciplines before their child obtained an autism diagnosis. Public Health Nurses (PHN) or community health nurse (54.8%, $n = 17$), followed by General Practitioners (GP) or family doctor (16.1%, $n = 5$), were the most frequently seen professionals at initial consultation. On average, 3.26 tools (SD = 3.71) were used in diagnostic assessments across the whole sample. An average of 5.17 tools (SD = 2.86) were used in the Assessment Protocol Tier 1 pathway and 2.8 (SD = 3.79) in the AON pathway.

Support services

Across the whole sample, 65.2% of families ($n = 23$) attended a follow-up appointment, and 95.5% ($n = 22$) received a post-diagnosis written report. In the Tier 1 pathway, 80% ($n = 5$) attended a follow-up, and all received a written report. Among families in the AON pathway, 61.1% ($n = 18$) had a follow-up appointment, and 94.1% ($n = 17$) received a written report.

Following diagnosis, of the 19 participants who provided information, most received universal supports (25.8%, $n = 8$). Among those in the Tier 1 pathway ($n = 4$), 75% received universal supports ($n = 3$) and one participant each (25%) received specialist or no supports. In the AON pathway ($n = 15$), 33.3% ($n = 5$) received universal, 33.3% ($n = 5$) specialist, 20% targeted ($n = 3$) and 13% ($n = 2$) no supports.

Parental satisfaction

Tables 2 and 3 present the satisfaction and stress levels for the whole sample (upper panel), Assessment Protocol Tier 1 (middle panel) and AON (lower panel) pathways. Some 65% ($n = 13$) of parents reported satisfaction with the overall diagnostic process. In all, 15 parents (79%) deemed the process stressful for themselves and 42.1% deemed the process stressful for their children ($n = 8$).

Differences in autism assessment pathways

Table 4 presents a Mann–Whitney U Test comparing parents' experiences between the Assessment Protocol Tier 1 and AON pathways. There was no significant difference in parent reported satisfaction or stress levels, age at diagnosis, number of referrals, number of tools, co-occurring diagnoses, number of clinicians seen, age of child at initial appointment or assessment length between both pathways.

A Chi-Square Test of Independence with Fisher's Exact Test revealed no significant association between assessment pathway and children's gender, the provision of a follow-up appointment, a written report or post-diagnostic support. The Monte Carlo Simulation displayed no significant associations between the assessment pathway and parents' gender and ethnicity, provision of a link worker and the type of support provided.

The results of a Spearman Rank Order Correlation are presented in Table 5. There was a strong, positive correlation between parental satisfaction with the overall diagnostic process and satisfaction with both the post-diagnostic support provided and the information provided at diagnosis. There was a strong, negative correlation between the time to

Table 2 Satisfaction levels for whole sample ($n = 22$), assessment protocol Tier 1 ($n = 5$) and AON ($n = 17$) pathways

Satisfaction outcomes	n	*M (SD)*	n *(%) Very dissatisfied*	n *(%) Quite dissatisfied*	*n (%) Neutral*	*n (%) Quite satisfied*	*n (%) Very satisfied*
*Whole sample (*n *= 22)*							
Information at diagnosis	22	3 (1.11)	1 (4.5)	1 (4.5)	4 (18.2)	7 (31.8)	9 (40.9)
Support during assessment process	21	2.76 (1.3)	2 (9.5)	1 (4.8)	5 (23.8)	5 (23.8)	8 (38.1)
Professionals conducting assessment	21	3.38 (1.02)	1 (4.8)		2 (9.5)	5 (23.8)	13 (61.9)
Support Post-Diagnosis	20	2.1 (1.33)	3 (15)	3 (15)	7 (35)	3 (15)	4 (20)
Overall process	20	2.55 (1.32)	2 (10)	3 (15)	2 (10)	8 (40)	5 (25)
*Protocol Tier 1 Path way (*n *= 5)*							
Information at diagnosis	5 (83)	3.2 (1.1)			2 (40)		3 (60)
Support during assessment process	5 (83)	2.6 (1.67)	1 (20)		1 (20)	1 (20)	2 (40)
Professionals conducting assessment	5 (83)	3.4 (0.89)			1 (20)	1 (20)	3 (50)
Support Post-Diagnosis	5 (83)	1.2 (1.3)	2 (40)	1 (20)	1 (20)	1 (20)	
Overall process	5 (83)	2.20 (1.64)	1 (20)	1 (20)		2 (40)	1 (20)
*AON Pathway (*n *= 17)*							
Information at diagnosis	17 (68)	2.94 (1.14)	1 (5.9)	1 (5.9)	2 (11.8)	7 (41.2)	6 (35.3)
Support during Assessment process	16 (64)	2.81 (1.22)	1 (6.3)	1 (6.3)	4 (25)	4 (25)	6 (37.5)
Professionals conducting assessment	16 (64)	3.38 (1.09)	1 (6.3)		1 (6.3)	4 (25)	10 (62.5)
Support Post-Diagnosis	15 (60)	2.4 (1.24)	1 (6.3)	2 (13.3)	6 (40)	2 (8)	4 (26.7)
Overall process	15 (60)	2.67 (1.23)	1 (6.7)	2 (13.3)	2 (13.3)	6 (40)	4 (26.7)

Source(s): Authors' own work

Table 3 Stress levels for whole sample ($n = 22$), assessment protocol Tier 1 ($n = 5$) and AON ($n = 17$) pathways

Pathway	*Person rated*	n *(%)*	*M (SD)*	*Not at all stressful* n *(%)*	*Not very stressful* n *(%)*	*Neutral* n *(%)*	*Quite stressful* n *(%)*	*Very stressful* n *(%)*
Whole Sample ($n = 22$)	Parent	19 (86)	3.16 (0.90)	1 (5.3)	3 (15.8)	7 (36.8)	8 (42.1)	
	Child	19 (86)	2.21 (1.48)	4 (21.1)	1 (5.3)	6 (31.6)	3 (15.8)	5 (26.3)
Protocol Tier 1 Pathway ($n = 5$)	Parent	4 (66)	3.00 (0.82)		1 (25)	2 (50)	1 (25)	
	Child	4 (66)	2.25 (1.71)	1 (25)		1 (25)	1 (25)	1 (25)
AON Pathway ($n = 17$)	Parent	15 (60)	2.20 (1.47)	1 (6.7)		2 (13.3)	5 (33.3)	7 (46.7)
	Child	17 (68)	2.94 (1.14)	3 (20)	1 (6.7)	5 (33.3)	2 (13.3)	4 (26.7)

Source(s): Author's own work

Table 4 Group differences for characteristics, satisfaction and stress variables ($n = 31$)

Variable Characteristics	*U*	*z*	*p*	*N*	*Tier 1 Pathway* (n = *6*) *M (SD)*	*Tier 1 Pathway* (n = *6*) *Md (IQR)*	*AON Pathway* (n = *25*) *M (SD)*	*AON Pathway* (n = *25*) *Md (IQR)*
Age at diagnosis	102	1.6	0.129	30	5 (3.63)	4 (4)	5.92 (2.28)	5.5 (1)
Number of referrals	87.5	0.66	0.542	31	1.67 (1.03)	2 (1.5)	1.88 (1.27)	2 (2.5)
Number of tools	43.5	−1.63	0.117	31	5.17 (2.86)	6 (4.25)	2.8 (3.79)	1 (4.5)
Co-occurring diagnosis	2	−0.65	0.8	5	2 (1.41)	2	1.33 (0.58)	1
Number of clinicians seen	87	0.63	0.575	31	2.67 (1.03)	3 (1.5)	2.84 (1.34)	3 (2.5)
Age of child at initial appointment	101	1.57	0.143	30	2.17 (1.33)	2 (1.25)	3.54 (2.11)	3 (2)
Time to assessment	75	0.16	0.9	30	791.67 (591.64)	703 (857.5)	807.92 (526.65)	739.5 (685)
Satisfaction with								
Information at diagnosis	37	−0.46	0.704	22	3.2 (1.1)	4 (2)	2.94 (1.14)	3 (1.5)
Support during Assessment	41.5	0.13	0.905	21	2.6 (1.67)	3 (3)	2.81 (1.22)	3 (2)
Professionals conducting assessment	41.5	0.14	0.905	21	3.4 (0.89)	4 (1.5)	3.37 (1.09)	4 (1)
Support post-diagnosis	56	1.66	0.119	20	1.2 (1.3)	1 (2.5)	2.4 (1.24)	2 (2)
Overall diagnostic process	43.5	0.55	0.612	20	2.2 (1.64)	3 (3)	2.67 (1.23)	3 (2)
Stress levels								
Parent	35.5	0.59	0.596	19	3 (0.82)	3 (1.5)	3.2 (0.94)	3 (1)
Child	29	−0.1	0.961	19	2.25 (1.71)	2.5 (3.25)	2.2 (1.47)	2 (3)

Note(s): Mann–Whitney U Test conducted
Source(s): Authors' own work

assessment and satisfaction with the overall diagnostic process. There was a medium, positive correlation between parental stress and the time to assessment.

From the analysis of parent responses to open-ended questions, four major themes emerged. *Falling Through the Cracks: Navigating a Fragmented System* describes the systemic challenges faced by parents. *Accessing Effective Supports* captures parents' evaluation of supports. *The Emotional and Psychological Impact of the Assessment Experience* depicts the emotional burden imposed by the diagnostic process, and *Being Seen, Heard and Understood* conveys parents' perceptions of the diagnostic process itself.

Theme 1: Falling through the cracks: Navigating a fragmented system

Parents described a disjointed health-care system fraught with delays where the onus of addressing their child's autistic symptoms falls upon them. Parents described a "referral loop" where services, like Primary Care and CDNT, operated in isolation and children received cyclical referrals without sustained intervention. Navigating a "broken" system with prolonged assessment waiting times was a common experience. Parents partially attributed their dissatisfaction with the diagnostic process overall to these delays spanning up to 1,825 days (five years).

In the absence of a diagnosis and professional services, parents reported assuming full responsibility in supporting their child's autistic symptoms and co-occurring difficulties. Some parents reported being advised to contact services and advocate for support themselves. Many parents engaged in self-directed learning, researching and implementing their own identified strategies to support their child.

Public nurse told to do an assessment of need myself (Participant 7; AON).

We were already living as though she had a diagnosis and the interventions we had researched and implemented ourselves (Participant 5; Assessment Protocol Tier 1).

Experiences of feeling unsupported, alone and "lost" amidst the diagnostic process were ascribed to these systemic gaps.

Table 5 Descriptive statistics and correlations for study variables for whole sample ($n = 31$)

Variable	n	*M*	*SD*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*14*	*15*
1. Assessment pathway	31			–														
2. Age at Diagnosis	30	5.73	2.56	0.3	–													
3. Number of Referrals	31	1.84	1.21	0.12	0.22	–												
4. Co-occurring diagnosis	30	1.6	0.89	−0.32	0.5	0.06	–											
5. Age of Child at Initial Appointment	30	3.27	2.03	0.29	0.48**	−0.14	−0.32	–										
6. Time to Assessment	30	804.67	529.5	0.03	0.16	0.2	−0.11	0.002	–									
7. Satisfaction with Information at Diagnosis	22	3	1.11	−0.1	0.26	0.29	0.82	0.18	−0.24	–								
8. Satisfaction with Support During Assessment	21	2.76	1.3	0.03	0.44*	0.44*	1**	0.26	−0.14	0.65**	–							
9. Satisfaction with Professionals Conducting Assessment	21	3.38	1.02	0.03	0.32	−0.03	0.2	−0.1	−0.17	0.34	0.13	–						
10. Satisfaction with Support Post-Diagnosis	20	2.1	1.33	0.38	0.36	0.33	0.54	0.13	−0.38	0.36	0.6**	0.42	–					
11. Overall, Satisfaction with Diagnostic Process	20	2.55	1.32	0.13	0.2	0.32	0.0	0.01	−0.5*	0.68**	0.44	0.4	0.56*	–				
12. Stress of Process for Parent	19	3.16	0.9	0.14	0.09	0.07	0.27	0.27	0.47*	−0.06	−0.17	−0.36	−0.32	−0.34	–			
13. Stress of Process for Child	19	2.21	1.48	−0.02	0.04	0.21	0.26	0.01	0.12	−0.09	−0.14	−0.4	−0.35	−0.21	0.39	–		
14. Number of Clinicians Seen	31	2.81	1.28	0.12	0.22	1**	0.06	−0.14	0.2	0.29	0.44*	−0.03	0.33	0.32	0.07	0.21	–	
15. Number of Tools	31	3.26	3.76	−0.3	0.28	0.37*	0.11	0.08	0.02	0.08	0.3	0.41	0.13	0.24	0.49*	0.2	0.38*	

Note(s): *$p < 0.05$; **$p < 0.001$; and using a Spearman Rank Order Correlation
Source(s): Authors' own work

The "exceptionally long" (Participant 16; AON) waiting lists for autism assessments and further waiting periods to access post-diagnostic support were identified as barriers to timely and early intervention, which may have negative repercussions for children.

Participants from both assessment pathways reported these experiences.

The waiting lists are endless, and children are suffering because of this (Participant 15; AON).

It took over two years for my child to be offered an assessment, which could have been very detrimental to her development had I not sought early intervention outside of this public system (Participant 5; Assessment Protocol Tier 1).

Theme 2: Accessing effective supports

The second theme comprised two subthemes:

1. access, adequacy and availability of supports; and
2. diagnosis as a gateway to supports.

Subtheme 1: Access, adequacy and availability of supports. Experiences of unmet support needs were common. Parents described being left without support post-diagnosis, or if supports were provided, then they were inadequate and unsatisfactory:

I just got 6 short sessions with an SLT after waiting 3 years. They were nowhere near enough.

Completely inadequate service (Participant 31; AON).

Parents' dissatisfaction with support provision was exemplified within survey responses, most parents reported receiving universal supports: "just recommendations" (Participant 4; Assessment Protocol Tier 1) and access to parenting groups. These generalised supports were identified as insufficient to meet families' and children's individual needs.

There has been no support for my child. I have been to one more than words parents' workshop so far (Participant 3; Assessment Protocol Tier 1).

Alternatively, for two parents, supports were satisfactory as they "were given all information and additional resources to help" (Participant 30; AON).

Subtheme 2: Diagnosis as a gateway to supports. Parents anticipated that their child's diagnosis would immediately unlock support services and resources, however, systemic barriers delayed access and dissatisfaction emerged.

The stressful part is school; they want a diagnosis. (Participant 7; AON) Most parents listed access to school supports as a driver for accessing an autism assessment, stressing that a diagnosis was necessary to access supports in mainstream school or to access an autism-specific class.

He was left to suffer attending school, and we could not access help because he hadn't been officially diagnosed. (Participant 15; AON).

Theme 3: the emotional and psychological impact of the assessment experience

Parents consistently highlighted the emotional toll of the diagnostic process, suggesting salient emotional responses arose at different points across the journey. For some parents, the entire diagnostic process felt "hopeless" and "stressful because we went through a lot of emotions" (Participant 20; AON). Parents attributed negative feelings to a fear of the unknown, worrying for their children's future as outcomes and the provision of support were unclear amidst long waiting periods. Numerous parents described feeling guilty that they were not "doing enough" to support their child's needs:

It's knowing that your child is facing challenges and complex needs, and you are trying to help them and also not sure if you are doing enough with limited support out there (Participant 15; AON).

The diagnostic process was identified as burdening parents' psychological well-being as it was both distressing and stressful (Participant 7; AON). The psychological impact was exemplified as Participant 21 (AON) ascribed their satisfaction with the information provided at diagnosis to the process simply being over.

The perception of diagnostic usefulness and accompanying emotions varied across participants. As they expected a positive autism diagnosis, most parents felt relieved.

I would have been shocked if they said he hadn't got it [autism] with the signs and symptoms that he was showing. It was a big relief for me (Participant 18; AON).

Parents noted their suspicion that their child was autistic before formal diagnosis, but a professional diagnosis validated their concerns. This confirmation helped parents to have "a better understanding of certain behaviours" (Participant 1; Assessment Protocol Tier 1) and afforded a sense of legitimacy when advocating for support.

We knew he was autistic. We were happy to just get an autism diagnosis (Participant 13; AON) Conversely, feelings of shock were described. One parent did not expect their child to be autistic, as they reported previously being told that their child was likely not autistic by a National Educational Psychological Service psychologist.

The value of a diagnostic label varied. For some parents, the diagnosis was instrumental in accessing support or understanding children's needs. For others, nothing changed as parents were already implementing the necessary techniques or supports. Some parents predicted a diagnostic label would have negative repercussions for their family's life because of "stigma associated with the diagnosis" (Participant 8; AON).

You are waiting for your world to be turned upside down and everything you thought your family would be changes in a split second of that diagnosis (Participant 4; Assessment Protocol Tier 1).

Theme 4: Being seen, heard and understood

The fourth theme comprised two subthemes:

1. parents' evaluation of assessment practices; and
2. parents' experiences with professionals.

Parents appraised the assessment itself and their interactions with professionals.

Subtheme 1: Parents' evaluation of assessment practices. Parents from both assessment pathways described their respective assessments as "quick", "easy" and "straightforward". They expressed confidence in and satisfaction with the assessment itself because it was efficient and comprehensive.

We knew that there was something wrong [. . .] but the meetings reassured us that it's ok to be different and he is just who he is (Participant 8; AON).

Alternatively, two parents who accessed the AON pathway felt the assessment was hastily conducted and complicated.

AON with HSE took half an hour without a psychologist and was shockingly inadequate (Participant 3; AON).

Families' sense of validation and inclusion in the diagnostic process varied. Most parents described a family- and child-centred process where their feelings were considered, and the diagnosis was delivered in a sensitive, strengths-based manner. Three parents

conveyed their children "enjoyed the staff and the process" (Participant 7; AON) and felt comfortable at the holistic assessment. Other parents reported a deficit-focused assessment, which put great pressure on children.

They spoke about my child in front of my child, it was very clinical and useless (Participant 31; AON).

The quality of communication was discussed in terms of parents' satisfaction with the assessment. Some parents felt they received effective communications from professionals, with clear and comprehensive information, which empowered parents by imparting knowledge. Some parents described receiving in-depth explanations of the process and diagnosis in a digestible manner.

Everything was explained thoroughly, with understanding of my son and with a warm and friendly manner (Participant 1; Assessment Protocol Tier 1).

In contrast, several parents reported unclear communication regarding the diagnosis and a lack of clarity surrounding next steps and future supports.

It [the report] was good to receive, but it's not something that you understand and know how to use (Participant 14; AON).

Subtheme 2: Parents' experiences with professionals. Parents' narratives surrounding the professionals involved in the diagnostic process were predominantly positive. Parents from both pathways referenced "professional", "supportive", "empathetic", "friendly" and "knowledgeable" clinicians. Numerous parents stressed that having a link worker was helpful as they were "amazing" and provided support. Parents suggested positive experiences with professionals improved their experiences despite dissatisfaction surrounding delays and poor experiences with the diagnostic process.

Although I was not offered a lot of support through the process, I was not unsatisfied with what I received during the process either. Everyone we encountered was nice and friendly (Participant 5; Assessment Protocol Tier 1).

Discussion

To the best of the authors' knowledge, this study was the first to explore parents' satisfaction with the Tier 1 component of the Assessment Protocol pathway in comparison with another public pathway (AON). It also explored if the former met its objectives of timely and efficient access to autism assessments and support. Most parents were satisfied with the autism diagnostic process overall, the provision of support during the diagnostic process, the professionals conducting the assessment and the information provided alongside the autism diagnosis. Parental satisfaction with post-diagnostic support was distributed relatively evenly across the three satisfaction levels. According to parent report, the process was stressful for both parents and their children. Parental self-reported satisfaction, stress levels and participant characteristics did not differ depending on which assessment pathway they accessed (Assessment Protocol Tier 1 or AON). Four main qualitative themes of *Falling Through the Cracks: Navigating a Fragmented System*, *Accessing Effective Supports*, *The Emotional and Psychological Impact of the Assessment Experience* and *Being Seen, Heard and Understood* were identified.

On average, compared with families who accessed the AON pathway, those who accessed the Assessment Protocol Tier 1 pathway first sought professional help over a year earlier, obtained a diagnosis approximately 11 months younger, waited 18 fewer days for assessment, saw one fewer professional and referral before diagnosis and encountered more assessment tools. Thus, the Assessment Protocol may be advancing appropriately towards its aims of timely and efficient access to autism assessments (Martyn and Brereton, 2024).

Descriptive statistics showed parents who accessed the Assessment Protocol Tier 1 pathway more commonly reported satisfaction with the overall diagnostic process. Those who accessed the AON pathway more frequently reported satisfaction with information at diagnosis, the professionals conducting the assessment and support post-diagnosis. Across both pathways, parents reported high levels of satisfaction with the support provided during the assessment. Participant characteristics, parental satisfaction and stress levels did not differ significantly between pathways; none was viewed as superior, and assessment characteristics were consistent. Thus, both pathways may adhere to the same professional guidelines and afford a similar standard of care, as recommended by the PSI (PSI, 2024). Considering parents' synonymous experiences, the findings will be discussed collectively to illustrate overarching patterns (Kattan and Vickers, 2020).

In this study, the average time to assessment (805 days) was shorter than in previous Irish research: 1,078 days in Martyn and Brereton's study (2024) and 1,059 days in O'Brien and colleagues' study (2024). This substantiates the Assessment Protocol's aim of reducing waiting times. Shorter waiting periods may reflect staffing levels in the CDNT, which participated in the Assessment Protocol Tier 1, and the AON's increase in contracted private providers (HSE, 2023; Hanley, 2025). Despite the present reduction in waiting periods, the age of children at diagnosis remains older when compared internationally (Brian *et al.*, 2019; Subramanyam *et al.*, 2019; WHO, 2023). Accordingly, opportunities for effective early intervention, central to the Assessment Protocol's aims, are being missed. Qualitative findings revealed parents' concerns about the negative consequences of these delays, including fears of poor developmental outcomes. Given existing evidence on the efficacy of effective early intervention practices, it is imperative, to not only reduce the delay in accessing autism assessments but also ensure that clear pathways to personalised, effective evidence-based interventions are available and implemented (Dawson and Zanolli, 2003; Schreibman *et al.*, 2015).

Reflecting well-established trends, parents described prolonged and circuitous referral pathways despite raising concerns before age three (Braiden *et al.*, 2010). Delays in accessing an assessment may have been exacerbated by limited autism knowledge among primary healthcare clinicians. One third of parents from the current study reported being advised "not to worry and return if difficulties persisted at first contact with services" (Langford *et al.*, 2007; Makino *et al.*, 2021; Smith-Young *et al.*, 2020). The current study demonstrated that longer assessment waiting periods correlated with lower parental satisfaction with the overall diagnostic process (Crane *et al.*, 2016; Moh and Magiati, 2012; O'Brien *et al.*, 2024).

Current parental satisfaction with the diagnostic process exceeded that reported by O'Brien *et al.* (2024) and Crane *et al.* (2016) but was lower than in Martyn and Brereton (2024) Assessment Protocol study, potentially reflecting the latter's participants' greater satisfaction with diagnostic information and post-diagnostic supports. Consistent with UK findings, in the current study, 52% of parents were satisfied with information provided at diagnosis, commending its thoroughness, clarity and accessibility (Brogan and Knussen, 2003). Supporting existing findings, parents qualitatively linked satisfaction to the interpersonal skills of assessing professionals, suggesting these qualities could mitigate negative perceptions of other assessment aspects (Finnegan *et al.*, 2014; Moh and Magiati, 2012; Templeman, 2019). A novel contribution was the reported value of the link worker role, described as therapeutically beneficial and enhancing the overall experience. However, only one-quarter of parents in each pathway reported being allocated a link worker, fewer than in Martyn and Brereton (2024) study, possibly reflecting resourcing constraints or limited parental awareness of such allocation.

Aligning with prior research, parents widely received generalised or no support (Hennel *et al.*, 2016). The incongruence between parents' expectation, that diagnosis was a gateway to specialist and tailored interventions, and reality facilitated the greatest levels of

dissatisfaction with any component of the assessment. These outcomes contradict the Assessment Protocol's aims of clearly outlined support trajectories and sufficient targeted and specialist resources (Martyn and Brereton, 2024). Additionally, as reported by parents, basing school resource allocation on diagnosis contradicts Ireland's special education guidelines, which recommend support be determined by each child's needs (Department of Education, 2024). Thus, transparent communication from professionals from the outset is essential to managing parents' expectations.

Aligning with the Assessment Protocol's objectives and the PSI's recommendations for a family-centred approach, parents qualitatively deemed the assessment itself efficient and consistent with the principles of FCC. Parents associated dissatisfaction with deficit-focused language and assessment tasks that exceeded their child's capabilities, illustrating the importance of balanced but optimistic explanations of a child's diagnosis (Langford *et al.*, 2007; Legg and Tickle, 2019).

This research afforded a comprehensive understanding of the relationship between parents' satisfaction with their child's autism diagnostic process and their experience, facilitating direct inferences to the Assessment Protocol Tier 1 pathway. However, the current study presents possible limitations. The recruitment of a small sample size from a single CDNT service may have reduced the generalisability of findings. The Assessment Protocol was in its pilot phase and available only in four of nine CHO areas, limiting eligible participants and creating uneven sample sizes. This reduced statistical power, making the findings exploratory and warranting cautious interpretation pending future research with more balanced samples. Considering time constraints, qualitative data were gathered using open-ended survey questions, which may have limited the richness of the data. Considering Assessment Protocol Tier 1 implementation differed across CHOs and service types, numerous primary care and CDNT services from across Ireland and other tiers should be studied (Martyn and Brereton, 2024). Interviews and focus groups could be used to gather a comprehensive understanding of parents' experiences. Finally, the preliminary finding that parents were overlooked by their GP or PHN when reporting early developmental concerns should be investigated to understand their relationship with timely autism assessments.

Conclusion

Ultimately, parents from the Assessment Protocol Tier 1 and AON pathways reported similar experiences and critiques, supporting the viability of the Assessment Protocol Tier 1 pathway. Parental dissatisfaction appeared not to stem not from the diagnostic pathway accessed but may be related to assessment waiting times and inadequate post-diagnostic supports. Transparent communication from professionals before assessment and after diagnosis, including clear explanations of the efficacy of parent-mediated interventions, may help manage expectations, enhance engagement and reduce dissatisfaction among parents. The delayed access to assessment and inadequacy of evidence-based post-diagnostic supports indicate that the opportunity for effective early intervention is still being missed. Service resource constraints should be addressed with a focus on reducing delays and increasing staffing to enhance the provision of support, particularly targeted and specialist interventions.

Ethics statement

It was obtained from the School of Psychology at Trinity College Dublin (06/12/2024) and HSE Research Ethics Committees (18/12/2024) with no revisions.

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