Experiences of Autism Assessment and Diagnosis in Scotland

Survey Report

AUTISM RIGHTS GROUP HIGHLAND

AUTISTIC MUTUAL AID SOCIETY EDINBURGH

SCOTTISH ETHNIC MINORITY AUTISTICS

SCOTTISH AUTISM

JUNE 2025

The project team:

Kabie Brook (ARGH),

Leo Starrs-Cunningham (AMASE)

Daniel Mayol Jiménez (Scottish Autism)

Laura Bilton (SEMA)

Fergus Murray (AMASE)

Mark McDonald (Scottish Autism)

Sofia Farzana (SEMA)

Khiah Strachan (ARGH)

Michelle Dodd (AMASE)

Zoe McIntyre (AMASE)

Dr Joe Long (Scottish Autism)

We would like to thank all those people that completed the survey and shared their experiences with us

Executive Summary

We surveyed 624 people about their experiences of autism assessment and diagnosis in Scotland. These included people in 31 of 32 local authority areas.

51% of respondents found it hard to get a referral. Some experienced frontline health practitioners who did not appear to have a contemporary understanding of autism.

Waiting times ranging from a few months to seven years were reported, with the experience of waiting in limbo causing considerable stress and anxiety.

62% of people did not feel well informed about the assessment process once referred.

64% said that they were not made aware of support services available during the referral and assessment period.

1 in 5 respondents had sought a private diagnosis. The average cost was £1540, with some people paying £4500.

39% of people receiving a private diagnosis reported this causing them significant financial hardship, including borrowing money from relatives, selling possessions, or incurring debt.

However, overall, respondents had a more satisfactory experience of private or third sector assessments.

Post-diagnostic support appears highly variable across Scotland, with little or no provision reported in some places.

Over one third of respondents had an overall negative experience of the assessment process.

Recommendations

- The Scottish Government should Introduce a **national neurodevelopmental assessment guarantee**, meaning any adult in Scotland can access an assessment pathway should they need to.

- **Waiting times** for assessment and diagnosis should be reduced and timely assessment provided.

- **Clear information** should be provided on what the assessment process will involve; the likely timescales expected; and reliable signposting to support services during and after assessment.

- **Access to quality advice and support** during assessment, and after diagnosis should be guaranteed across Scotland.

Background

Receiving an autism diagnosis can be a pivotal moment in the life of an autistic person. It can be an important step in a person's self-understanding; it may be the point at which a person feels able to access a wider community of autistic people; and it should be a step along the pathway to someone receiving the support and services that they need in order to thrive.

Services in Scotland have, for many years, struggled to provide timely assessment and post-diagnostic support. In this context, many specialist services have followed the autistic community's lead in accepting self-identification as legitimate grounds for support provision, and education services should be able to build a profile of an individual learner's needs without formal diagnosis (sometimes called a 'working diagnosis'). However, in practice, support is not always forthcoming without a diagnosis. Moreover, self-identification and working diagnoses do not obviate the need for timely, neuro-affirmative, and person-centred assessment and diagnosis as crucial to a person making sense of their life experience, identity, and being able to identify their own needs going forward.

In 2023, a group of Autistic Peoples' Organisations (APO's) comprising Autism Rights Group Highland (ARGH), Autistic Mutual Aid Society Edinburgh (AMASE) and Scottish Ethnic Minority Autistics (SEMA) came together with Scottish Autism, a third sector organisation, to conduct a survey of people's experiences of assessment and diagnosis. Long waiting times for assessment have been a feature of service provision for some years, and we sought to understand the experience and impact of this situation. We also wanted to go further in understanding the whole experience of assessment and diagnosis from referral, through the process itself, to post-diagnostic support. In recent years, the Scottish Government has commissioned the National Autism Implementation Team to review and pilot holistic, neurodevelopmental pathways for assessment and support. It is hoped that our survey could help to inform future provision. Since the survey was undertaken, however, the difficulties in accessing assessment have become more acute. In the Spring of 2025, several Health and Social Care Partnerships in Scotland have announced cuts to the provision of assessment diagnosis. In recent weeks, all of our organisations have been contacted by members of the autistic community who are deeply worried by these developments. For example, Scottish Autism's National Advice Line, funded by the Scottish Government, has seen a considerable increase in enquiries related to diagnosis, from people who are very anxious about access to assessment.

This survey highlights the impact of delays to assessment for people exploring a diagnosis, the experience of diagnostic pathways, which often create barriers to accessing support, and the paucity of post-diagnostic support in Scotland. The survey shows very clearly where provision in Scotland needs to improve, and the human cost of failing to do so.

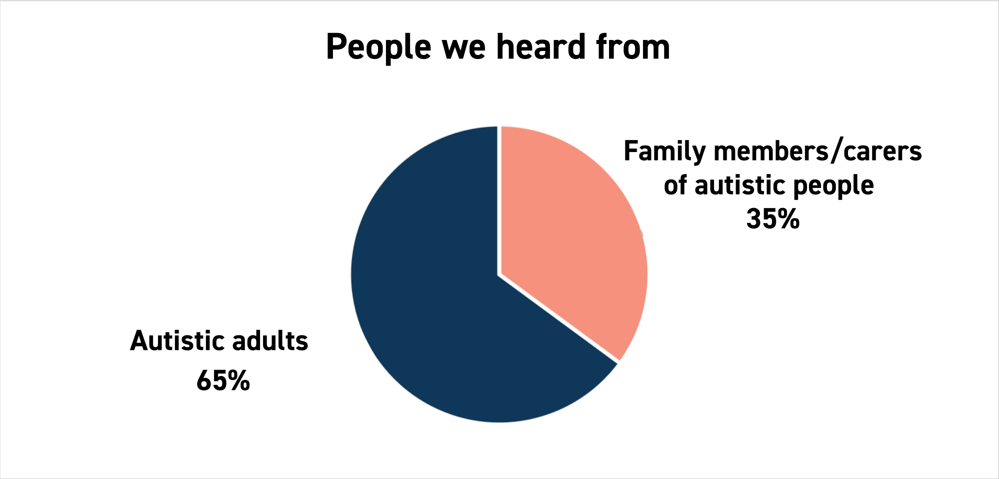
Our Approach

No external funding was received for this work. The survey was collaboratively designed by a team drawn from all four organisations. It included the collection of both quantitative and qualitative data, as presented here. The survey was created online and publicised by all four project partners through our networks. Coding of answers was undertaken by different team members and reviewed by the whole team, who met throughout the process as data was analysed and the report written up.

Who We Heard From

Our survey was carried out online and publicised through a range of social media channels.

We heard from 624 respondents in all: 405 autistic individuals and 219 family members and carers of autistic people.



76% of respondents, or people whose family responded, (381 people) reported that they did not have a learning disability, while 24% (120) had a co-occurring learning disability.

The age of autistic people responding, or on behalf of whom family members responded, was fairly well distributed across age groups up to 55, with fewer older autistic people responding (likely reflecting the number of older autistic people who remain undiagnosed/unaware that they may be autistic):

Age of respondents	No.	%
3-18	136	28.30%
19-35	148	30.80%
36-55	161	33.50%
56-72	35	7.30%

We asked respondents to identify their own ethnic identity, with replies summarised below:

Ethnicity	No.	%
White	459	95%
Mixed/white	10	2%
Black	3	< 1%
Asian	2	< 1%

We also asked respondents to identify their own gender, with the distribution of answers as follows:

Gender	No.	%
Female	281	58%
Male	158	33%
Non-binary	31	6%
Agender	8	2%
Genderfluid	2	< 1%
Genderqueer	2	< 1%

We did not ask respondents to identify whether they were trans- or cis-gender, so ‘Male’ and ‘Female’ categories include both cis-and transgender men and women.

We received responses from individuals across Scotland, representing 31 of 32 local authority areas. The distribution of responses varied considerably, with the highest proportion, (18.63% of the sample), coming from the Edinburgh region, while the lowest representations, (at 0.39%), coming from Orkney and Na h Eileanan Siar. We had no responses from Shetland.

Local Authority Area	No. of respond	Percentage of
Inverclyde	6	1.18%
Renfrewshire	12	2.35%
West Dunbartonshire	5	0.98%
East Dunbartonshire	8	1.57%
Glasgow	36	7.06%
East Renfrewshire	8	1.57%
North Lanarkshire	22	4.31%
Falkirk	11	2.16%
West Lothian	22	4.31%
Edinburgh	95	18.63%
Midlothian	15	2.94%
East Lothian	9	1.76%
Clackmannanshire	18	3.53%
Fife	40	7.84%
Dundee	16	3.14%
Angus	8	1.57%
Aberdeenshire	16	3.14%
Aberdeen	10	1.96%

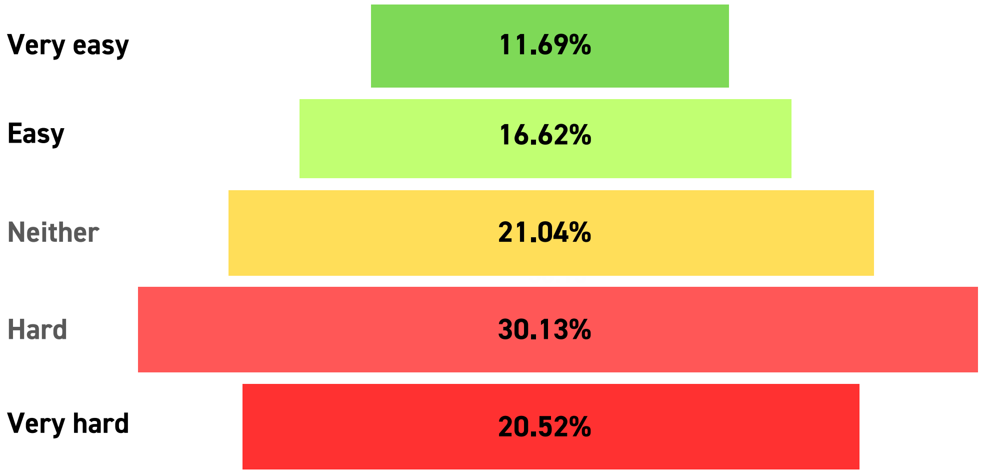
Moray	9	1.76%
Highland	35	6.86%
Na h-Eileanan Siar	2	0.39%
Argyll and Bute	5	0.98%
Perth and Kinross	4	0.78%
Stirling	15	2.94%
North Ayrshire	5	0.98%
East Ayrshire	5	0.98%
South Ayrshire	12	2.35%
Dumfries and Galloway	7	1.37%
South Lanarkshire	42	8.24%
Scottish Borders	10	1.96%
Orkney	2	0.39%
Shetland	0	0.00%
TOTAL	**510**	

Findings

1. Access To NHS Diagnosis

When respondents first approached public health services for support in getting an autism assessment, they frequently reported barriers that complicated the process, making it difficult to get the help they need. Respondents report healthcare professionals refusing referral, or educational services dismissing their concerns, citing insufficient 'evidence' to justify the assessment process.

How easy did you find the process of seeking a referral to receive an assessment?



While 28% of respondents found it easy or very easy to get a referral, just over 50% found it hard or very hard to get a referral for assessment. 21% of our respondents said they had been refused a referral at some point.

Referral and Gatekeeping in Public Services

Reasons for refusal included a range of gatekeeping issues relating to professional misunderstandings of autism, as well as a lack of availability of assessment. Responses were categorised as follows:

- No diagnostics services were available in an area, or services were oversubscribed and not taking referrals.
- Frontline health staff considered that respondents' mental health was not affected enough by their autistic experience to warrant a referral.
- Professionals considered a person 'not autistic enough' (often due to

outdated stereotypes), including not considering a person who had a job or children as warranting a diagnosis.

- Some individuals were advised that a diagnosis, or ‘ a label’ would not help them (regardless of whether someone might meet the criteria).
- Some diagnoses were not taken forward because the process required family / childhood development history and not enough information was available for some adults.
- In some instances presentation was attributed to other conditions (bipolar disorder, depression, bowel problems).
- Some services would not consider referral for someone without a learning disability.
- Traits displayed were attributed to parenting style.
- A young person was not considered by their school to have ”challenging behaviour” and so not referred for diagnosis.

People also experienced administrative failures:

- Referrals were lost
- Referrals were refused but the individual was not told this had happened
- Referrals were rejected because the ‘wrong person’ was referring (e.g. a teacher instead of a school nurse)
- Being told that a referral had been made only to find that it had not
- Being referred from frontline services but then then rejected by diagnosis service / CAMHS before being seen.

The data suggest that healthcare and education professionals often displayed an outdated or stereotyped understanding of autism and neurodivergence. As a result, some individuals were told their ‘symptoms’ weren’t ‘severe’ enough to warrant referral (where an in-depth assessment might better determine whether someone would meet a threshold for diagnosis, or was effective at masking). Young people didn’t display ‘challenging behaviours’ at school and were also not referred. In some cases, respondents reported professionals suggesting that medical conditions such as bipolar disorder, depression, or bowel conditions better explained an individual’s presentation. Respondents also reported professionals blaming parenting for the struggles discussed with them.

Some indicative quotations are provided here:

> *“I got refused due to not being ‘severe enough’ and they think it’s all mental health problems.”*

> *“My doctor dismissed my suggestion as ‘he could just tell’ and I was looking (at) him in the eye.”*

> *“I spoke to mental health professionals who advised at my age a diagnosis would make no difference.”*

These referral issues can lead many to explore alternative routes for assessments, such as private diagnosis, or even to give up seeking diagnosis. The lack of clear, accessible routes to diagnosis in these early stages clearly fosters feelings of skepticism and mistrust towards the state healthcare system and its professionals.

Awaiting Diagnosis

The Period of Time Between the Referral and the Assessment

The most notable feature of the diagnostic process is the long wait between when individuals and families first seek a referral and when the assessment takes place. This waiting period is filled with uncertainty and anxiety, not just because of its length but also due to the lack of communication that is reported to accompany this.

We asked respondents when they were referred and when they received a diagnosis. Of the 137 people who were able to answer this in relation to statutory health services, replies suggested waits ranging from 1 month to seven years and two months from referral, with an average wait of 23 months. A small number of respondents (5 people) described a period of ten years from first approaching health services to receiving a diagnosis. This appears to have occurred when someone did not receive a referral in the first instance, or went through multiple referrals or assessment processes. Many respondents were still awaiting a diagnosis at the time of being surveyed.

The combination of silence, an unclear schedule of events, and a lack of understanding of the process caused psychological distress for many respondents. This experience is particularly acute for a population that are likely to find uncertainty and a lack of planning difficult.

People reported:

- Not being told what they were being assessed for (especially in childhood).
- A lack of information of the process: such as the constituent stages, the information sought, and whether they would be 'tested'.
- Uncertain timescales and a 'limbo period' in which difficulties have been identified but no clarity or support is yet in place.
- Poor information causing anxiety.
- Changing stories and expectations from professionals, leaving people feeling "pushed from pillar to post'.

- A lack of clarity clear about who would be involved in the process.
- ‘Cold starts’ in some instances, such as being given questionnaires to fill out but not told about the rest of the process or how the questionnaires would be used.

Indicative comments included the following:

“We've just been left dangling with no idea how long for.”

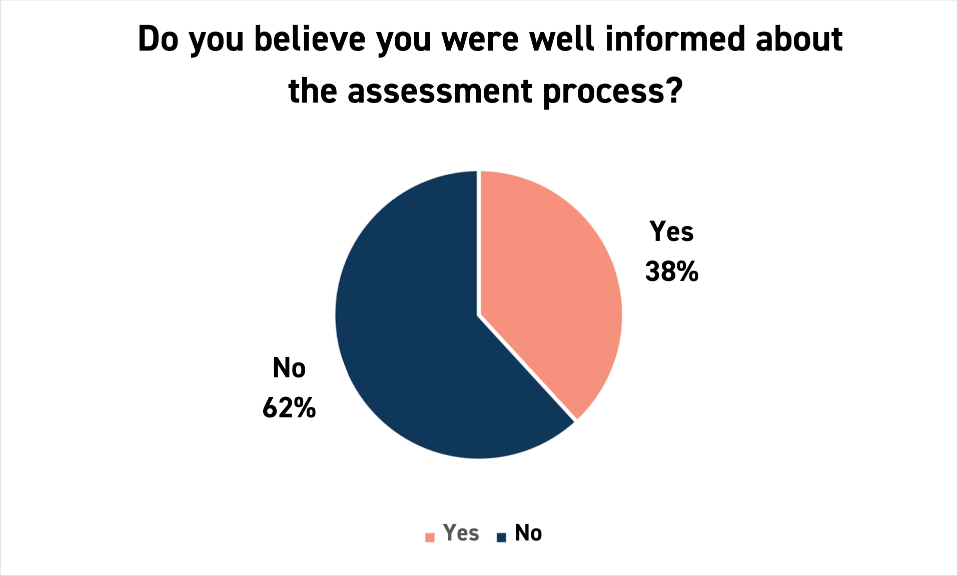
“The process was long (3 years) and damaging to my mental health.”

“There is no acknowledgement of the referral, so [you] are left anxious that it has not been received or that you have dropped off the list. There are no updates as you progress through the waiting list, or estimate of how long you may be waiting. This causes unnecessary frustration and anxiety.”

Provision of Information about the Diagnostic Process

Throughout this process, the availability of information plays a crucial role in shaping the diagnostic experience. When individuals received sufficient communication and information about the process, respondents reported positive outcomes. However, this was a rare occurrence, and typically limited to the private diagnosis pathway. On the other hand, the public health care system was often characterised by silence, infrequent communication, and a significant lack of follow-up. Many described the time between referral and assessment as a “limbo”, characterised by uncertainty, neglect and a lack of a clear direction or resolution.

A majority of respondents reported a significant lack of information about the process (62% - 235 people) compared with 38% (145 people) who said they felt well-informed.



Respondent comments:

"I think clear-cut guidance on what to expect would be beneficial, perhaps in the form of a flow chart with timescales…"

"I wasn't given any specific information about the assessment process (…) No counselling was offered regarding how I might feel about the outcome, and no mention was made about the lack of treatment or support afterwards. At this point my only knowledge of autism was from 'Rain Man' and I didn't identify with that character."

Without a clear outline of the process and proper guidance, many individuals and families report being left to navigate this uncertainty on their own:

- People reported a lack of emotional support to accompany the information they received.
- A significant lack of join-up between services was reported, that to led to gaps in information about what to expect.
- Respondents were left to take the initiative in gathering information about the process and become a "researcher" for themselves.
- People drew information from prior experiences, or from other family members when faced with a vacuum of information from services.

We asked respondents what information about the process was provided and by whom, and they reported:

- The majority of respondents stated that information about the process and assessment was non-existent.
- Some people reported being informed by reminder letters, however the information included was poor. Some letters included unexpected questionnaires.
- People resorted to phoning up health services to get updates and further information, but this was frequently unsuccessful and led to further distress.
- Siloed services made the process of information gathering difficult for some people.
- Respondents researched information by themselves, or learned about assessment from family and friends who had been through the process.
- Some people reported being signposted to different 3rd sector resources to gather the necessary information.
- Some people received the information from different professionals (health visitor, private counsellors, private psychologists).

However,

- Some people reported having been well-informed throughout the process. This was repeatedly attributed to a specific third sector assessment service that kept respondents updated meticulously after a referral was assigned to them.
- In some cases, GPs and CAMHS explained the process thoroughly after referral was made.

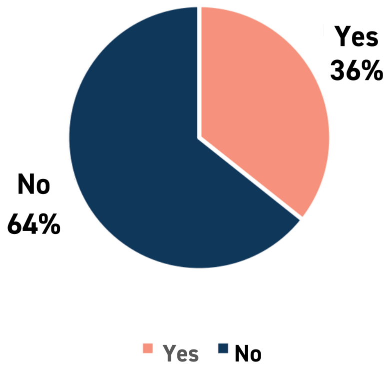
Information about Support Services Available

Given the long wait for diagnosis, those referred might reasonably expect to be signposted to support that they might receive while awaiting assessment.

However, a majority of **64%** (248 people) reported that they did not, compared with **36%** (137 people) who were made aware of the support available.

Filling this information gap during the waiting period would lead to a more informed process, reduce anxiety about what to expect, and provide individuals and families with the support they need to understand autism and the diagnostic journey more clearly and meaningfully.

During the process of referral and assessment, were you made aware of any support services that may have been helpful to you?



“My daughter was handed a poly pocket of photocopied papers with names and numbers of support groups. Told she was now nearing 18 so could not be helped. Half the support groups were out of date or no longer existed.”

We asked respondents what information about available support services they were made aware of, and they reported:

- Many received no information. Numerous respondents stated they were not given any information about support services.
- Some found out about resources only through personal research or family members.
- Information about support services often came only after diagnosis.
- Support services were geographically dependent.
- Online resources and leaflets were commonly given, but these were described as outdated, generic or inadequate by many.
- Support was often self-sought. Respondents claimed this strategy led them to community forums, social media sites or peer support groups.
- Some cited specific charities or 3rd sector organisations, such as One Stop Shops, as the main sources of support during this time.

Indicative comments

“Before and during the assessment nothing was offered, but after the diagnosis (which was 4 years later) I was initially told that no help was available. After repeatedly asking how that could be, I was eventually emailed a leaflet which contained live links to some organisations’ websites.”

“We get given loads of leaflets but no actual support. Information only. It's really not helpful ... The advice given is barely adequate and mainly tailored towards males. I could Google more relevant material. No actual help given.”

“I found out this information through non NHS services like my autistic friends and my university disability support services.”

“Was told after diagnoses, no support before that.”

“All info was out of date, phone numbers unusable.”

“Was completed [completely] left on our own to work things out & research support ourselves.”

“One stop shop gave me info on their services and other autistic organisations.”

“There aren’t any specific support groups in [my local area] so, it’s just the National ones.”

“Very little information was provided, as a parent working in the education system, I have had to use professional knowledge and other connections to try and support my daughter.”

Seeking Private Diagnosis

21% of respondents (69 of 323 people) with a diagnosis had received their diagnosis from a private provider.

A summary of reasons for seeking a private diagnosis were given as follows:

- The long waiting times involved in waiting for NHS services led people to seek alternatives.
- There was no confidence in frontline NHS services to make a referral.
- Additional support was needed quickly, and a diagnosis required to access this.
- Respondents experienced 'gatekeeping' of diagnosis services from frontline health professionals (as described above).
- No adult assessment pathway was available in the local area.
- Poor practice.
- Those experiencing long wait times were experiencing exacerbated stress/mental health difficulties as a result.
- Young people were 'ageing out' of local CAMHS services and likely to experience longer waits in adult services.

"There were no free or publicly funded diagnostic services in my area."

"I worried that I wouldn't cope well with the waiting time."

The costs of private diagnosis was reported as ranging from £200 to £4500, with the average reported costs being £1540.

Of those who had obtained a private diagnosis, **39%** stated that this had caused them financial hardship.

Respondents described borrowing money to pay for private assessment, racking up credit card debt or loas; relying on relatives to pay; going without holidays, selling their car; and cutting back on other costs and necessities.

“The assessment cost more than my monthly salary is. I don't have a lot of savings.”

“My mother, a single parent, took out a loan to pay for the diagnoses.”

My parents couldn’t afford the full amount so we had to save up and take money out of the money saved for university.”

We asked those who had received a private diagnosis whether they had their diagnosis accepted by employers, public services and GPs.

86% (51 people) told us that the diagnosis had been accepted with **14%** (8 people) saying that it had not.

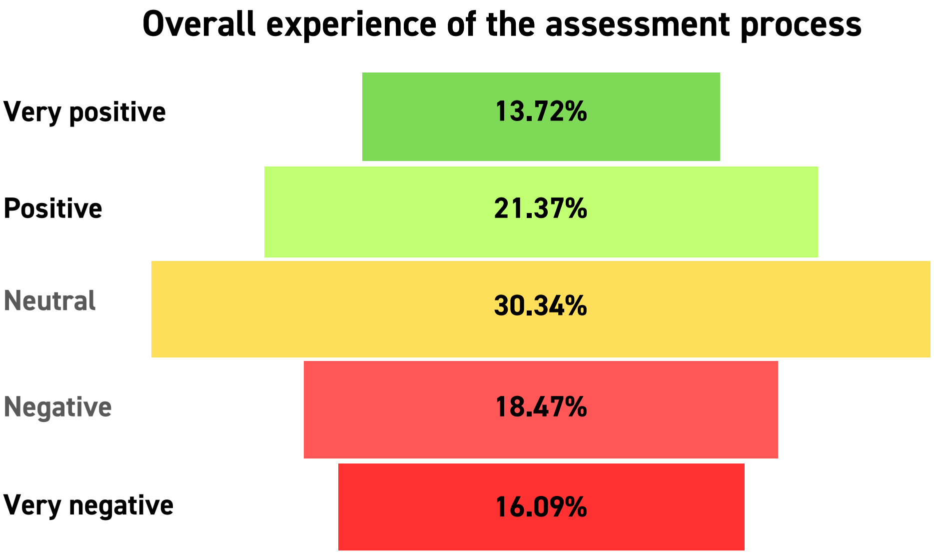
Though the number facing problems with having their private diagnosis accepted were a minority, the barriers that they faced were significant when this occurred:

“ School refused to look at the file I sent via email of the diagnoses and recommendations put in place for education.”

“[I am] constantly asked for proof.”

Experiences Of The Assessment And Diagnosis Process

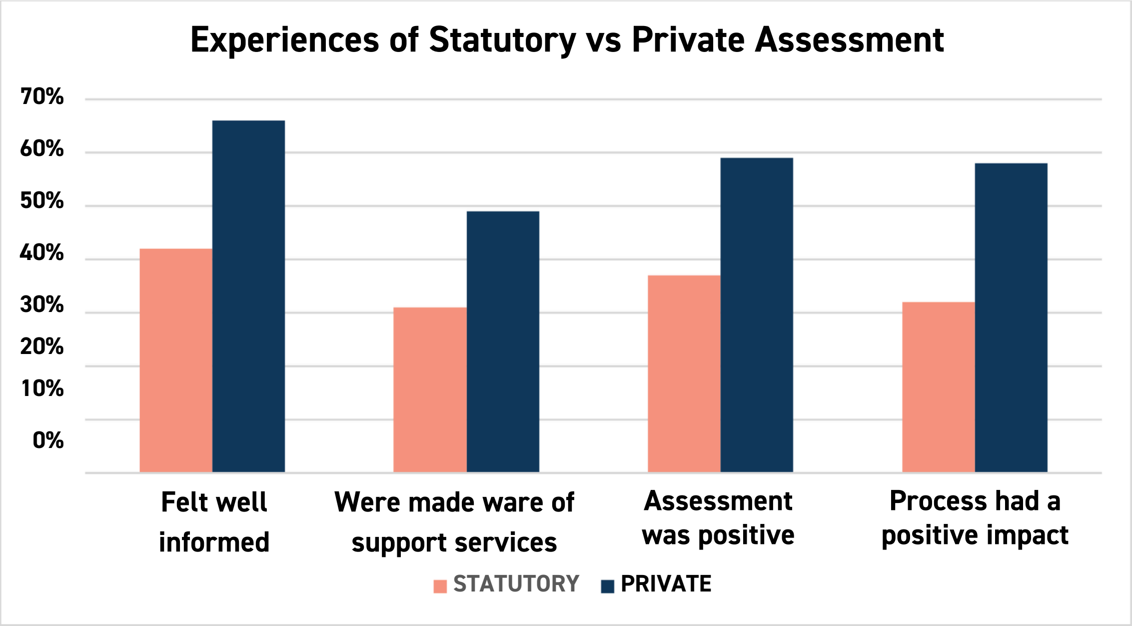
Overall experiences of the assessment process across sectors was highly mixed with **34%** reporting a net positive process and **24.5%** a net negative process.



Experiences of Statutory vs Private Pathways

We looked more closely at the data to compare the experiences of people who went through private assessments with those who stayed in the public system. The graph below shows how these two groups responded at key stages of the diagnostic journey.

First, we looked at the period of time between referral and assessment, including how well people felt informed during that stage. Then, we looked at how they experienced the assessment itself and what happened afterwards.



The results in the table show a clear trend: individuals and families who went through a private autism diagnosis generally had a better experience than those who used the public, statutory route. This trend is consistent across the different stages of the diagnostic process.

For example, when we asked participants how informed they felt between the referral and the assessment, those who went private said they had a better understanding of the process (66% vs 42%) and were more aware of support services available to help them navigate it (49% vs 31%). The assessment itself was also rated more positively when it happened through a private provider (59% vs 37%). In contrast, negative ratings were twice as high in the public system (30% vs 14%).

When it came to the emotional impact of receiving a diagnosis, the results were less significant but still leaned in favour of a private diagnosis. Reports of negative effects were low in both groups, but even lower among those diagnosed privately (5% vs 9%).

Positive outcomes were more common in the private group (58% vs 32%), while a mix of both positive and negative feelings was more common among public pathway respondents (48% vs 33%).

These findings suggest that private diagnostic services tend to offer a smoother and more supportive experience, not just because the waiting times are considerably shorter, but because the communication and care along the way seem to be better accommodative of neurodivergent needs. In contrast, the public system often suffers from delays and a lack of clear, consistent communication, which seems to make the whole process more stressful and less supportive for individuals and families.

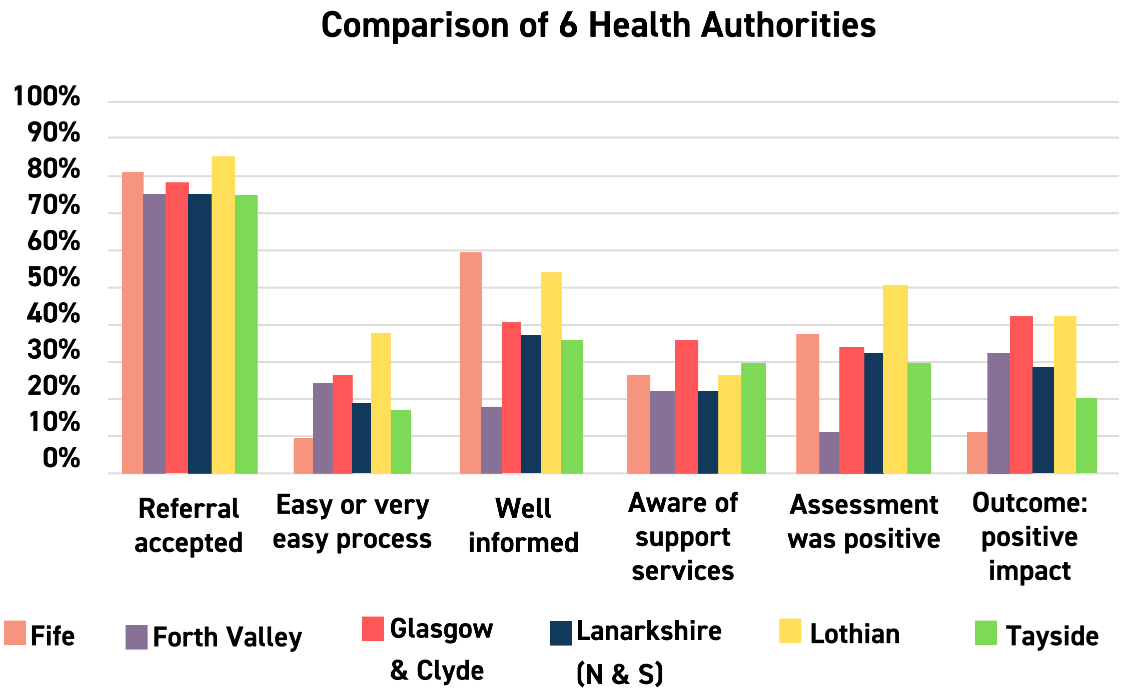
In summary, the data points to a noticeable gap in the quality of experience between private and public autism diagnosis pathways. This is not a suggestion that private diagnosis should be the norm. particularly given the financial costs outline above. Nor is it an argument for outsourcing services. Rather, It highlights the need to improve how public services manage and support people through the diagnostic journey in the overall experience and emotional support they provide. Moreover, while private diagnosis was rated more favourably than statutory services, the findings do not necessarily indicate that the private service is of exceptional quality. Rather, they suggest it performs comparatively better, though still leaves room for improvement.

Comparison of Experiences in Different Health Authority Areas

We did not have a large enough data set to meaningfully compare experiences in all health authority areas. We thought it useful to compare the six authorities from which more than 15 respondents had received a diagnosis to see if any patterns were visible.
This necessarily excludes areas that had smaller populations and fewer respondents – but our aim was not to provide a comprehensive/definitive conclusion rather to see if variations were evident.

Those six areas were

1. Fife
2. Forth Valley
3. Glasgow & Clyde
4. Lanarkshire (N & S)
5. Lothian
6. Tayside



Overall, the results show a degree of variability across the six health authorities, with different areas performing better at different elements of the process. Among the six local authority areas, Lothian stands out as ranking highest/joint highest in five of six domains. A closer look at the data found a specific service named consistently in positive reports of the assessment experience.

The assessment service operated by the third sector organisation Autism Initiatives at its 'Number Six' base in Edinburgh, was rated consistently positive in both the quantitative and qualitative data. Directly funded as a pilot by the Scottish Government, Number 6 provides a dedicated Autism Diagnosis Service established in 2019, and a Late Diagnosis Group Programme that is co-designed by participants and led by autistic staff. Local health services were able to refer into the service. It is particularly notable that the service is provided in an existing autism-specific service environment rather than in a busy clinical setting. The diagnostic service was developed in direct response to extensive waiting lists and the resulting strain on mental health services. It appears to offer a clear and accessible pathway for referral to diagnosis and robust post-diagnostic support. Respondents commended its responsiveness, structure, and the quality of care delivered.

“The number 6 staff outlined everything very clearly and answered any questions I had. The therapist who referred me handled most of the referral process beyond the questionnaires I had to fill but she gave me as much information as she could.”

“It was a bit vague till I was referred to Number 6, then all was explained.”

“Number 6 the place that I was diagnosed at has many additional support services, like social groups and one to one talks. I was made to feel as though I wouldn’t be alone after getting my diagnosis.”

“Everything I have been offered was by number 6 autism initiatives, I am currently doing a 8 week post diagnosis course and have been offered ongoing support and activities through this service.”

What Made for a Positive Experience of Assessment and Diagnosis?

While most respondents reported a degree of dissatisfaction with the diagnostic journey, we looked at those who reported having had a good experience to be able to pinpoint the characteristics of their experiences. This can be summarised as follows:

- Clear information available about the process in advance.
- A good flow of information throughout the process.
- Respectful, non-judgemental, kind, and understanding dialogue from diagnostic teams.
- Members of the diagnostic team with lived experience.
- A specialist, neuro-affirmative environment.
- Clear signposting to support services.
- Neuro-affirming post-diagnostic support, that helped people address their needs and understand the meaning of their diagnosis and identity.

“I received an email outlining the step by step process, which was helpful.”

“Very clear idea given about process and timescale.”

“We were kept fully informed and reassured about the assessment process.”

“Staff ... made me feel relaxed and talked me through everything, nothing felt rushed or a hassle so i felt at ease and could talk freely.”

“I was treated with kindness, decency, and respect. I understood what was going on at all times.”

“The people there are lovely and so welcoming and easy to talk to and very helpful and made the process so easy for us.”

“I actually enjoyed the assessment I undertook. It was finally an opportunity to speak with people who were not challenging me and the way I felt and understood the world. It was breathtakingly refreshing.”

“Neuroaffirmative diagnostic process and many of the diagnostic team are also ND.”

“The whole process was supportive, autistic-positive, caring, and involved me. It didn't feel so much like an assessment as a conversation that encouraged me to think about my autism. It was rigorously based on assessment criteria, but a partnership process, during which I was kept informed of where we were at every stage. I was very impressed with them.”

Intersecting Identities And Barriers To Assessment

The survey data gathered illustrated some of the common barriers that autistic and other neurodivergent people face in accessing healthcare more widely. Given the public sector equality duty that requires equitable access to public services, and the barriers reported for other marginalised and minority groups, we wanted to find out if respondents felt that their experience of diagnosis was affected by any intersecting characteristics protected under the equalities act.

Age and gender were the most frequently cited examples in which intersecting characteristics affected experience of diagnosis:

- Gaining a diagnosis in adulthood, and particularly advanced adulthood, was reported as difficult in several instances. This included professionals questioning why someone would want or need diagnosis at the that stage in their life.
- Many respondents identifying as female, or Assigned Female at Birth, felt that they were not taken seriously; that they experienced a bias towards traditionally 'male presentations' of autism; or reported being assigned a different diagnosis, such as personality disorder, due to what they felt was a lack of understanding of masking, or diverse manifestations of autism.
- Some respondents identifying as transgender felt that they were not taken seriously by the health system more generally, including being misgendered by professionals. In some instances respondents felt that they were dismissed as 'confused' or, in other instances, their gender identity or sexuality was pathologized within the diagnostic process.
- More positively, some identifying as female felt affirmed by specific and explicit attention to traits such as masking, or more 'female oriented' diagnostic questions from professionals in instances where this had been incorporated into assessment processes.
- Some respondents who identified as LGBTQ+ felt that diagnosis, and more affirming diagnostic processes where available, gave them access to a community where they were accepted and found others with shared experience.

“Common assumption is that it would have been picked up in childhood but back then, it wasn’t routinely looked for. I was just labelled as ‘weird, odd and not normal.’”

"...I believe that as a woman, I would have been assessed younger in life and had more support if I was male."

“Felt like my assessor thought my difficulty with relationships was down to my bisexuality. The fact I was perceived as a girl also impacted the assessors opinion of me.”

No respondents cited ethnicity as a barrier they experienced, yet it is notable that our respondents overwhelmingly identified as white (97%). It might be hypothesised that the networks through which research was disseminated may reflect this demographic, and that take up of public services may be similarly skewed, rather than to conclude that ethnicity presents no barrier to support, or that minority ethnic groups are fully engaged with public services. Rather, the sample may reflect a wider disengagement from services and existing networks due to the barriers faced by minority communities. Although SEMA was a partner in this research, the organisation was relatively new when the survey was launched and its networks less established than they are today, which may have yielded a more diverse sample.

Experiences Of Both Autism And ADHD Diagnosis

Given the increasing understanding that people frequently fit both Autism and ADHD profiles, we asked respondents if they had, or were awaiting further diagnostic assessments

- 52 people identified as autistic and ADHD.
- 40 respondents told us that they are autistic and waiting for an ADHD assessment.
- 13 respondents identified as having a diagnosis of ADHD and waiting for an autism assessment.

Given the experience of autism diagnosis given here – with the attendant lack of information, prolonged waiting, and stressful experiences - awaiting multiple diagnoses will exacerbate these stresses and concerns, as one respondent noted:

> *"There should be a joint pathway for assessing neurodevelopmental conditions. I've been assessed separately for ADHD, dyspraxia, autism, and had to seek private on two occasions before then having NHS accept it. This has been exhausting and traumatic going over and over my challenges time and time again. It is also a waste of NHS money. There is clearly a need for better knowledge and understanding of how conditions intertwine and then may present."*

The Scottish Government has recently piloted combined neurodevelopmental diagnostic pathways that require only one assessment for various profiles – including autism and ADHD. The intersection of these profiles, and the number of people in our sample awaiting a second diagnosis suggest that this work should be expedited and rolled out consistently across Scotland.

Post-Diagnostic Support

Exploring the respondents' experiences with post-diagnostic support, we can state that these were generally poor. Overall, the data suggests that upon receipt of an autism diagnosis, individuals and families feel forgotten by the health system and that navigating this key milestone engenders further uncertainty and stress. We asked respondents what post-diagnostic support had been provided and by who, and they reported:

- In most cases, individuals are signposted to resources from the 3rd sector, in some cases to autistic-led organizations and also educational resources.
- The signposting is mostly provided by diagnostic services through some reported signposting from their GP, school, or CAMHS.
- Information often consists of leaflets or links to websites.
- Post-diagnostic support from statutory services is very rarely reported.
- In some cases, individuals had to continue their own search for support as some had been signposted to resources or services that are no longer available.
- In many other cases, the information did not reflect gender or age inclusivity, nor did it accommodate a wider range of neurodivergence.
- Individuals outside of Scotland's central belt in particular reported a lack of support services available.

"There needs to be major changes throughout, the healthcare system, education system and beyond in terms of Neurodevelopmental Differences. There is next to no post-diagnostic supports for Autistic individuals like myself, even diagnosis of a child there is very little options of supports or information offered."

"The diagnosis is only that a diagnosis. We have been offered zero support for us as a family or more importantly our son. No regard to how to navigate the minefield of services and organisations out there that could help our son in his journey."

“What happens to me now in terms of accessing any support or help?”

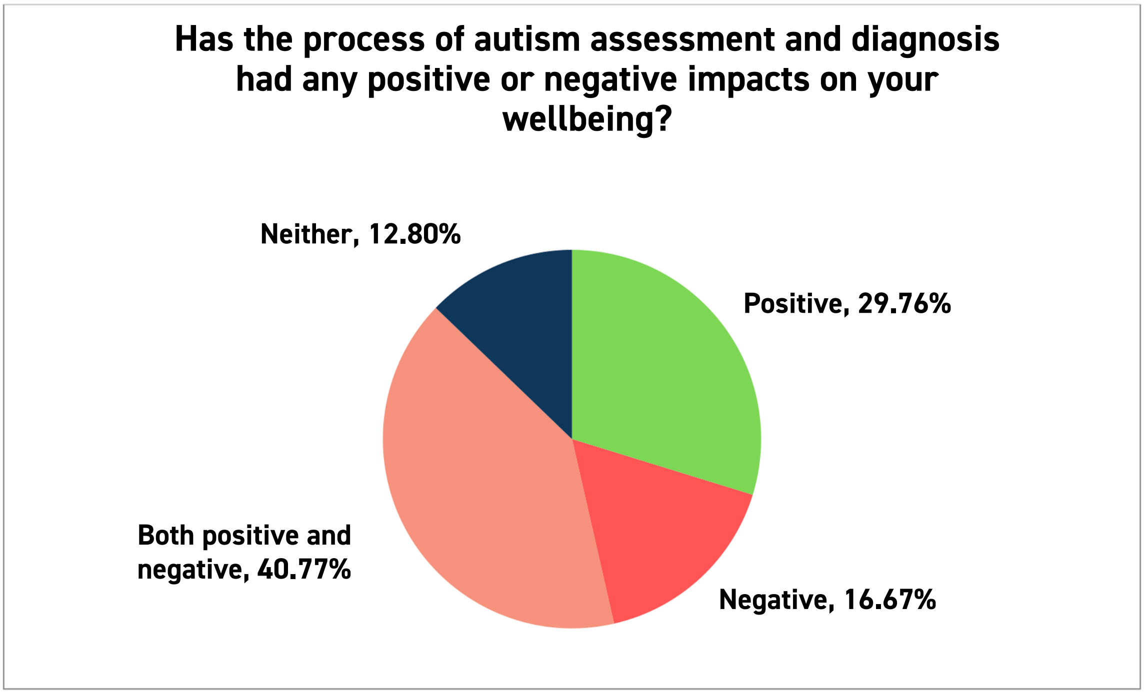
“Following my diagnosis I was signed off! I went from three years of intervention to nothing. They said, 'now you are diagnosed, you'll manage from here'. I have had no follow up. I still have unresolved trauma that's just been written off and causes me issues with flashbacks etc. Also, it's common for people with ASD to have ADHD so this should have tested. I am further forward but I also feel I've just been discarded following the diagnosis.”

“Very traumatic to reflect on your whole pre diagnosed life without support to help adjust. Absence of aftercare is a real factor that I think contributes to mental health issues and high suicide rates in autistic young adults. Really vulnerable time in a young persons life.”

“Lack of post diagnosis support and transition from CAMHS to adult support needs looking into. Just feels like we have been left to figure everything out for ourselves.”

The Impact Of Diagnosis On Personal Wellbeing

We asked respondents of the impact of their diagnosis on their wellbeing.



While **30%** reported a net positive comparted to **17%** reporting a negative impact, **41%** reported a mixture of positive and negative impacts.

Respondents were given the opportunity to explain their responses. Positive Impacts were identified as follows:

- Respondents felt validation of their identity and experiences after diagnosis (particularly when they had previously felt disbelieved).
- People received ‘answers’ and an explanation of a their own history, experience, and why they had felt ‘different’ or struggled.
- Receipt of appropriate support (sometimes following inappropriate support previously) made a big difference to some peoples lives.

"Finally having a formal diagnosis has validated what I already knew for a while... I am now able to give myself some grace."

"For the first time I understood who I was and why, I've been so happy since my diagnosis it's allowed me to understand my needs."

"The diagnosis has been helpful for getting support at university ... I now have an 'autism-informed' study skills tutor and therapist."

Words such as feeling 'liberated', and 'relief' were common in positive responses, as was 'validation'.

"It has allowed me to understand myself better, to support and advocate for myself, I am in employment for the first sustained period ever and I am more comfortable with myself than I have ever been before."

"It enabled me to understand why I find things hard and struggle with certain things. I'm a happier person now. The diagnosis also helped me get more appropriate support set up."

"There's a lot to process, but I feel I understand myself better and can start to think about how to support myself more effectively."

"Having the diagnosis has turned my daughters life around. She was very mentally unwell. She is now a different child, happy, confident and receives the support she needs at school."

"Overall, I feel a lot more assured about myself knowing that I'm autistic, and understanding my behaviour and what I've been struggling with all these years. It was very validating, and while there's still difficulties, it's helped immensely knowing why that is and what steps I can take."

Negative Impacts were also recounted:

- A loss of perceived certainties or previous identity was highly disorienting for some respondents.
- Respondents sometimes felt confused, or ashamed about new their status and identity – apparently linked to stigma in some instances.
- No follow-up support to diagnosis in some cases left people feeling 'cut loose', continuing to face difficulties and, in some instances, suicidal.
- Trauma and stress relating to the process of assessment outweighed the benefits to diagnosis for some, including exhaustion at the long waiting times.
- Others felt that the diagnosis made them perceived as a bigger risk and compromised their agency.

"The information gathering brought up a lot of trauma and now I am really struggling with these topics and memories, and feel very burned out and depressed."

"Daughter wants to be normal ... severe anxiety has led to school avoidance."

"I was diagnosed and then just left to deal with it, had no support, no information or no direction given."

"It's just a useless bit of paper that can be used to restrict, make insurance more expensive or impossible to maintain, and used to deny self-advocacy when needed."

In these negative answers respondents expressed anger, loss, frustration and potentially severe impacts on mental health of a diagnostic process undertaken without proper support and guidance.

In combination, these responses show the value of diagnosis and appropriate support where they are received. However, they also underline the harm that a poor experience can have and the need for holistic pathways that include post diagnostic support, access to community and spaces were identity can be validated and affirmed, and the need for wider societal change and understanding in place of stigma and exclusion.

Discussion And Conclusions

The survey results presented In this report depict a system of autism assessment and diagnosis in Scotland that is highly variable across localities and sectors, and too often serves autistic people and their families poorly. The survey aimed to look beyond the headline figures of long waiting times in order to understand in a more holistic way the experiences of diagnostic pathways at every stage - from referral through assessment to post-diagnostic support. At every point in this process, we heard from respondents who had been let down by statutory services in one way or another.

The data relating to referral reinforces earlier research that points to a gap in the understanding of autism among frontline health professionals. Failure to recognise diverse manifestations of autism, particularly in relation to gender, can leads to the rejection of individuals who do not fit stereotypical profiles. This has, in some cases, resulted in misdiagnoses and unmet needs, often creating poorer mental health outcomes.

The long and uncertain wait between the initial referral and the assessment is a source of great anxiety and stress. Respondents described feeling in limbo, sometimes for years, with no updates or guidance on what to expect. Those who went through the private pathway generally received more consistent information and support, although the overall standards were still uneven. The relative advantages of private assessments, mostly noticeable during this waiting phase between referral and assessment, should not be seen as ideal models, but rather as indicators of the urgent necessity for improvement within the statutory healthcare system. The reports of people entering financial hardship in order to access private assessment underline this need.

A great deal of difference was noted between those who felt supported, well informed and experienced respectful and transparent communication throughout the process and the large numbers who did not. It was notable diagnostic services in which neurodivergent professionals were involved were rated particularly highly.

These experiences suggest that when assessment services are shaped by autistic people, these become more inclusive, person-centred, and affirmative.

Better post-diagnostic support is critical. Respondents report receipt of a diagnosis as a deeply emotional and life-changing moment, but the support that follows has been reported as minimal and inconsistent. In some cases, individuals were given nothing more than a leaflet or some website links. When post-diagnostic support is lacking, the entire process can feel incomplete and even damaging. Participants described feelings of anger, isolation and confusion. On the other hand, when support was available and tailored to individual needs, the outcome was more positive. The research suggests that access to relevant and appropriate post-diagnostic support can make a huge difference, helping individuals to make sense of the outcome of the diagnosis, navigate their identity positively, and access a network of support.
However, such services are mostly provided by third sector and autistic organisations, and coverage across Scotland is highly variable, making this support difficult to sustain without greater, sustained investment.

Limitations and the Need for Better Data

There are limitations to the data presented here: The sample was large enough to show clear patterns and trends in the experiences recounted, but we do not have access to 'whole system' data that would allow a detailed comparison of different Health and Social Care Partnerships' provision, or provide a definitive figure as to how long people are waiting.

Additionally, the data presented here includes the experiences of adults diagnosed at different times – so a more fine-grained analysis may show changes in the salience of certain issues over time (e.g. gatekeeper attitudes towards gender and presentations of autism). However, our aim here has been to show the experiences – in many cases, deeply problematic experiences – of assessment that the contemporary autistic population carry with them. The themes are common enough that we are confident they describe issues that still need to be addressed.

We note that our sample was not ethnically diverse, with minority groups under-represented among respondents. The growth of Scottish Ethnic Minority Autistics over the two years since the survey was administered may have brought us a more diverse sample if repeated today, but the response rate does suggest a need for organisations and services alike to broaden their reach.

The experiences we present here suggest the value of better, systemic data collection on these issues by those that have access to that data. Indeed, mandating of better data reporting is something that we feel is an essential part of the proposed Learning Disability, Autism and Neurodiversity Bill in Scotland.

The Current Landscape

Although the survey was undertaken in May 2023, the experience of the organisations involved does not suggest that the situation has improved. Indeed, our day-to-day work supporting autistic people and their families indicates a situation that has become markedly worse, with increasingly anxious and concerned people contacting us. In early 2025 news emerged of two Health and Social Care Partnerships suspending adult diagnosis for autism and ADHD (with one gaining a six-month reprieve). We have also heard of one NHS CAMHS service closing its waiting list for young peoples' assessment.

When the Scottish Government undertook a wide-ranging consultation for a Learning Disability, Autism and Neurodivergence Bill in 2024, diagnostic pathways were not included in the subjects considered. Rather, the autism community was told that policy changes and service reform would be forthcoming ahead of the presentation of a Bill. Our organisations have welcomed the work undertaken by the National Autism Implementation Team to design and pilot combined neurodevelopmental assessment pathways. Such pathways stand to open up different routes to diagnosis and to save the stress of multiple assessments for Autism and ADHD. However without significant adoption and roll-out across Scotland, the situation will remain challenging.

Autistic-led organisations and specialist third sector organisations have, in many instances, recognised the delays to assessment and accept self-identification of people as autistic as grounds for service provision. Our organisations also provide support and resources for people awaiting assessment, rather than focus solely on 'post-diagnostic support', which was the norm until recently. However, we have recently seen the example of a Health and Social Care Partnership responding to this change by delaying entry onto diagnosis pathways ***until*** third sector support has already been accessed. Where the survey data recounts many people being directed to third sector provision or Autistic People's Organisations in lieu of statutory post-diagnostic support, we now see those organisations being seen as a first port-of-call in instances where diagnosis is hard to come by. However the importance of a diagnosis as a means to self-understanding and advocacy underlines the fact that more proactive support in the community should not be a reason to reduce assessment services.

Conclusions and Recommendations

It is clear that statutory autism assessment and diagnosis in Scotland requires urgent and systemic change in order to adequately serve autistic people and their families. This report points to the value of greater training of health professionals to recognise the diversity of the autistic population; investment in reducing waiting times; clearer information about the assessment process; regular, respectful communication during the process; signposting of available support throughout; and a clear pathway to support after diagnosis. It is clear that the incorporation of neurodivergent people into the design and delivery of services can be highly beneficial. By putting autistic people at the centre of this process, Scotland can move towards a public diagnostic pathway that truly serves its neurodivergent population with respect, transparency and care.

It is our recommendation that the above measures and practices are incorporated into a guaranteed national neurodevelopmental assessment pathway. This pathway should include timely assessment; clear information and regular communication throughout; and access to quality support and advice during and after assessment.

Information and contact details for our organisations can be found on our websites as follows:

AUTISM RIGHTS GROUP HIGHLAND

www.arghighland.co.uk

AUTISTIC MUTUAL AID SOCIETY EDINBURGH

www.amase.org.uk

SCOTTISH ETHNIC MINORITY AUTISTICS

www.sema.scot

SCOTTISH AUTISM

www.scottishautism.org

For enquiries about this report please contact:
Mark McDonald
Media and Policy Officer, Scottish Autism
Tel: 07517911420
Email: mark.mcdonald@scottishautism.org