

National Autism Post-Diagnostic Support Service

Evaluation of pilot programme 1st Dec 2020 - 1st June 2021

Executive summary and consolidated report

February 2022



Scottish Government
Riaghaltas na h-Alba
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National Autism Post-Diagnostic Support Service - Evaluation of pilot conducted 1st Dec 2020-1st June 2021 Executive Summary

Introduction and summary of the aims of the pilot project.

Despite the wider awareness of autism among professionals and the public, the process of obtaining an autism diagnosis is reported as protracted, fragmented, and challenging. The immediate post-diagnostic period remains uncertain and difficult, even though individuals and families report that receiving an autism diagnosis is helpful.

Several voluntary agencies across Scotland, led by Scottish Autism, came together as part of a government-initiated pilot to respond to the post-diagnostic needs of families of autistic children, and the needs of adults. Some are led and managed by autistic people. Responses indicate the varied services and activities of these agencies are highly valued by those who use them, and they undoubtedly provide essential support to their communities and to government.

This executive report summarises an evaluation of a pilot programme between 1st December 2020 and 1st June 2021 of the post-diagnostic support services delivered via the following seven agencies.

1. AMASE (Autistic Mutual Aid Society Edinburgh) <https://amase.org.uk>
2. ARGH (Autism Rights Group Highland) www.arghighland.co.uk
3. AI (Autism Initiatives) <https://www.autisminitiatives.org>
4. The National Autistic Society <https://www.autism.org.uk/what-we-do/scotland>
5. Scottish Autism (Get Set 4 Autism) <https://www.scottishautism.org>
6. Scottish Women's Autism Network (SWAN) <https://swanscotland.org>
7. Triple A's One Stop Shop Aberdeen (TA-OSS) <https://webpace.oss-aberdeen.co.uk>

Short summary of the evaluation methodology and process

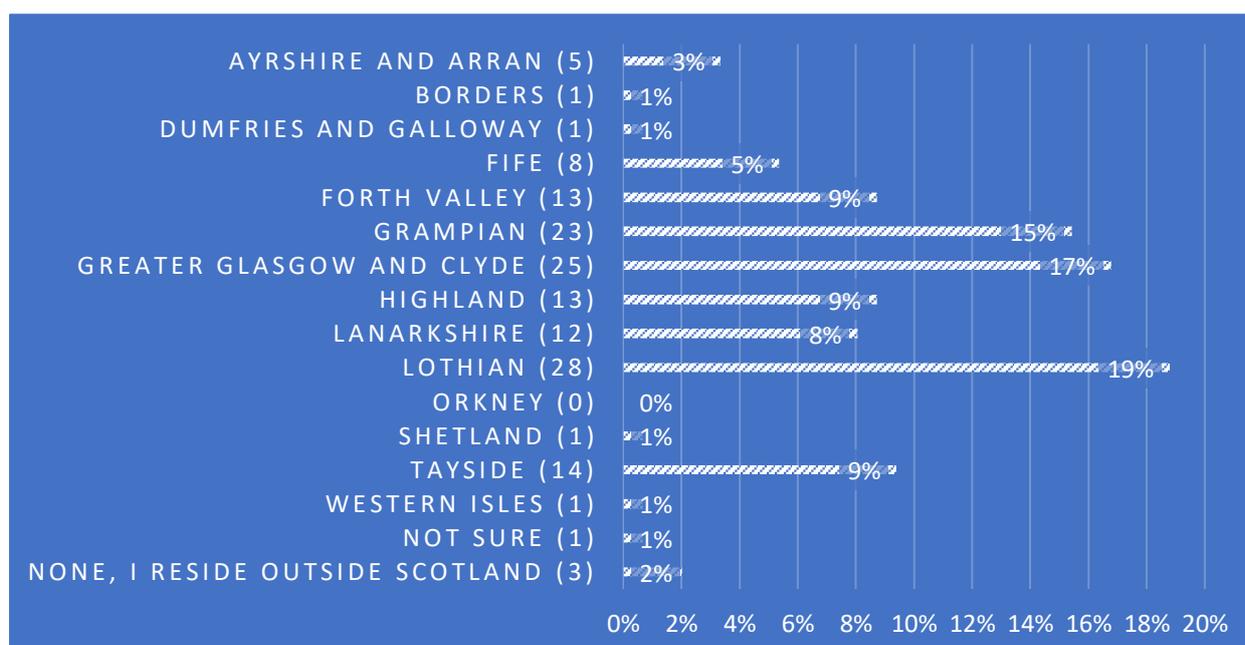
AT-Autism was commissioned by the Scottish Government to provide an independent evaluation of the effect of NPDS programmes delivered as part of a pilot programme.

The format and processes involved in the evaluation were developed and approved by the Scottish Government and all participant agencies. As part of this, agencies defined their operation and aims and outcomes (PICO). Registrations for all programmes were recorded. For those people who completed the NPDS pilot programme a confidential link would be sent to the evaluation.

Data were obtained via a confidential survey of participants, developed through a Delphi process, with all service organisations acting as the expert panel. The link was sent out by participant organisations to people who had used their services, with the predominant focus on those who had received an autism diagnosis within the past three years.

The survey ran from February 2021 and received 149 responses. All Health Regions are represented except for Orkney (see Fig 1.). The responses comprised quantitative and qualitative data and detailed commentary. The response rate varied between 86% and 20% with an average of 35% across agencies, a confidence level of 95% and a margin of error of 7%.

Fig. 1: Location of respondents



Profile of respondents

- 66% autistic people post 16
- 34% families in respect of a child
- 73% post 16 received diagnosis within past 3 years (M 31%: F 67%: Not declared 3%)
- 88% families received a diagnosis for their child within past 3 years

Fig. 2. Age at diagnosis (post 16)

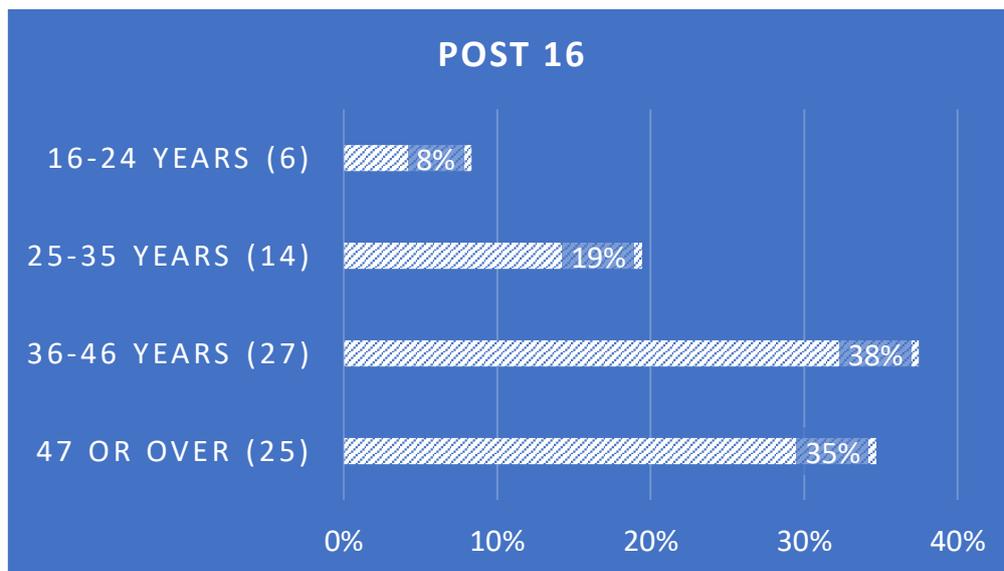
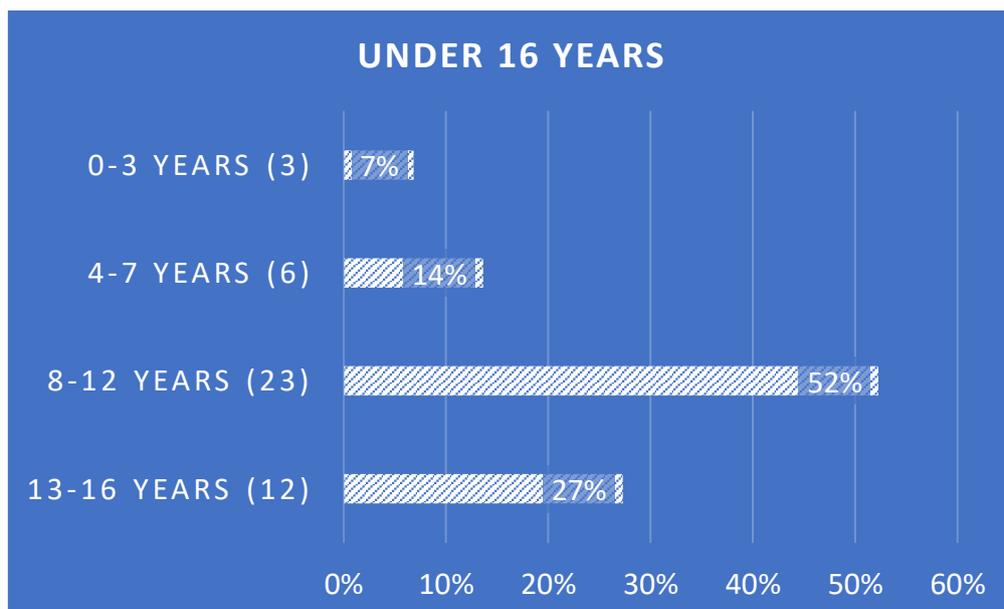


Fig. 3. Age at diagnosis (under 16)



Summary of key findings

- Family and adult respondents consistently reported a protracted struggle to obtain recognition and responses. 'A battle' was the term commonly used by families and by autistic adults to describe the often lengthy and stressful process of getting a diagnosis. Many reported that lengthy delay or concerns about the quality of the process forced them to seek a private diagnosis.
- Significantly, most of those diagnosed as adults were female (67%)
- Frequently, respondents reported they received little practical or emotional help during the process. This confirms the need for pre- as well as post-diagnostic support. But we also had reports where the process was well handled, and these examples can be built upon.
- Several respondents expressed concern about outdated knowledge of many professionals on the nature of autism, particularly in women and girls, and what they experienced as inconsistent, stigmatising, inaccessible, and fragmented diagnostic pathways. They often felt such 'othering' added to their difficulties.
- Respondents reported a lack of support, information or contacts and follow-up immediately after their diagnosis. Many felt 'abandoned' or left in limbo.
- Respondents reported that despite the difficulties, a diagnosis had been helpful to them, on several levels, including navigating future directions, connections, health and wellbeing, identity, education, and work, and in dealing with professionals.
- For many, a diagnosis was self-affirming as they had felt they had self-identified as autistic before seeking a diagnosis. For families, three quarters felt their child was autistic prior to embarking on the diagnostic journey.
- Respondents reported a much more positive experience on the post-diagnostic phase, with most having their expectations fully met, or exceeded, and that the information provided to them was clear and accessible. Most reported that they were listened to. Importantly, a majority reported their goals for what the programme would achieve were fully met or exceeded.
- A significant number felt that their self-confidence and self-esteem had improved since participation in the programme and that they now knew where and how to get further help if they needed it.

- Respondents reported that their connections with other autistic people had increased, and that they had a better understanding of autism and how it impacted them. Others reported a reduction in social isolation and anxiety and developed an improved ability to cope with uncertainty.
- A smaller number of respondents reported reduced stress and improved quality of life and an improvement in general health. A larger number reported improved mental health.
- Almost all said they would recommend the programme that they attended to others.
- It was clear from the comments that the support from other autistic people was a significant plus for autistic respondents, in reducing their feelings of being an 'outsider'. They reported that they finally felt comfortable, understood, and 'a part of something' – in many instances for the first time.
- For families, support in the form of listening and active follow-up was highly valued.
- Gaps in local provision and information were highlighted by many respondents and distance and geographical location was cited as problematic, even though the programmes were delivered remotely.

Sample of quotes from respondents

'It would have been beneficial had there been an NHS autism pathway available for me to access as this would have hopefully offered continued support or referrals after diagnosis and reduced financial burden to myself. I am aware there is one now however this has left me concerned my private diagnosis will no longer be validated based on reports heard from others or private vs NHS which has been a huge source of worry to myself'

'Although I have received a diagnosis, I have felt somewhat abandoned since, with not much support, certainly not from the Health Board'

'Would have loved to have had this service at the time of diagnosis. Instead, we were given a page of links to useful websites'

'We received a same day assessment and diagnosis feedback. This was a fantastic process and we found not having to go away and come back another day. The team at the Vale of Leven Hospital were fantastic and very reassuring'

'We had no idea our daughter was autistic as she was always so sociable. We had been blamed for poor parenting'

'The diagnostic process has added to the damage inflicted. We were handed a piece of A4 with outdated information on it and shown the door – no explanation of what autism was'

'I have found the post-diagnostic service to be a lifeline. I feel much more confident, and brave and can live life on my own terms in this world'

The (post-diagnostic) support has been life changing. Don't feel alone anymore and really benefitted'

'Some of the professionals I met before the final diagnostic meetings had very outdated information about autism. Particularly about women and girls. There were a lot of stereotypes. I was asked repeatedly why I wanted to be diagnosed and as I am able to mask well in public, I found this really upsetting'

'The service was brilliant throughout. Has improved my understanding of myself and others and my mental health has improved since attending'

'They were so biased against women, and in the diagnosis, there were so many barriers and unpleasant people to navigate as well as a long waiting list so in the end I had to go for a private assessment'

'The programme was well run, in small groups. It was great meeting other adults diagnosed late in life such as myself. I had not met other autistic adults prior to this.'

'We ended up getting a private diagnosis due to struggles getting NHS support'

Summary of recommendations, way forward, and next steps

Recommendation 1 – Assess need. Strengthen and expand support network

The current network of agencies providing support are innovative, valued by those who use them, and fulfil an important role. Many are small and respond to the best of their ability with the skills and resources they have at their disposal. They 'play to their strengths', which although commendable, potentially leaves gaps. (e.g., racial/cultural minorities, remote or isolated geographical locations) They should be supported to strengthen their expertise and efficiency and working in partnership, expand their capacity and reach.

Recommendation 2 – Develop consistent integrated support, pre- and post-diagnosis

Review the approach to diagnosis at all stages of the diagnostic journey. This will include evaluating existing and novel systems of pre- and post-diagnostic support developed by these groups. In this, a sufficiently sophisticated 3 -tiered approach should be taken, reflecting the levels and complexity of need.

Recommendation 3 – Reaching out –connecting and establish a formal

Consider setting up a 'hub and spoke' system of pre- and post-diagnostic support. Led by Scottish Government but with the support of a key lead third sector agency. All participant organisations would contribute to a vision to support people of all ages, and at all stages. Connecting the statutory and third sectors.

Recommendation 4 – Simplify and streamline

Review and develop systems to simplify and streamline the diagnostic process and pathway; to reduce delay, clarify expectations, ensure consistency, effectiveness, and accessibility at all stages of the diagnostic journey. This to include a '*now that you have your autism diagnosis*' pack (10 points for those receiving a diagnosis).

Recommendation 5 – Ensure quality and accountability

Ensure participant organisations are supported to meet quality standards, and effective administration and evaluation. This should be built on lived experience and Participatory Action Research (PAR). This will help to ensure relevance, improve consistency, access, and public accountability, and inform official guidance.

Recommendation 6 – Update training resources

The training of professionals to be updated to include informed and current thinking around autism, neurodiversity, and neurodivergence, and on how to work effectively with autistic people and families. Ideally, this would be co-produced and co-delivered.

Way forward: Next steps

It is hoped these recommendations inform and facilitate discussion that will explore demand and responses as part of an action plan to be developed by Scottish Government, participant organisations, and other stakeholders.

Limitations

This evaluation covers a six-month period of the pilot during the pandemic. No in-person work was possible during this time. All groups operated remotely.

The overall Margin of Error (7%) should be considered, although data received showed a consistent pattern and the narrative content contained rich first-person accounts related to lived experience.

No data were obtained re specific minorities as it was reported that all agencies collected and monitored all such data. It is recommended that this be included in future studies of this sort.

Note. Participant organisations have each received a full and detailed report on their own organisation, and a redacted copy of the consolidated report.

Consolidated report

Introduction and overview

1. Preliminary discussions took place in September and October 2020. This project started in November 2020, in preparation for the first intake in December 2020. It was proposed that evaluation data would be generated and provided to AT-Autism throughout 2021. The project has generally proceeded in accordance with the planned outline. AT-Autism was asked to provide preliminary findings September 2021. This report is therefore earlier than planned.
2. Initial scoping meetings were held with Scottish Autism and Scottish Government to devise a formal structured evaluation of all NPDS programmes, which would demonstrate the degree of efficacy of the various programmes, collectively and individually, in the context of public accountability.
3. Several follow- on meetings involved the whole Service Provider (SP) group. to discuss the rationale and approach to evaluation and to clarify format and processes.
4. It was agreed that this evaluation would use a hypothesis-testing model that drew on Participatory Action Research (PAR) methods. This would reflect the NIHR PICO framework and would generate both quantitative and qualitative data.
5. Data would be obtained primarily from users of services, post intervention via a confidential and anonymous survey. The opportunity to withdraw from the programme or from the evaluation was agreed. All SP organisations agreed to provide information and data to ScotGov and to AT-Autism as required, and to emphasise to the user the importance and value of participation in the independent evaluation.
6. Several meetings of the whole group including all SP's were dedicated to designing, defining, refining and simplifying the processes to be used, which would require the minimum of effort to participant SP organisations. SP orgs were also advised not to undertake their own evaluation of the programme during this pilot as this would detract from, and could undermine, the independent evaluation.

7. A DELPHI process was used to develop and refine questions for the survey from the SP group, with ScotGov and Scottish Autism acting as core reference group. Questions were circulated to the SP group as part of ongoing consultation.
8. Based on this and the returns from group members relating to a summary description of their services and the PICO framework, questions were developed to be applicable to all services. The final questions for the evaluation were then agreed and signed off by the group, and in turn, by ScotGov.
9. These questions were turned into a platform using SNAP software, which is held by AT-Autism. In May 2021 one SP belatedly asked for changes to the survey platform. This request was denied as it would have reversed the agreed SP group and ScotGov position obtained via the DELPHI, but amendments to the introduction were accommodated. It would also have been disruptive at a technical level at this late stage.
10. It was agreed by the SP group to provide information to AT-Autism for all users registered post December 2020 and to keep records of attendance, goals, and completions.
11. It was initially agreed that contact emails for users to complete the evaluation would be provided to AT-Autism by all SP organisations once the user had completed the programme. At the request of the SP group this was amended, and all SP members would now send these details (including the link to the evaluation survey) to users. This to ensure all users are contacted and to maximise uptake. The survey would be confidential and anonymous.
12. SP members also agreed to maintain and safeguard a record of location and race, gender, and ethnicity. These would remain confidential to the service but disclosed to ScotGov as required or requested.
13. AT-Autism opened the survey in February 2021 and received 149 responses concerning all organisations. All health Regions are represented except Orkney. The responses comprised quantitative and qualitative data, and comments from respondents, many of which were extensive.
14. SP organisations were asked for
 - a. Number of users registered post 1 December 2020.
 - b. Number of users completed the programme by end of July 2021.
 - c. Number of evaluation links sent out.

Organisation	Total	Completed	Links sent	Responses
AI	139	73	62	33
ARGH	26	NK	16	5
AMASE	89	NK	36	13
NAS	144	121	120	24
SA	115	30	29	25
SWAN	224	224	NK	30
TA-OSS	229	20	72	19
Total				149

15. This report contains responses in respect of all organisations and are extensive in scope and range. The quality of responses from participants is high, with a wealth of lived experience captured within them. They are produced in full, without editing or redaction.
16. The responses support the perceived value of the range of post-diagnostic support services across Scotland in the eyes of the users of these services.
17. The data also suggest areas where individually and collectively, providers can address issues of importance to users or where performance is below the standard expected.
18. The true value of the report will be as a mechanism for reflection and action on the findings presented.
19. A composite report collates data from across all respondents plus additional reports for each of the service providers.
20. The full set of reports plus individual reports are the property of the Scottish Government.
21. It is proposed to make the composite report, plus their own report available to the individual service providers.

Preliminary conclusions

1. The responses to the survey indicate that for most respondents, the aims and outcomes set out by services providers are substantially achieved, and in many instances exceeded.
2. The services reviewed offer a valuable alternative and complementary addition to statutory services.
3. These limited data offer a valuable insight into how these services are experienced by users, and a steer on future direction. They also offer a baseline, a benchmark for comparison, and a mechanism for reflection and change.
4. I propose they also serve as a basis for discussion on future direction of these services. We are prepared to participate and assist in this.

Richard Mills
AT-Autism
26 August 2021

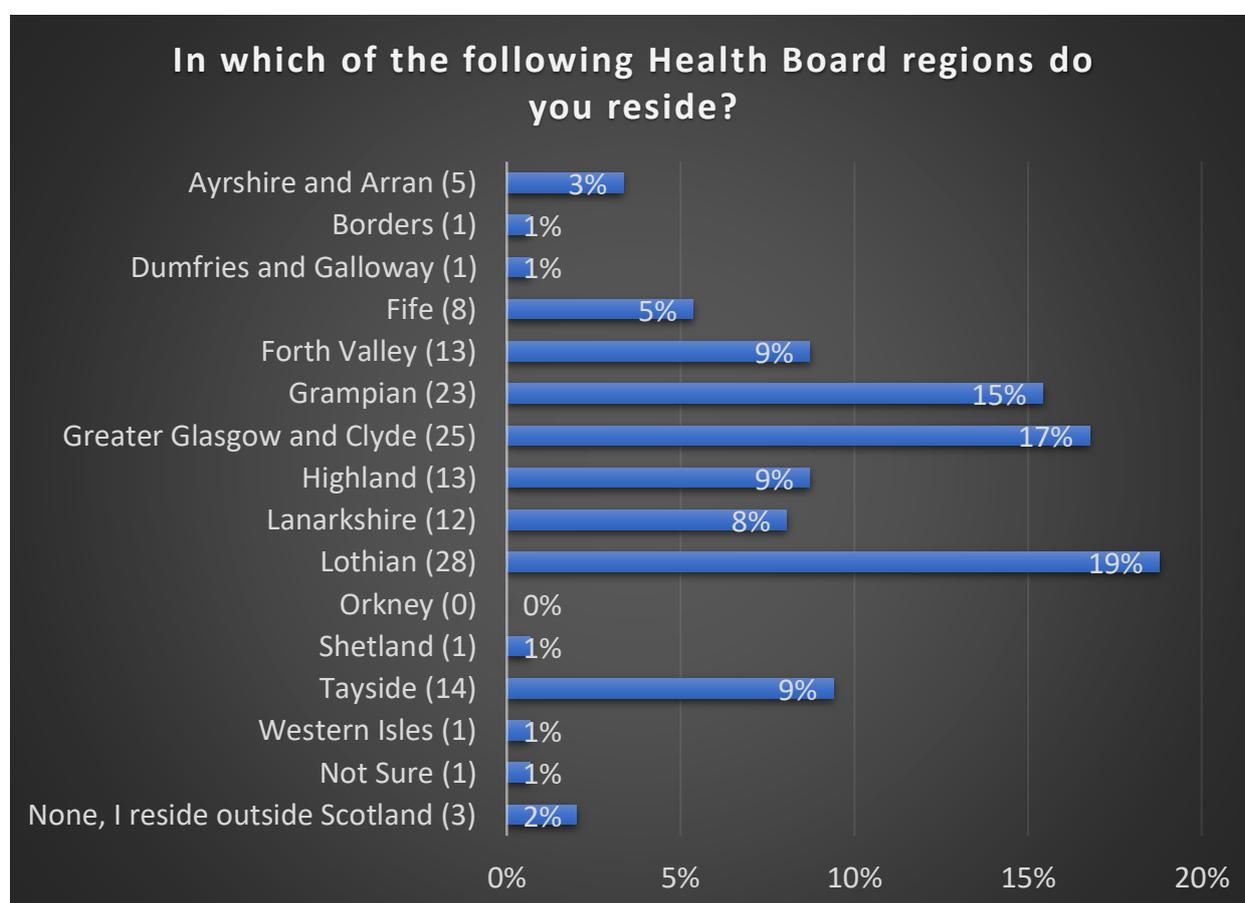
Confidential consolidated report of survey responses (redacted)

Respondents

The survey went 'live' on February 15th 2021 and remained open until July 14th 2021. There were 149 responses.

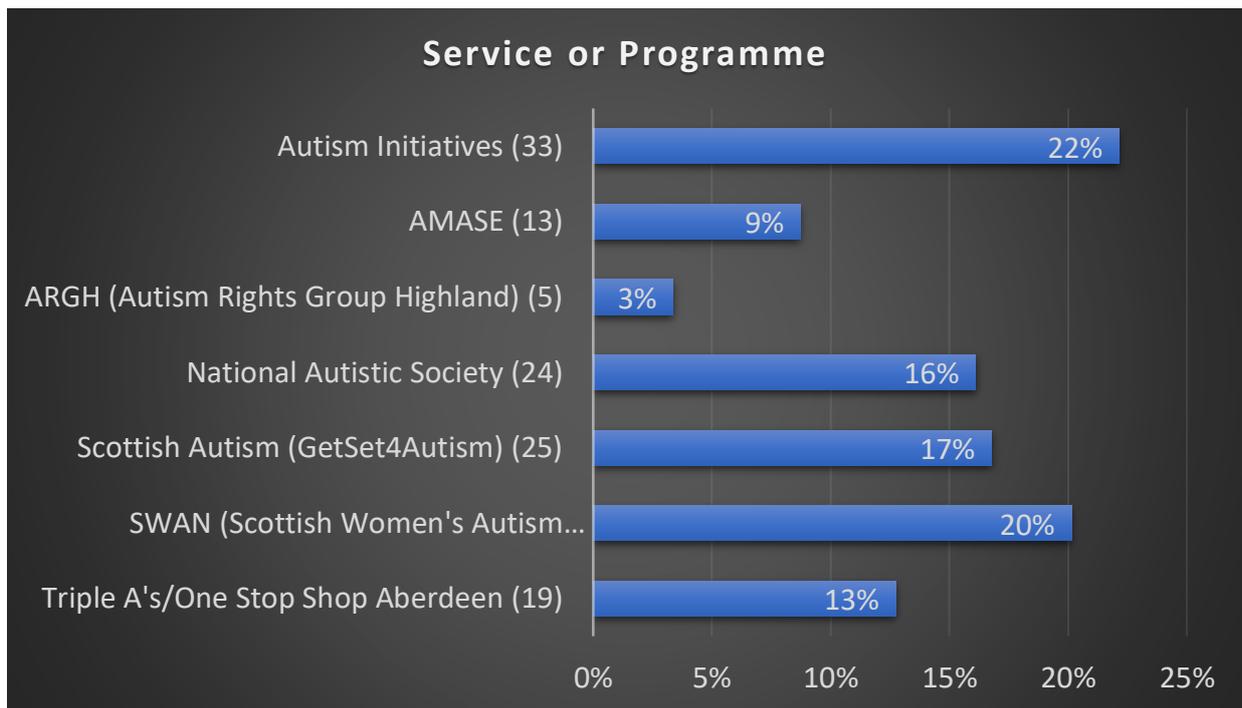
Respondents came from the Health Board regions across Scotland, with 3 respondents residing outside Scotland. Numbers (in brackets) and percentages of respondents by region are shown:

In which of the following Health Board regions do you reside?



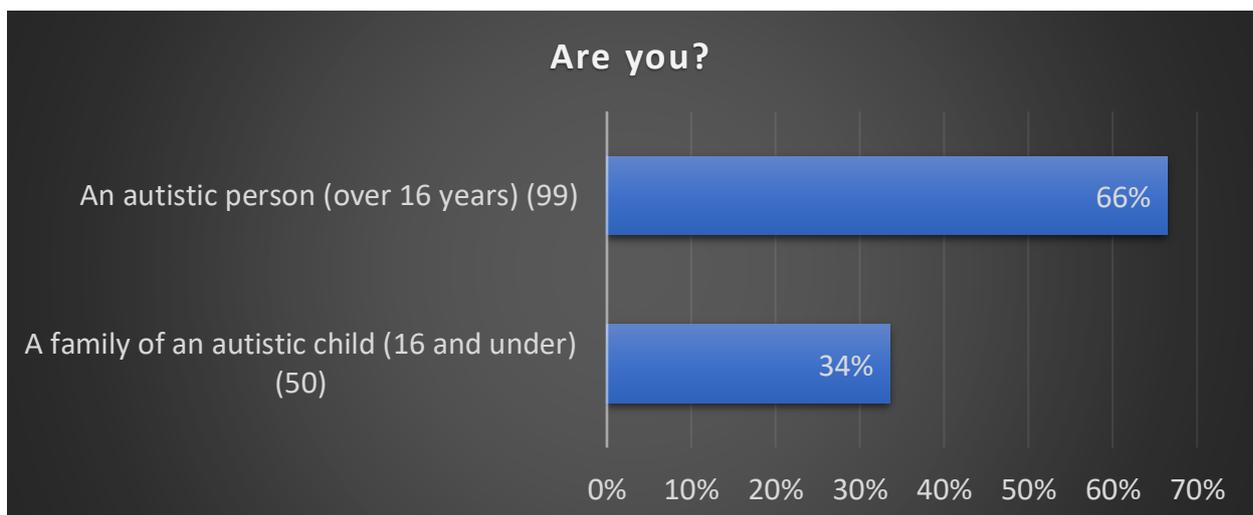
The service or programme accessed by respondents is shown in the table below. Where respondents accessed more than one service or programme they were asked to identify the primary service or programme they had most contact with, or had most help from only.

Service or Programme



The majority of respondents (99, 66%) are 'An autistic person (over 16 years old)', the remaining 50 (34%) are 'A family of an autistic child (16 and under)':

Are you?

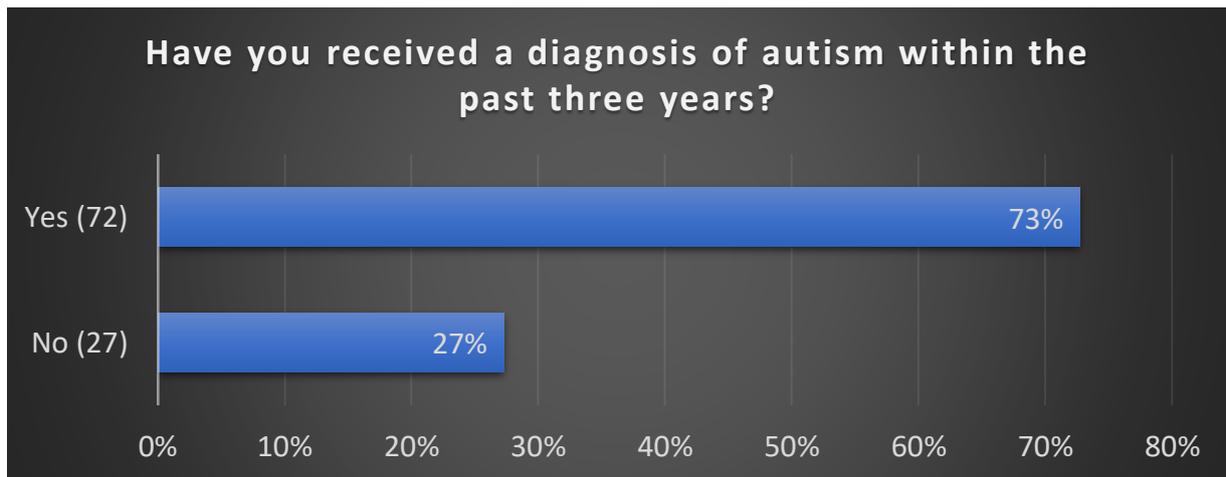


Respondent profile

For Individuals: Autistic person (over 16 years)

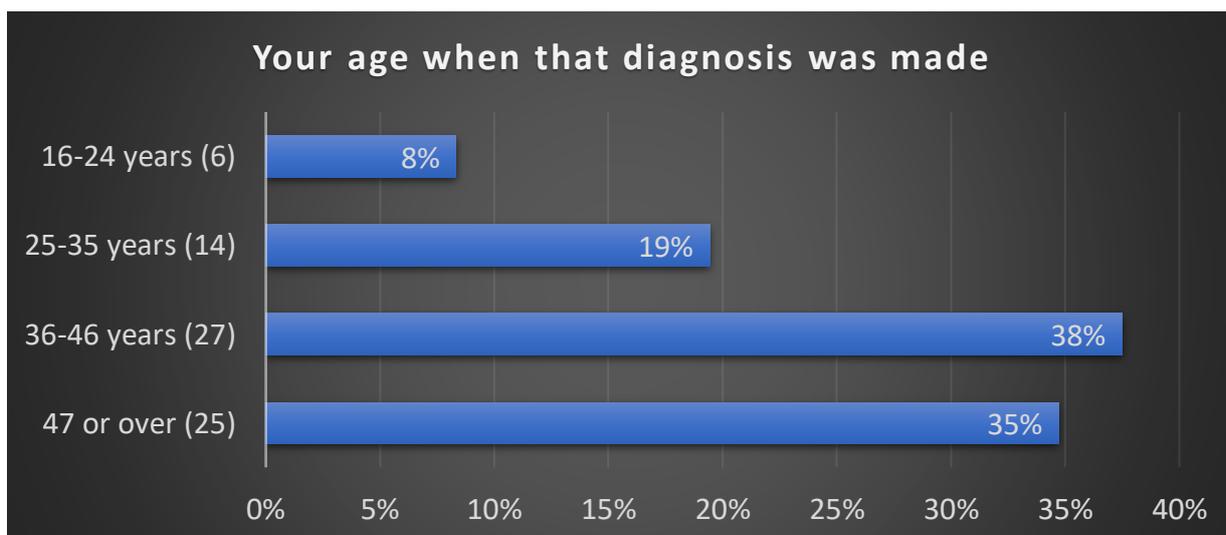
Of the 99 respondents, 72, (73%) have received a diagnosis of autism within the past three years, the remaining 27 (27%) have not.

Have you received a diagnosis of autism within the past three years?



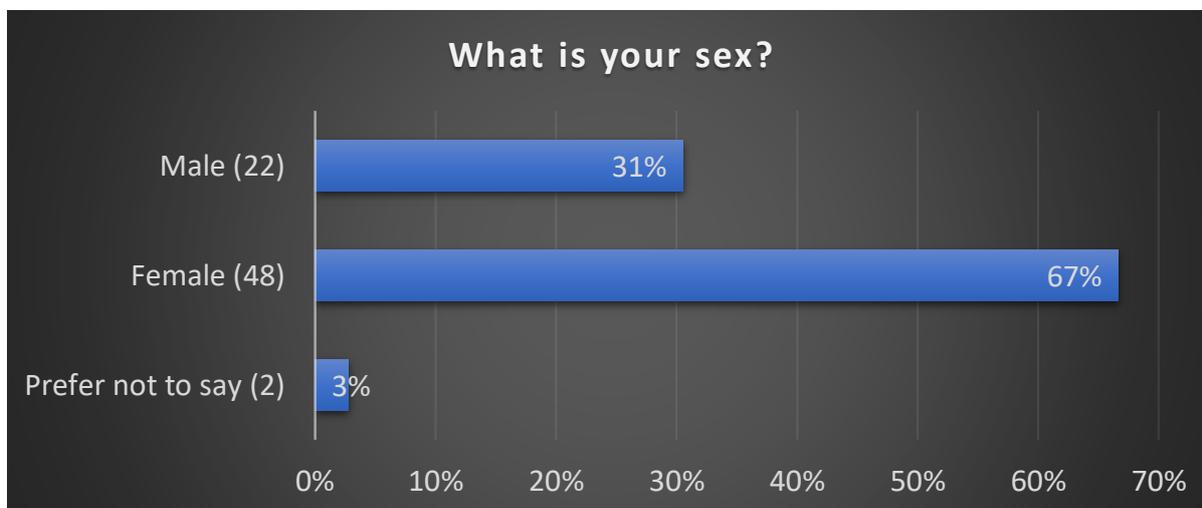
The age profile of those who have received a diagnosis of autism within the past three years is as follows:

Your age when that diagnosis was made



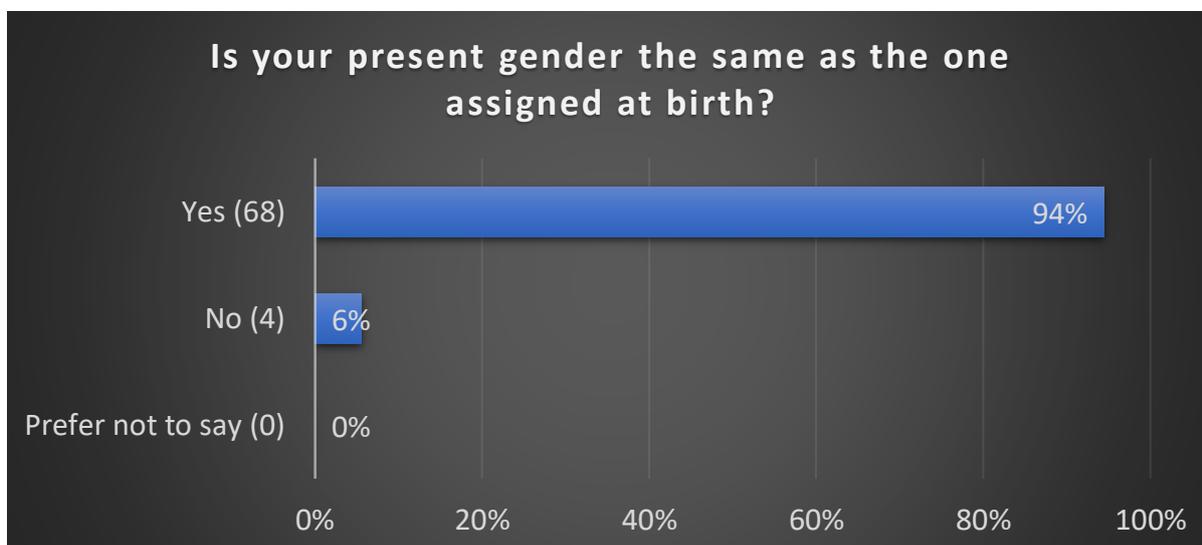
For the same cohort of 72, the profile in respect of their sex is as follows:

What is your sex?



For those above, for the majority their present gender is the same as the one assigned at birth:

Is your present gender the same as the one assigned at birth?



Optionally respondents could 'enter in words your preferred gender identity'. The 16 responses are given with the numbers responding using that description in brackets:

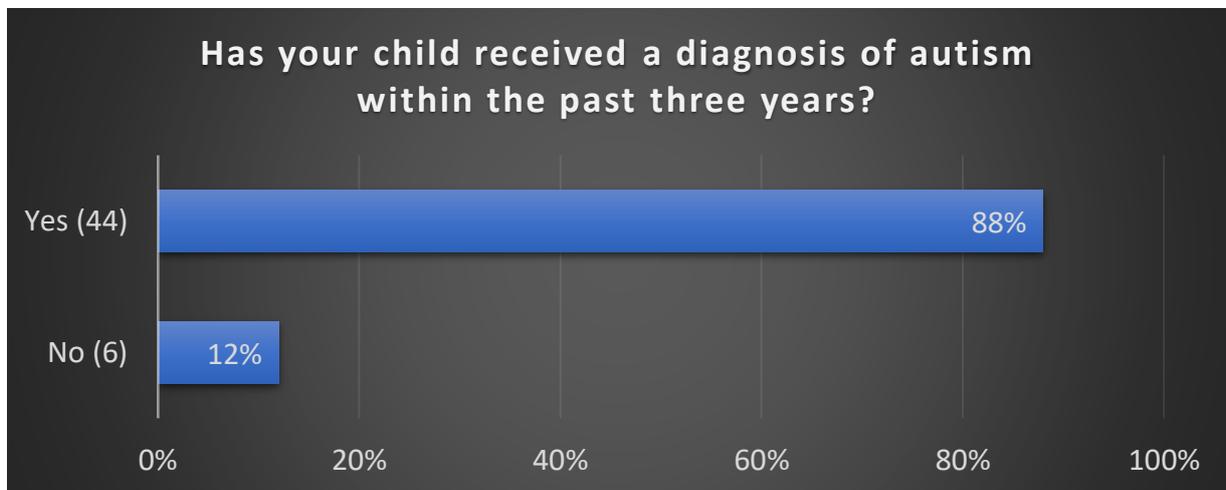
- Male (3)
- Female (6)
- Genderfluid (1)
- She/her (1)
- Heterosexual (1)

- Non-binary (1)
- Woman (1)
- I am a man, then, now and forever (1)
- Nonbinary woman (1)

For Families of an autistic child (16 and under)

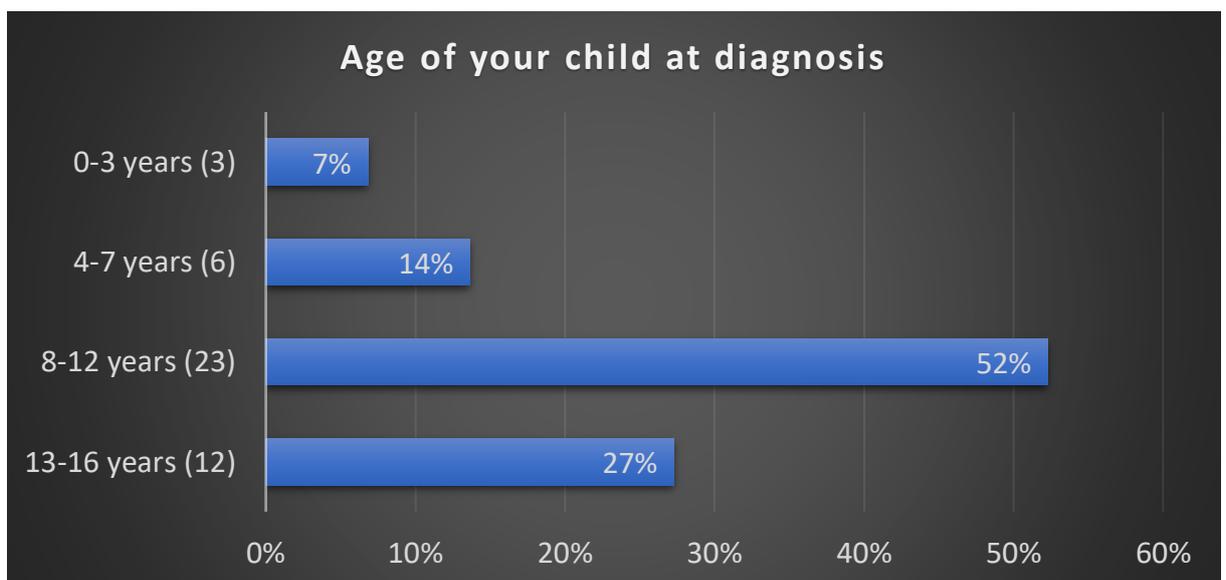
Of the 50 respondents, 44, (88%) say their child has received a diagnosis of autism within the past three years, the remaining 6 (12%) say their child has not.

Has your child received a diagnosis of autism with the past three years?



The age profile of the child at diagnosis is given below:

Age of your child at diagnosis

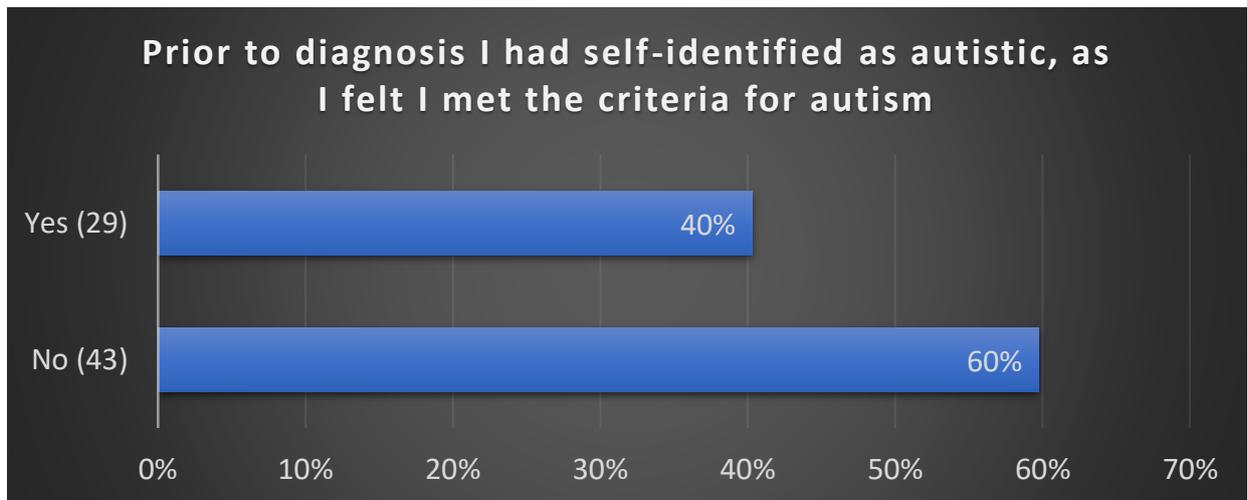


Responses for Individuals: Autistic person (over 16 years)

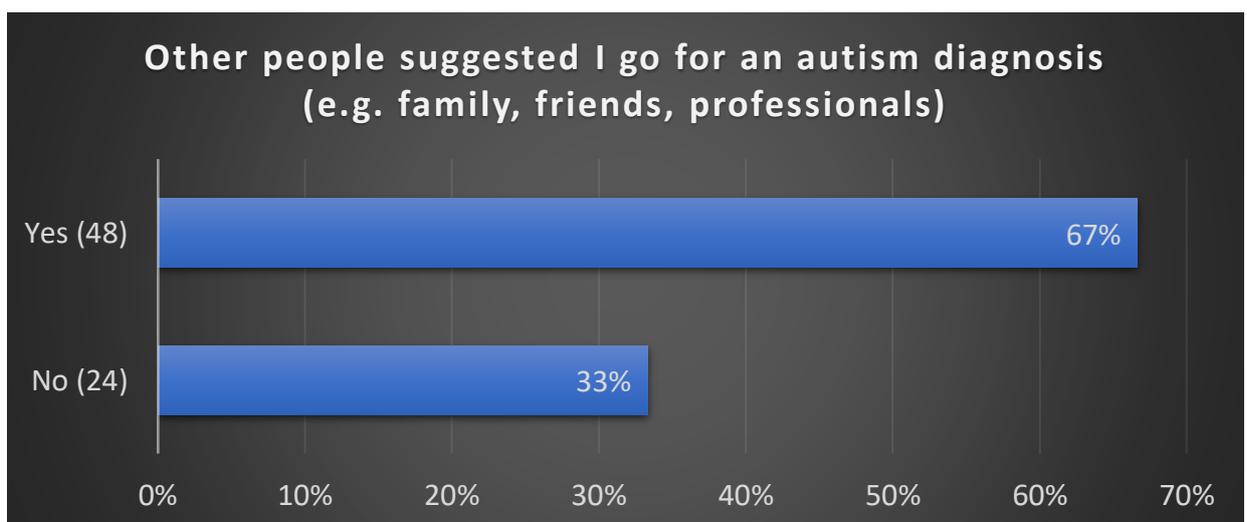
Regarding an autism diagnosis:

It was noted above, that of the 99 respondents who are 'An autistic person (over 16 years)', 72 had received a diagnosis. Responses for these are given as follows.

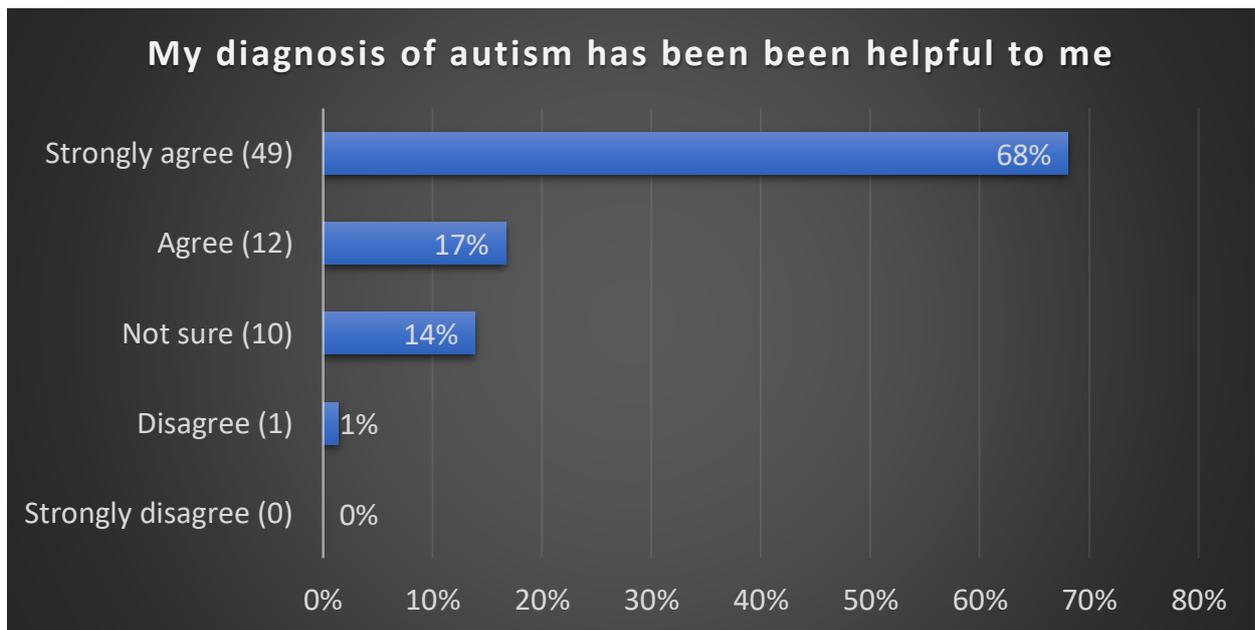
Prior to diagnosis I had self-identified as autistic, as I felt I met the criteria for autism



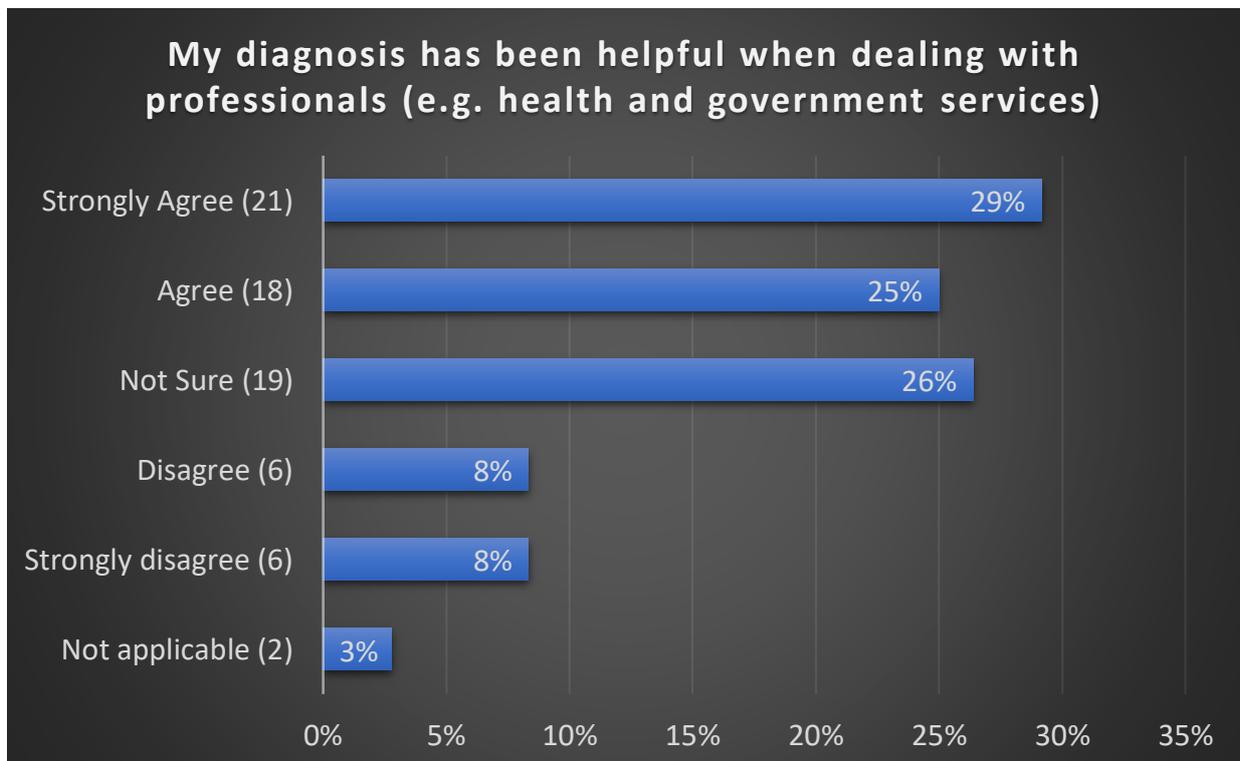
Other people suggested I go for an autism diagnosis (e.g. family, friends, professionals)



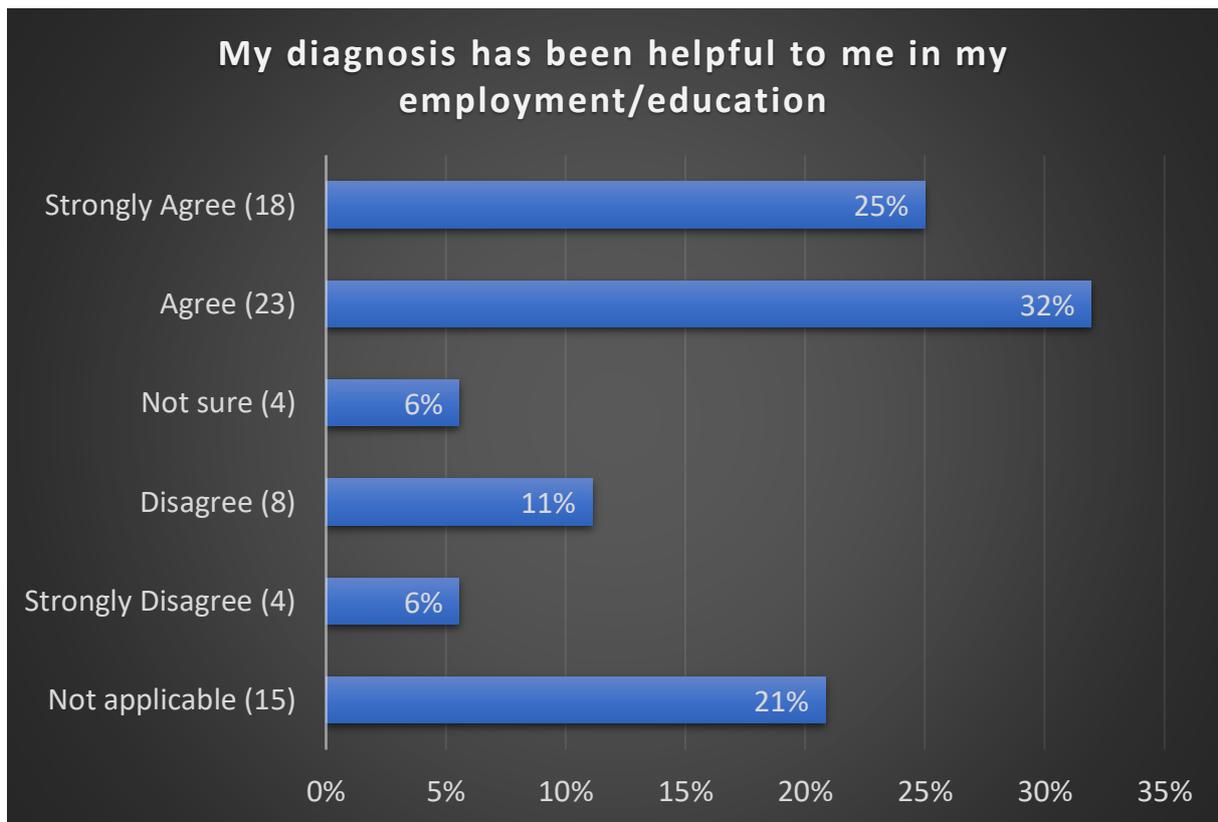
My diagnosis of autism has been helpful to me



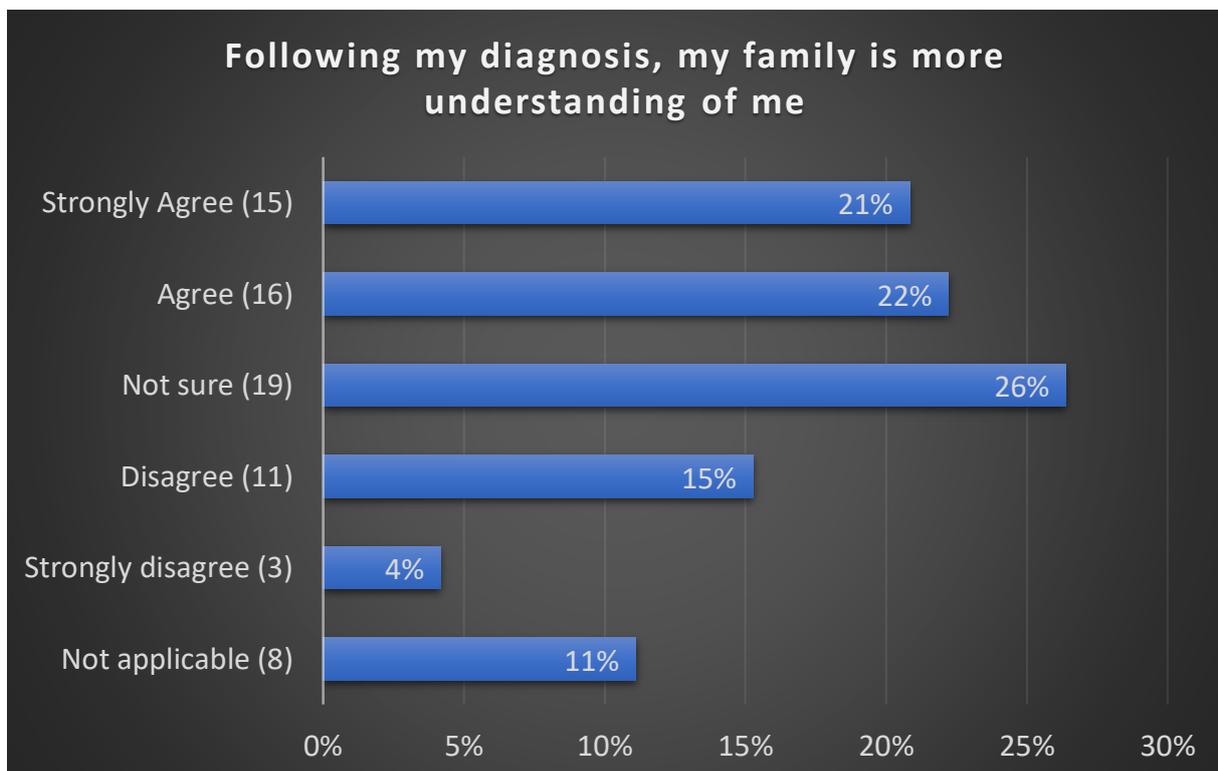
My diagnosis has been helpful when dealing with professionals (e.g. health and government services)



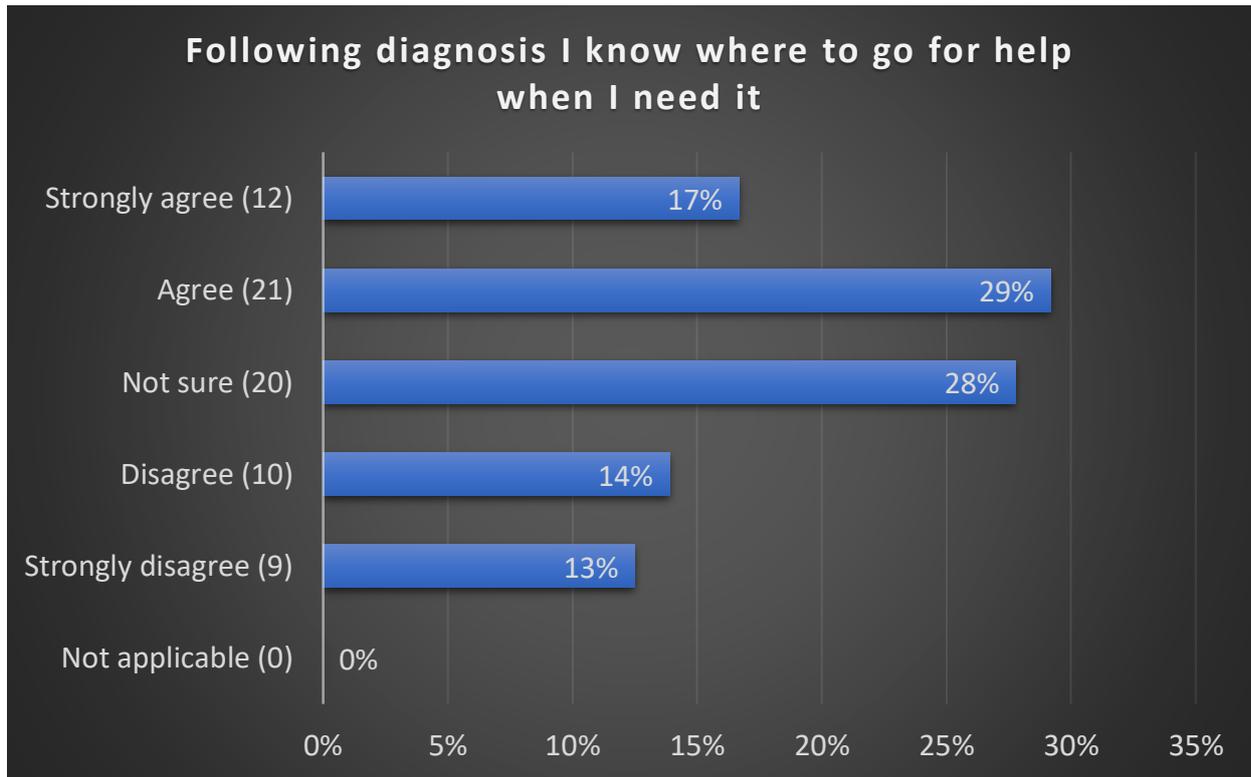
My diagnosis has been helpful to me in my employment/education



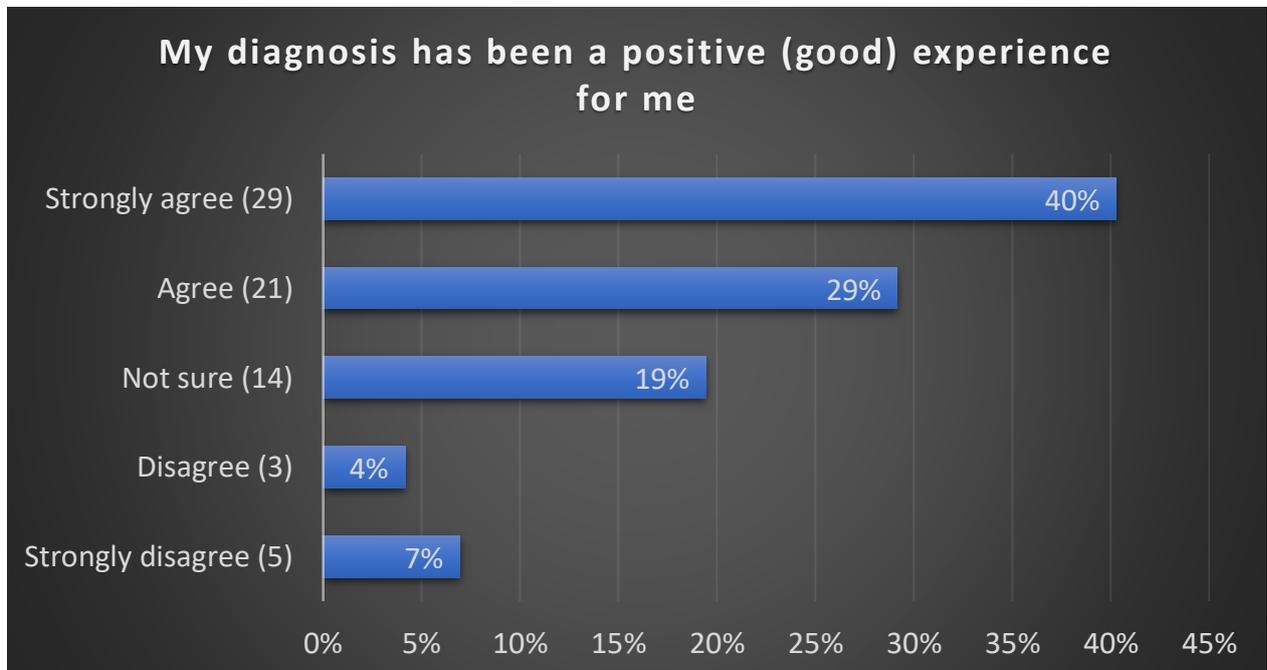
Following my diagnosis, my family is more understanding of me



Following diagnosis I know where to go for help when I need it

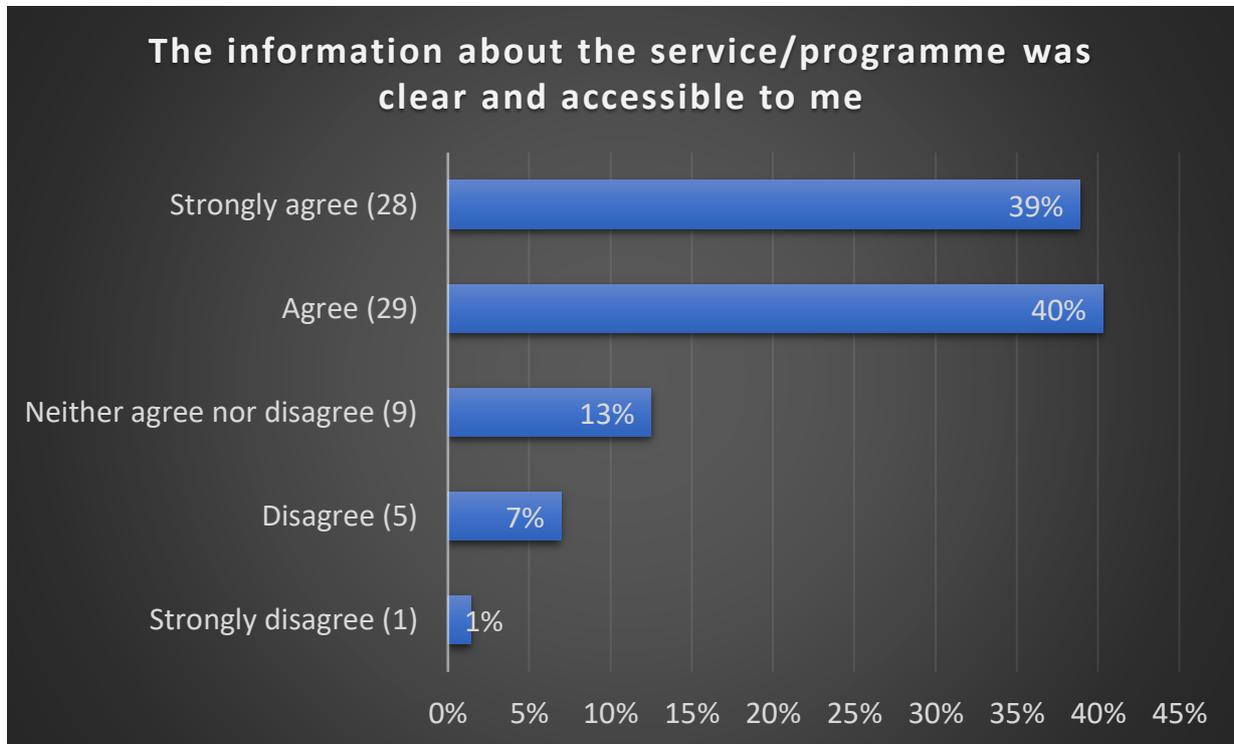


My diagnosis has been a positive (good) experience for me

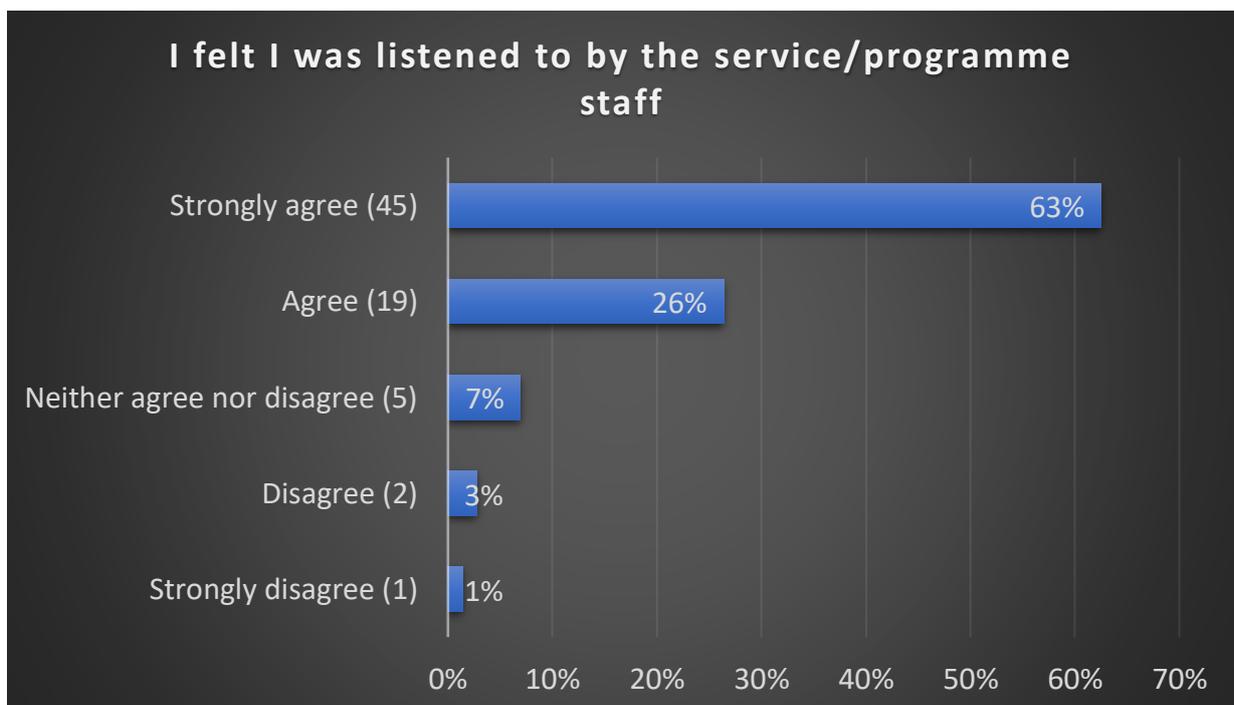


Regarding the service/programme

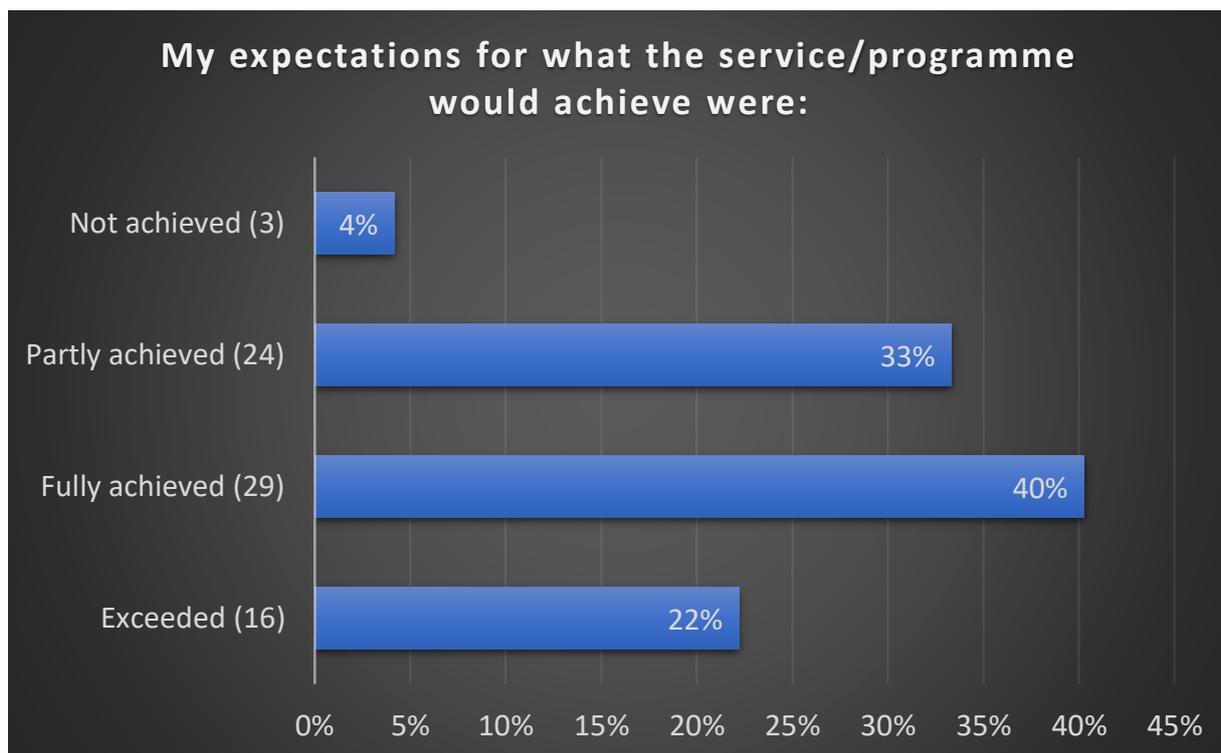
The information about the service/programme was clear and accessible to me



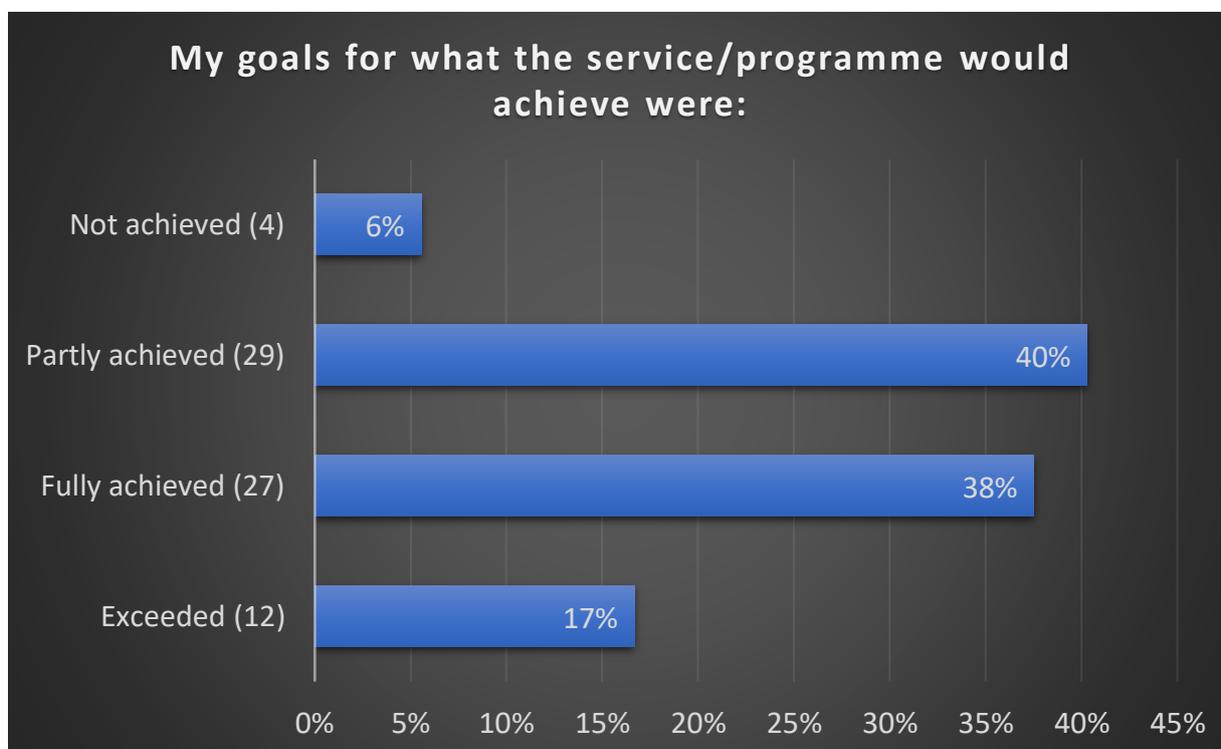
I felt I was listened to by the service/programme staff



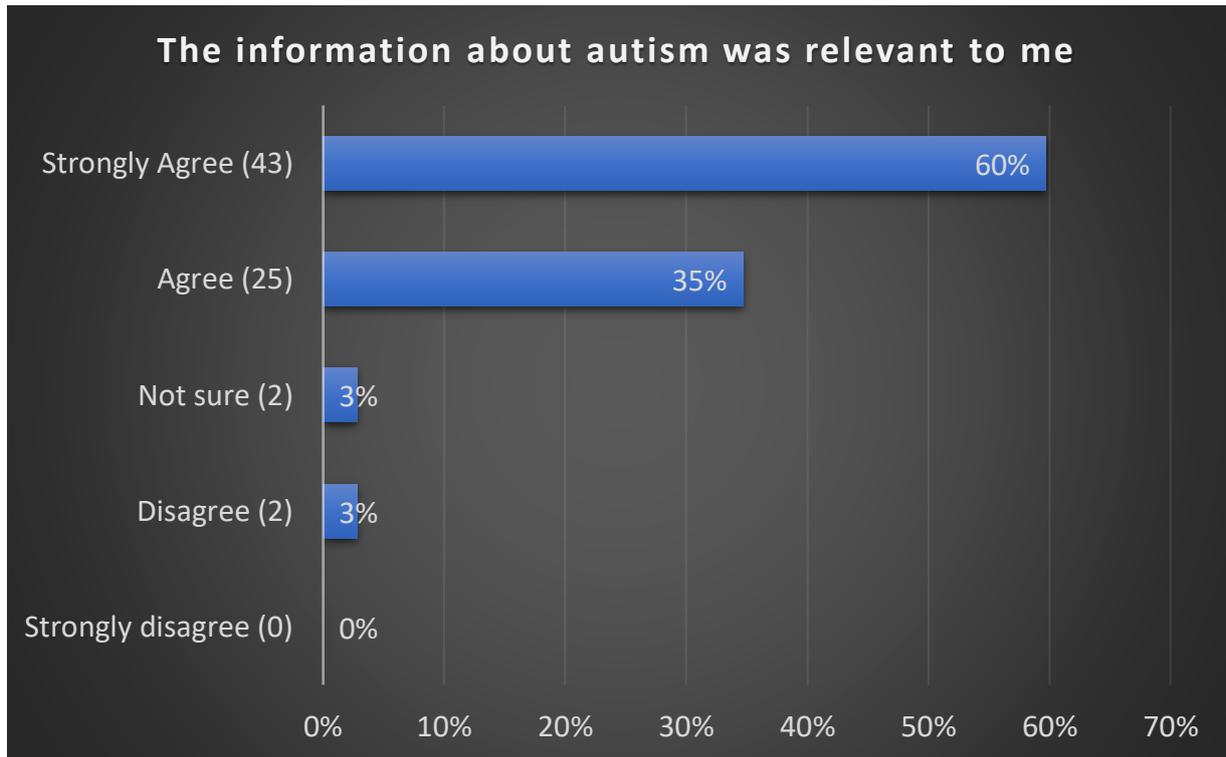
My expectations for what the service/programme would achieve were:



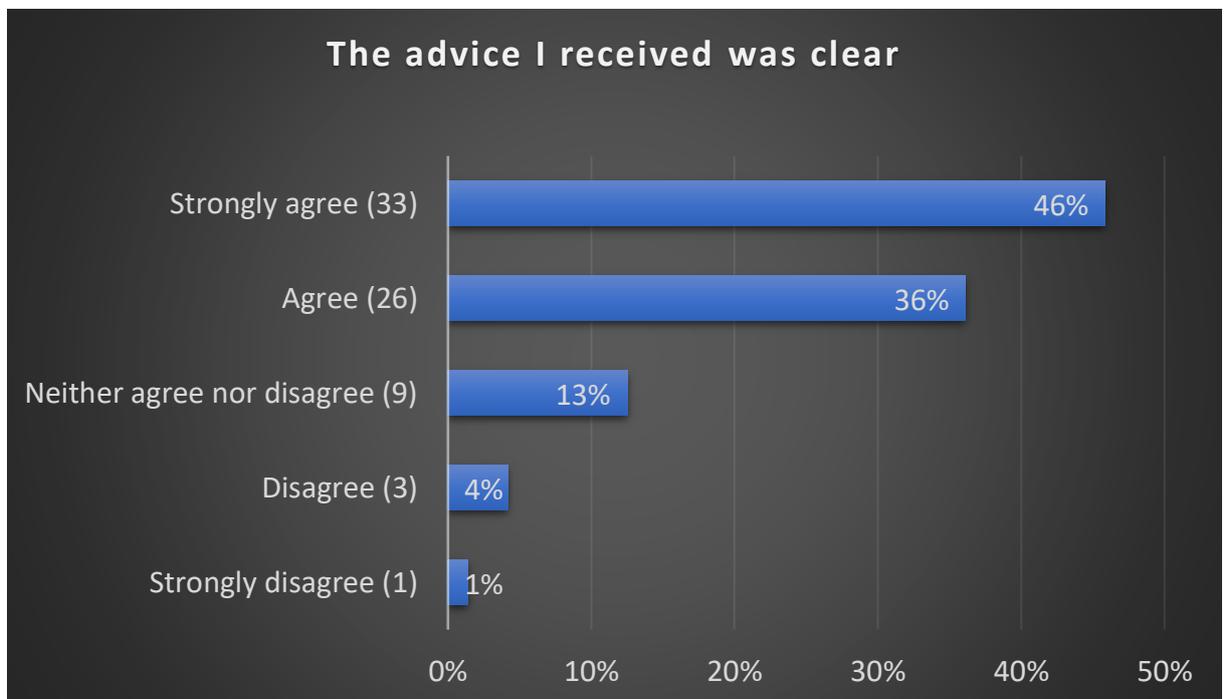
My goals for what the service/programme would achieve were



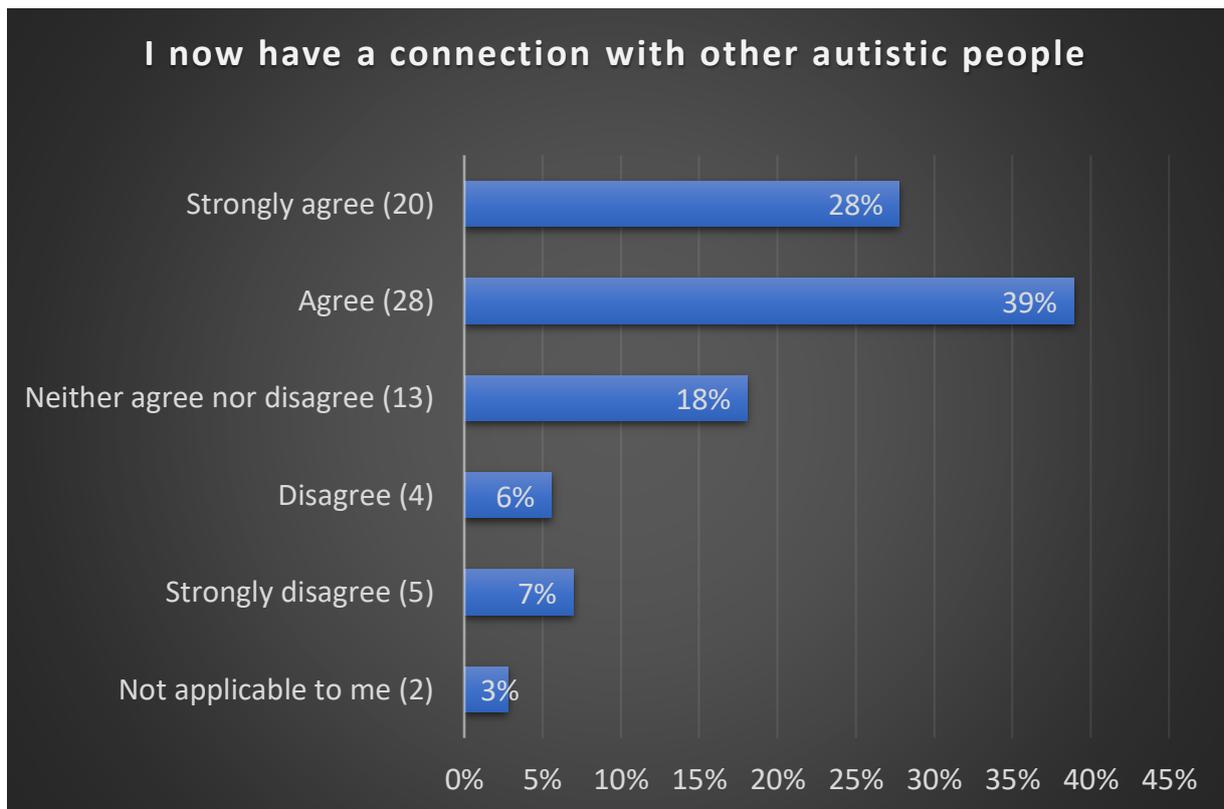
The information about autism was relevant to me



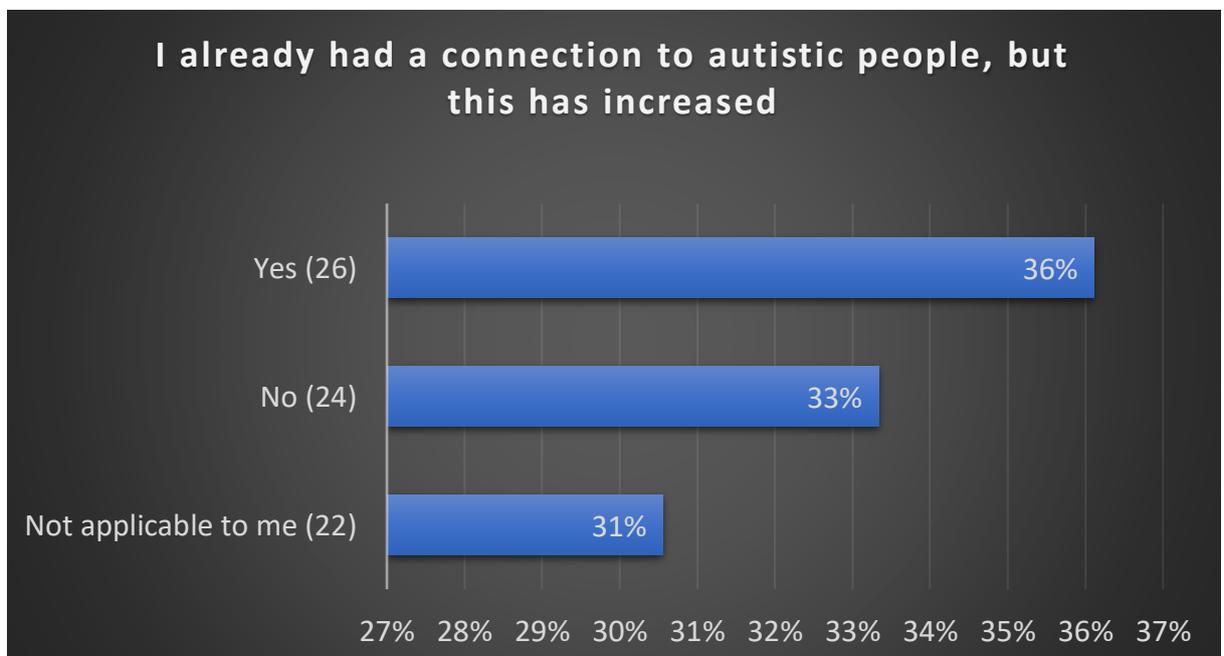
The advice I received was clear



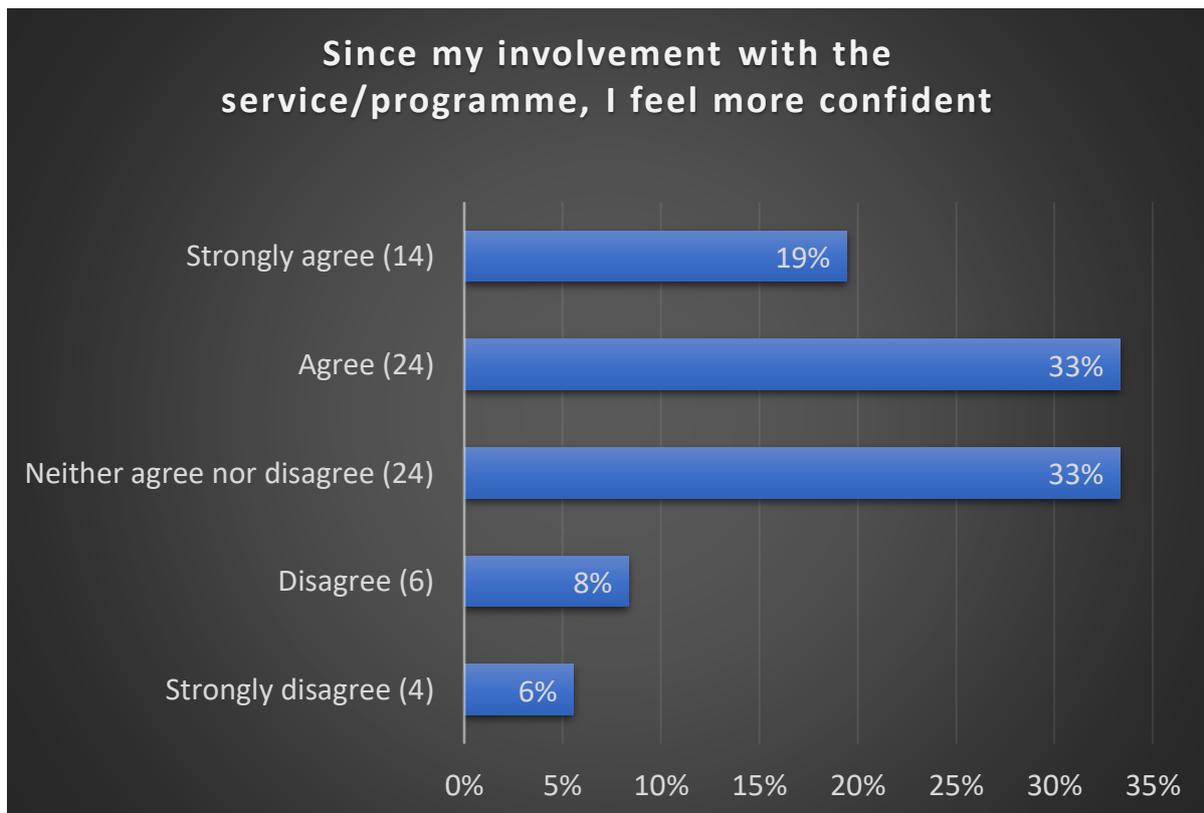
I now have a connection with other autistic people



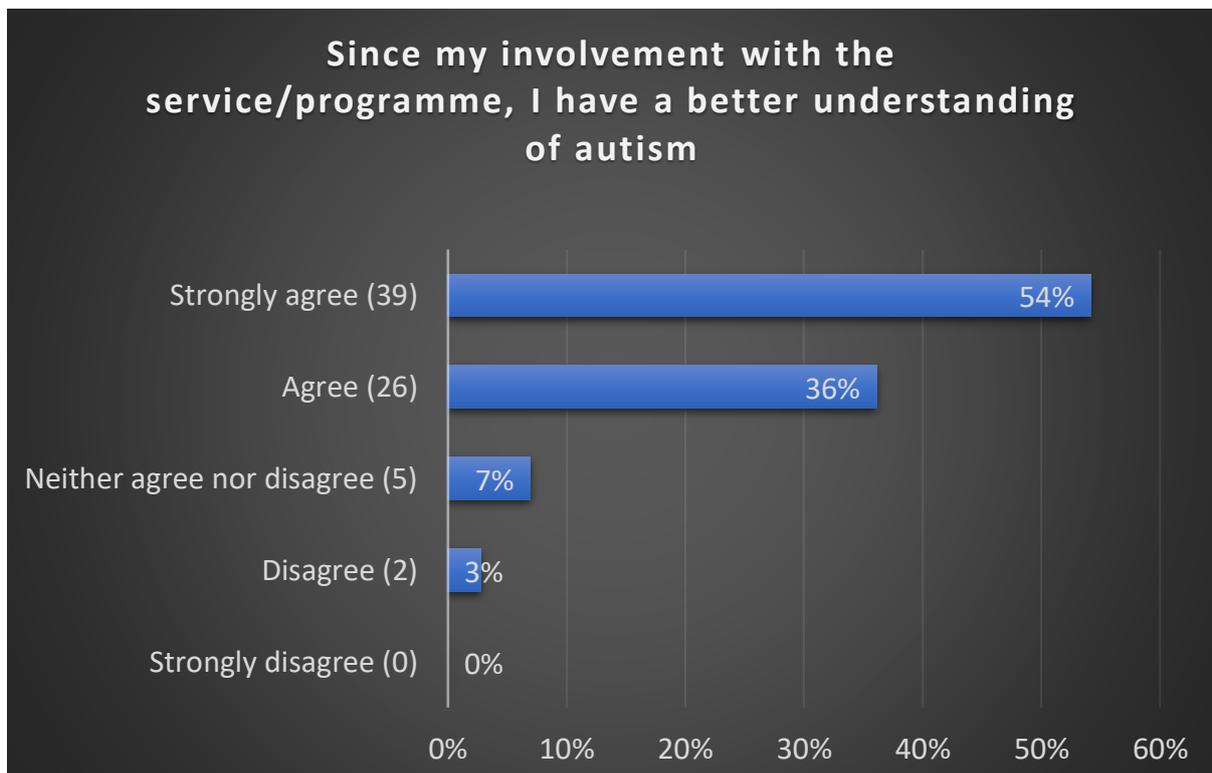
I already had a connection to autistic people, but this has increased



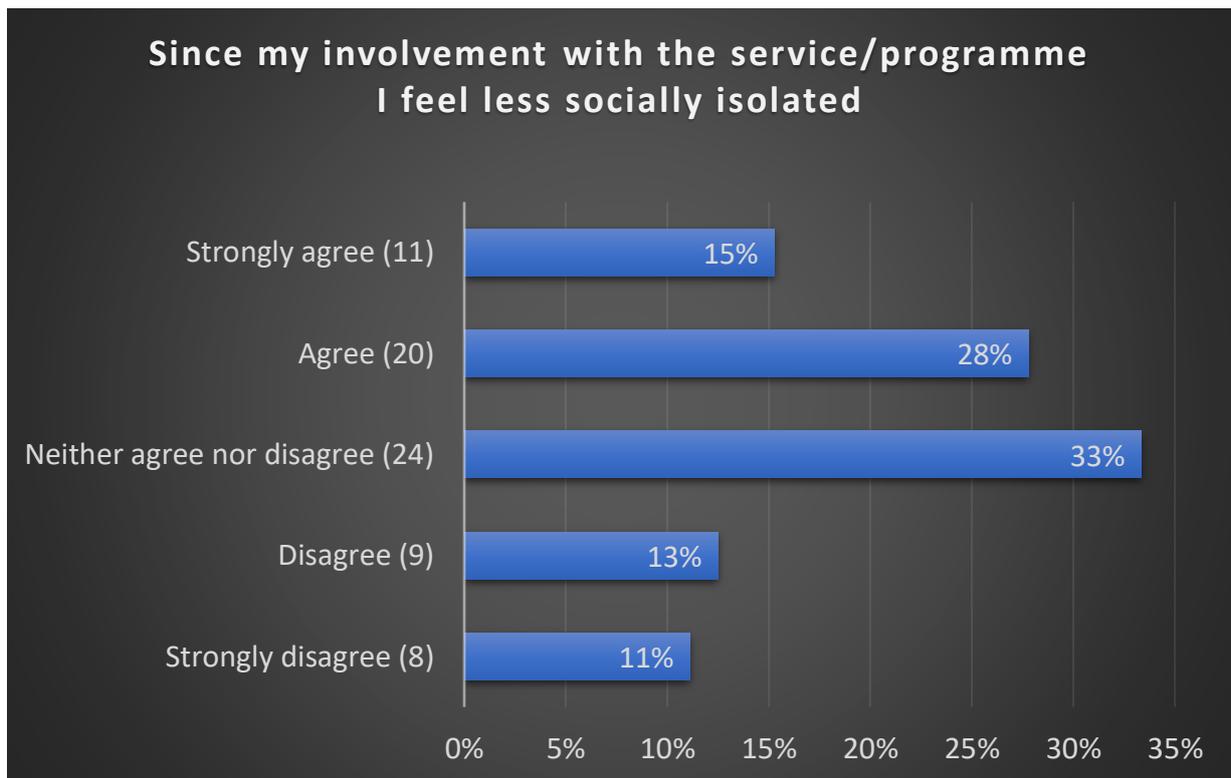
Since my involvement with the service/programme, I feel more confident



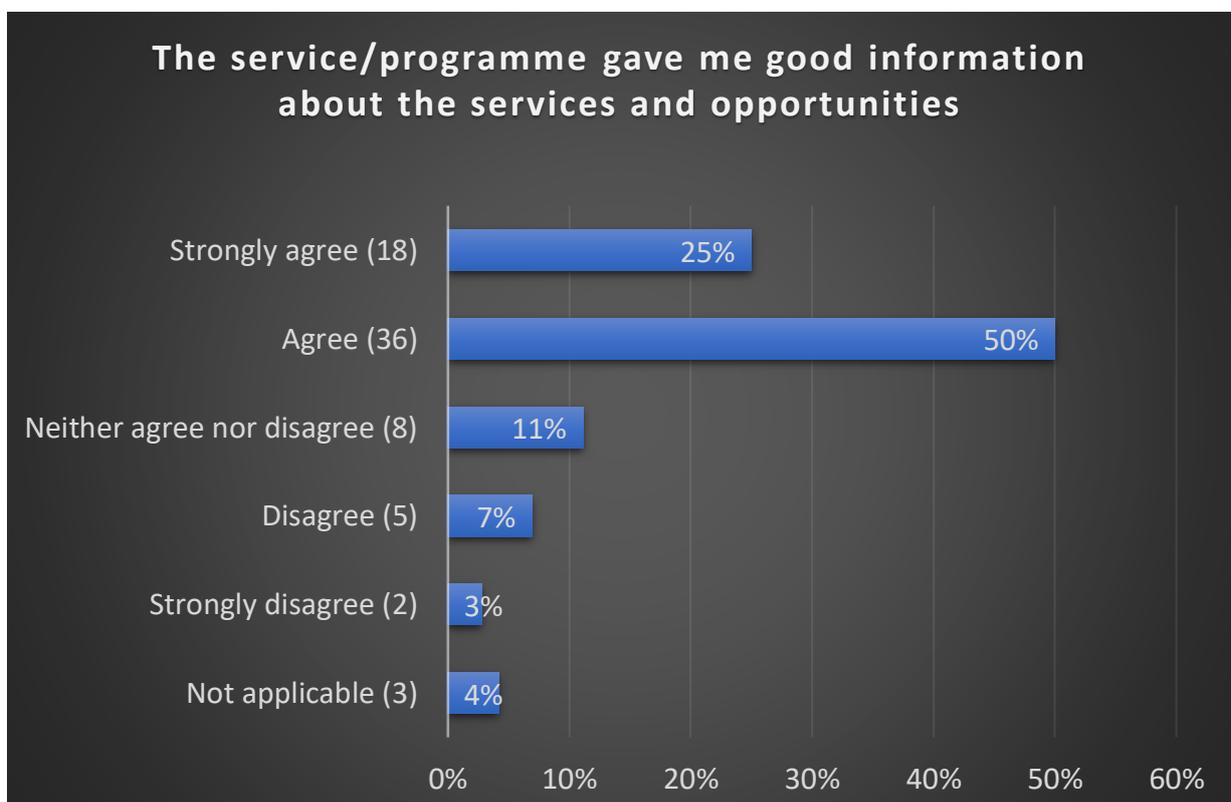
Since my involvement with the service/programme, I have a better understanding of autism



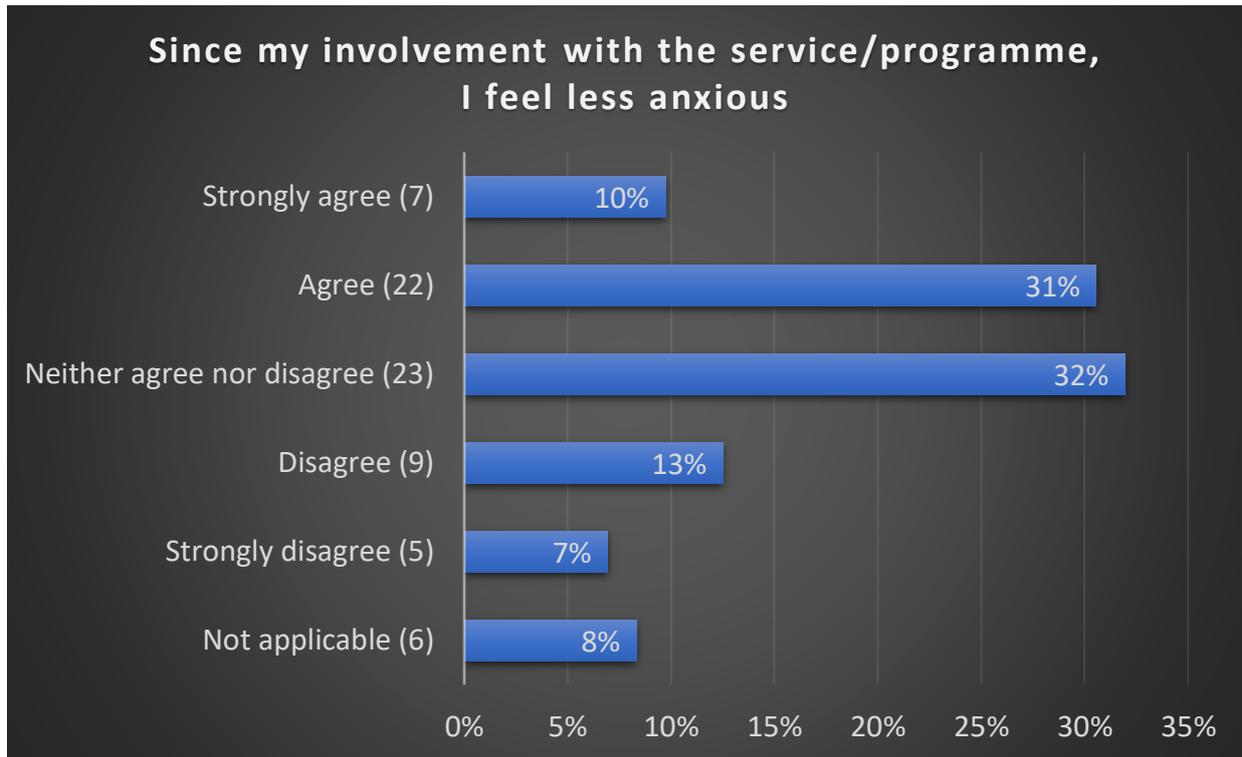
Since my involvement with the service/programme, I feel less socially isolated



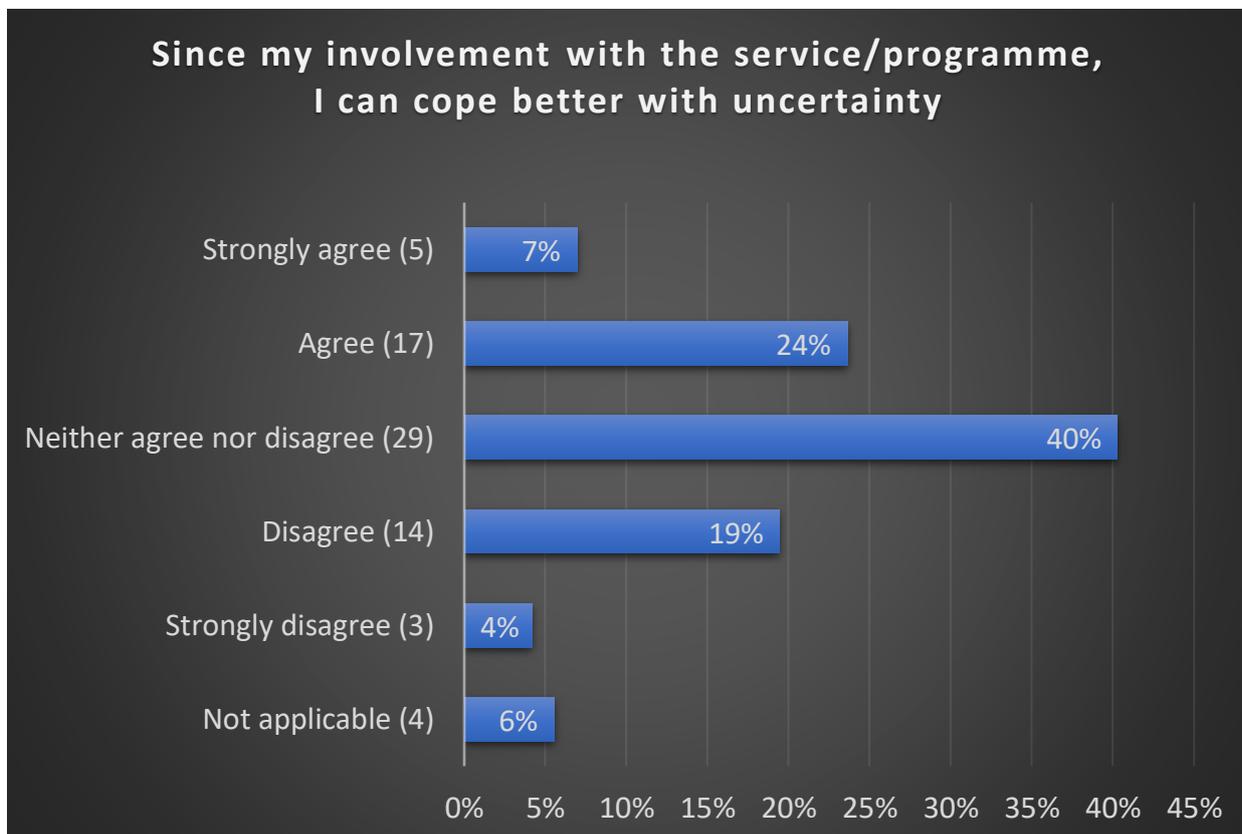
The service/programme gave me good information about the services and opportunities



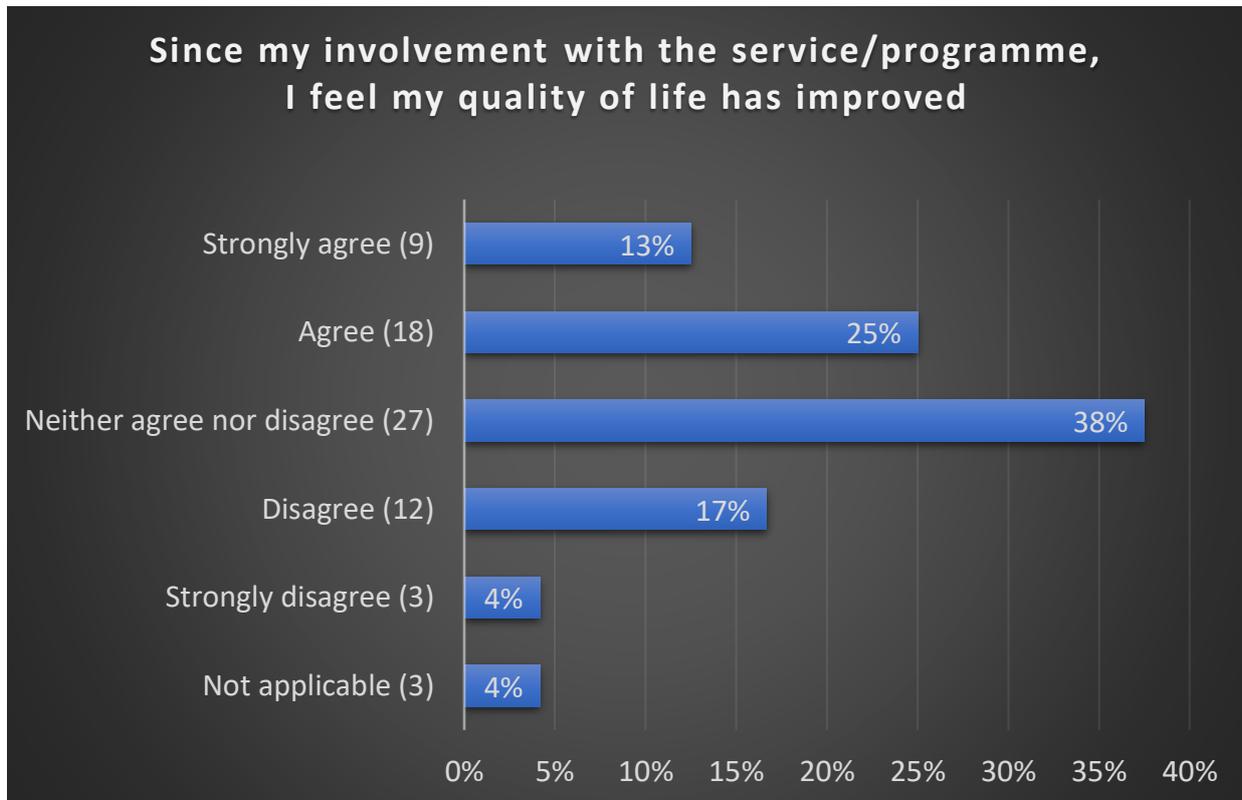
Since my involvement with the service/programme, I feel less anxious



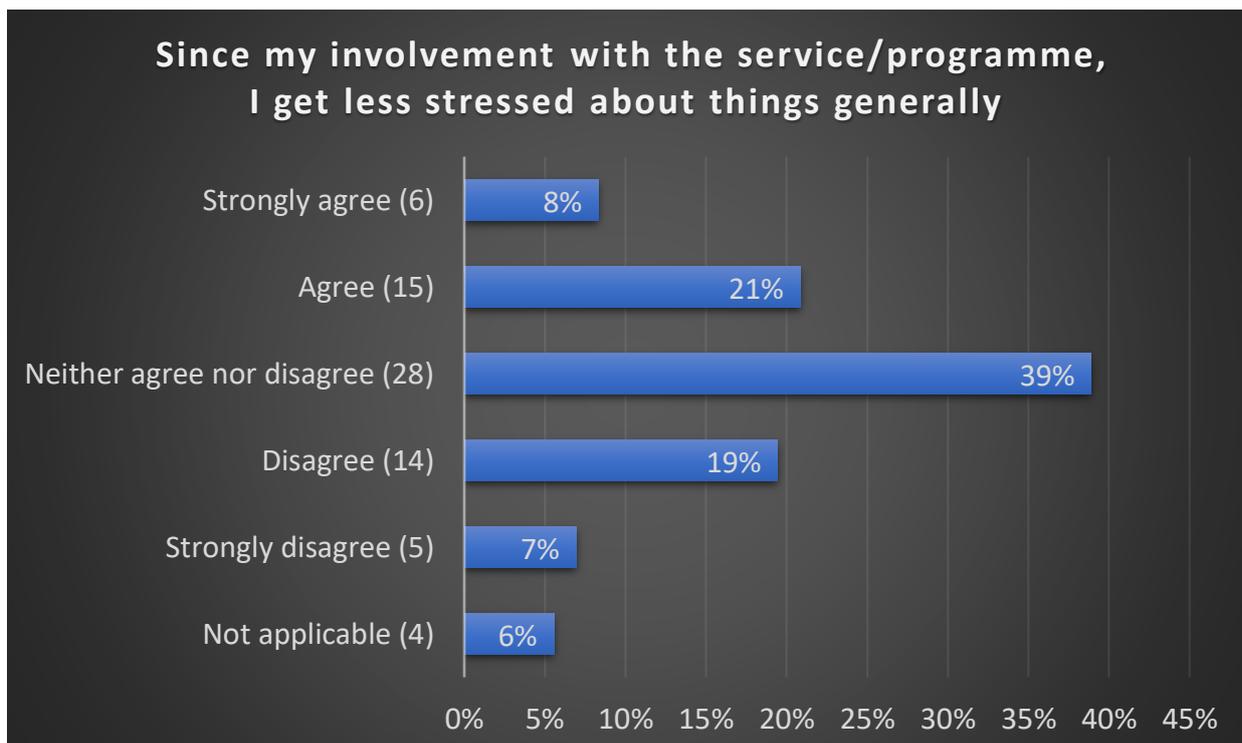
Since my involvement with the service/programme, I can cope better with uncertainty



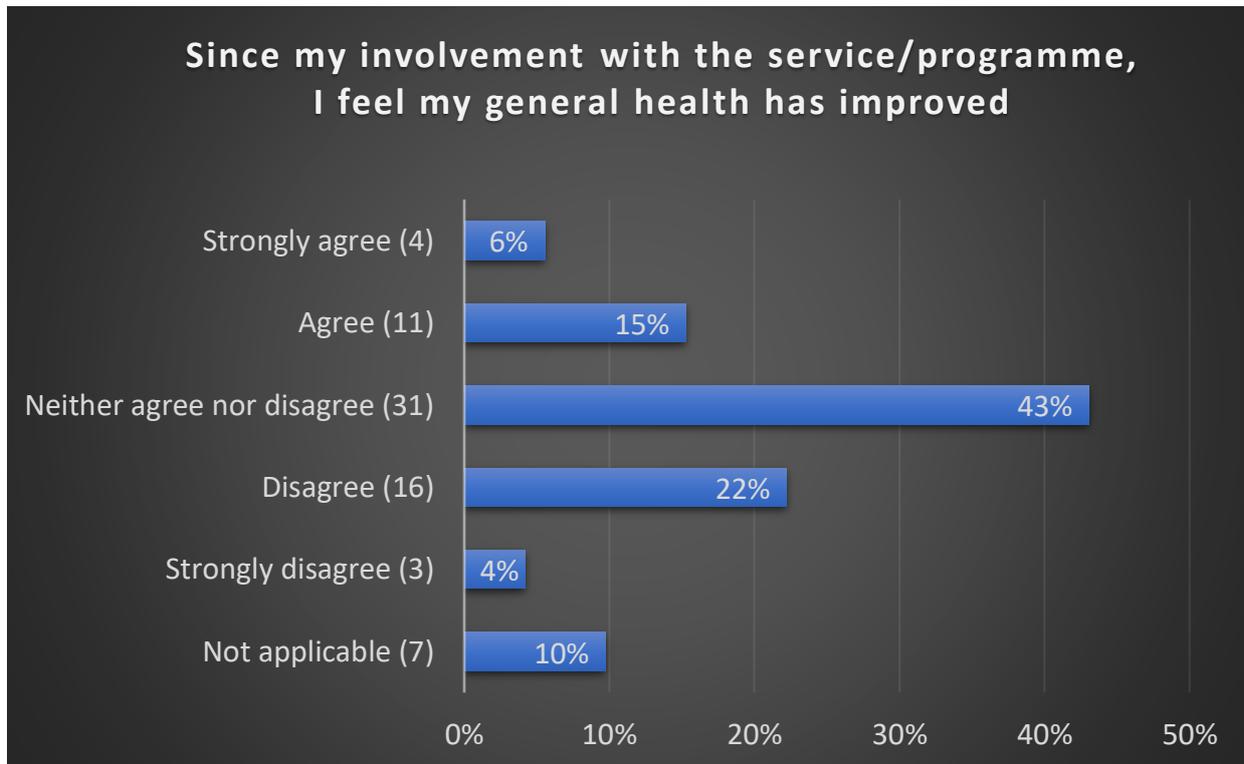
Since my involvement with the service/programme, I feel my quality of life has improved



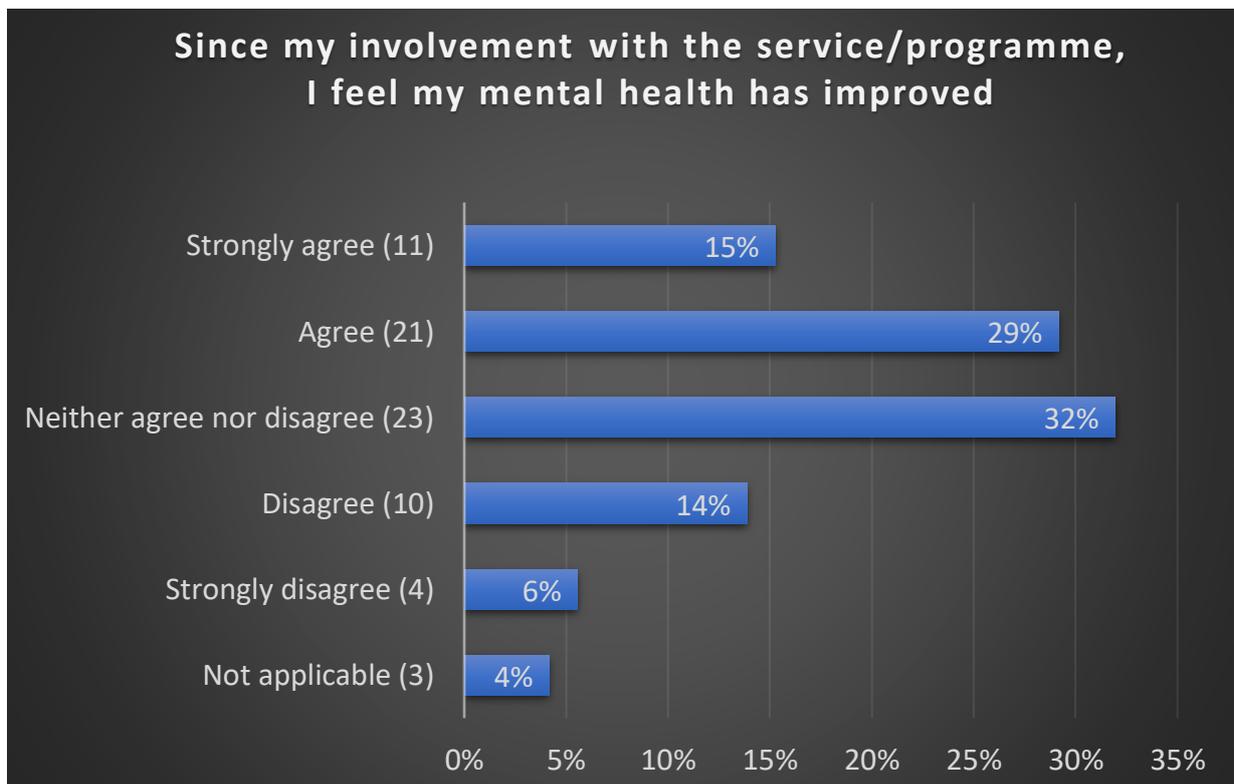
Since my involvement with the service/programme, I get less stressed about things generally



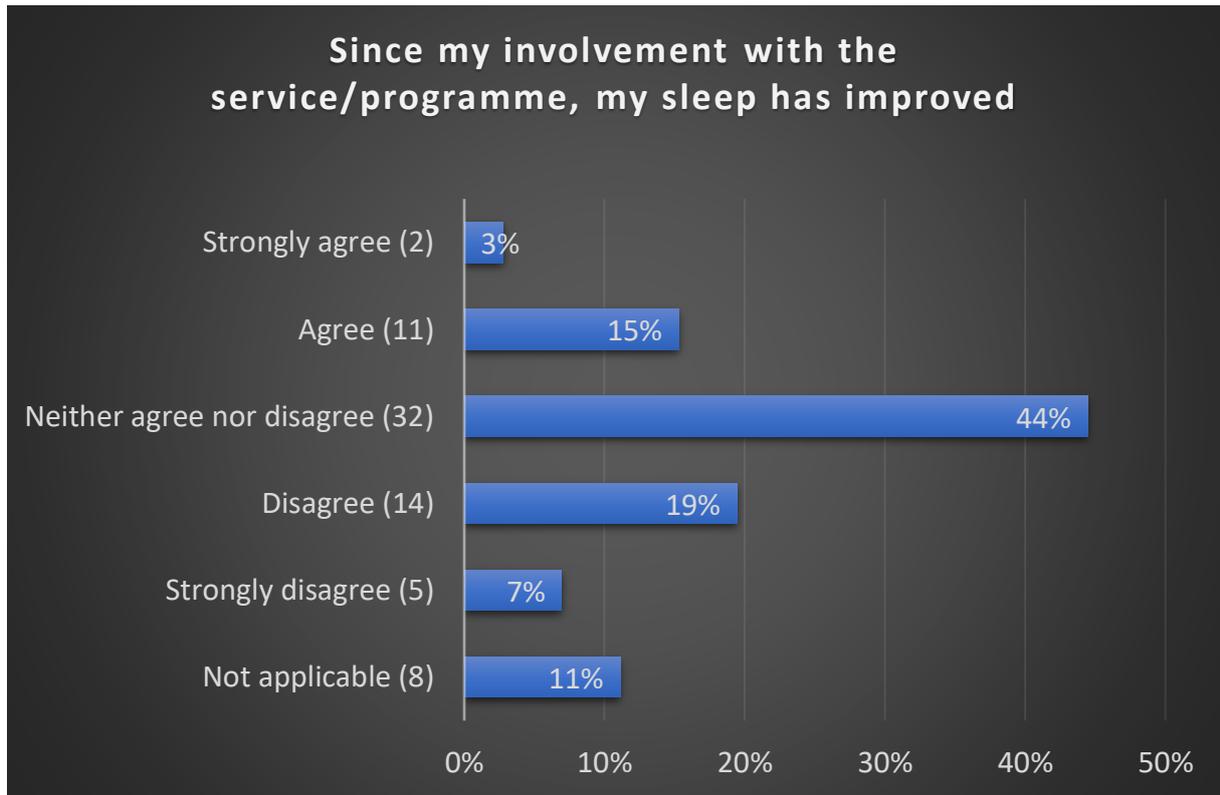
Since my involvement with the service/programme, I feel my general health has improved



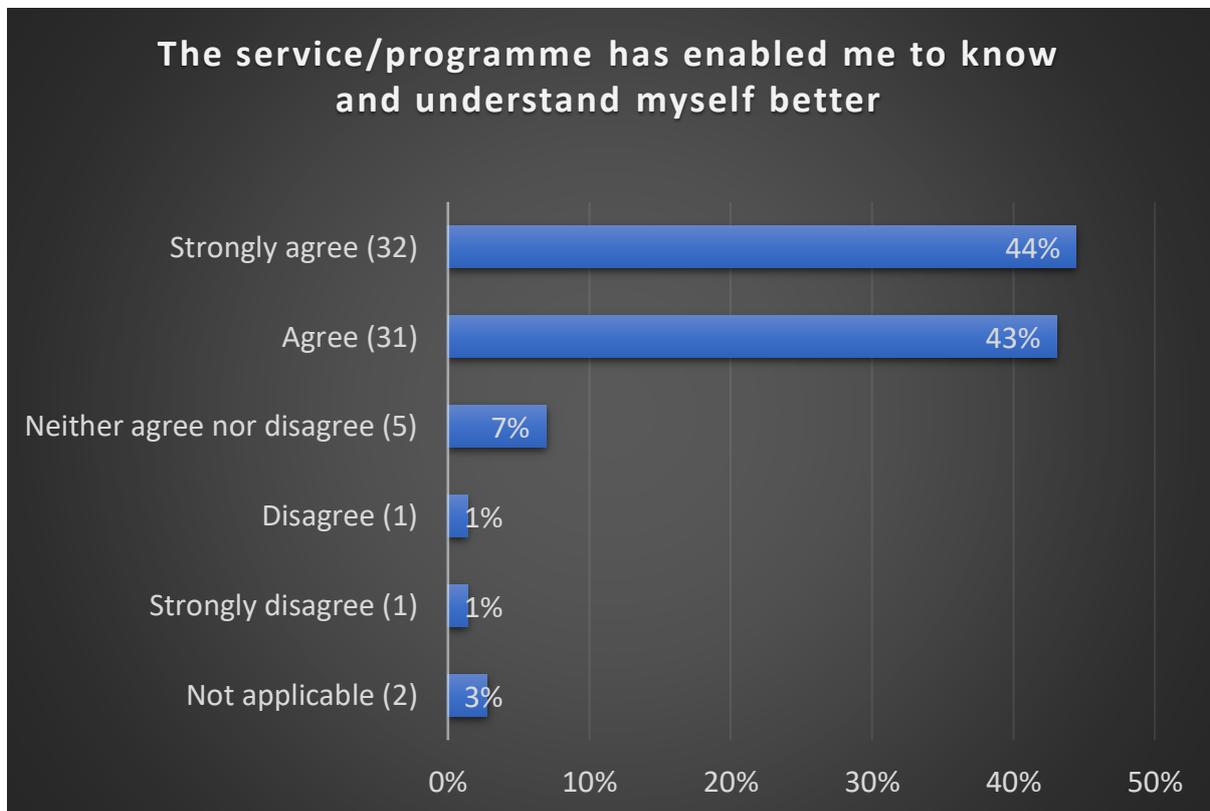
Since my involvement with the service/programme, I feel my mental health has improved



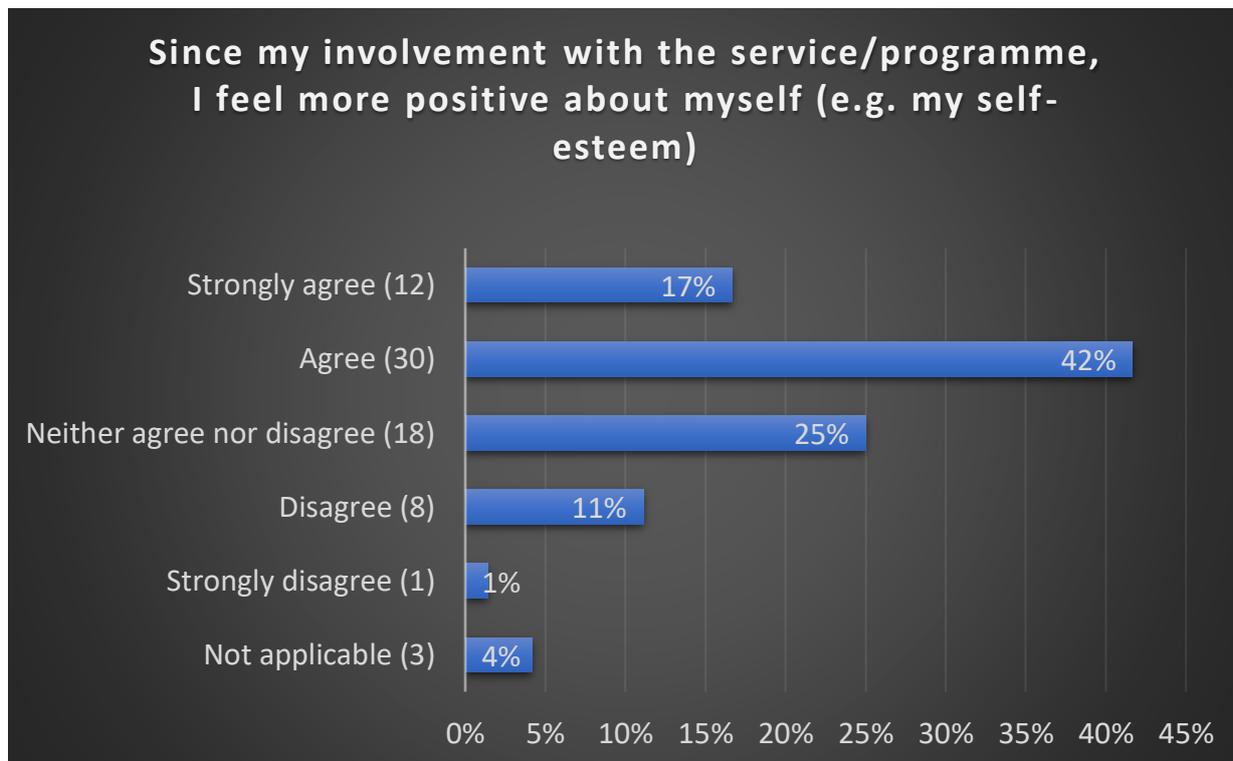
Since my involvement with the service/programme, my sleep has improved



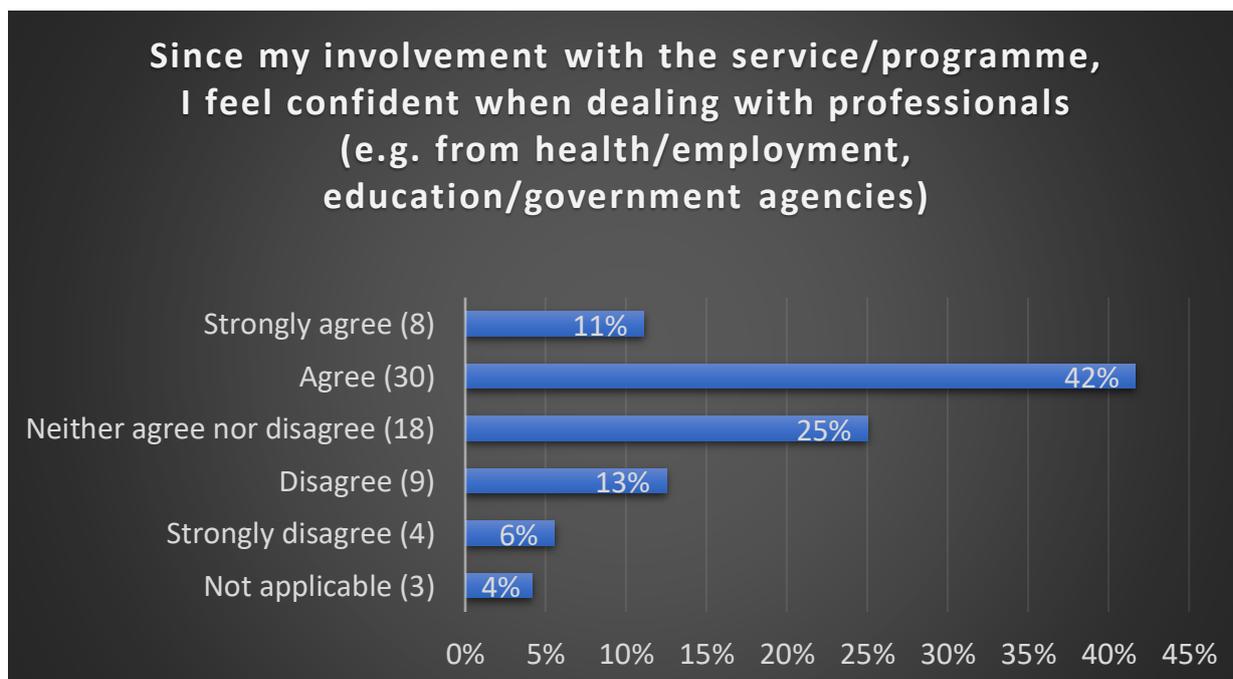
The service/programme has enabled me to know and understand myself better



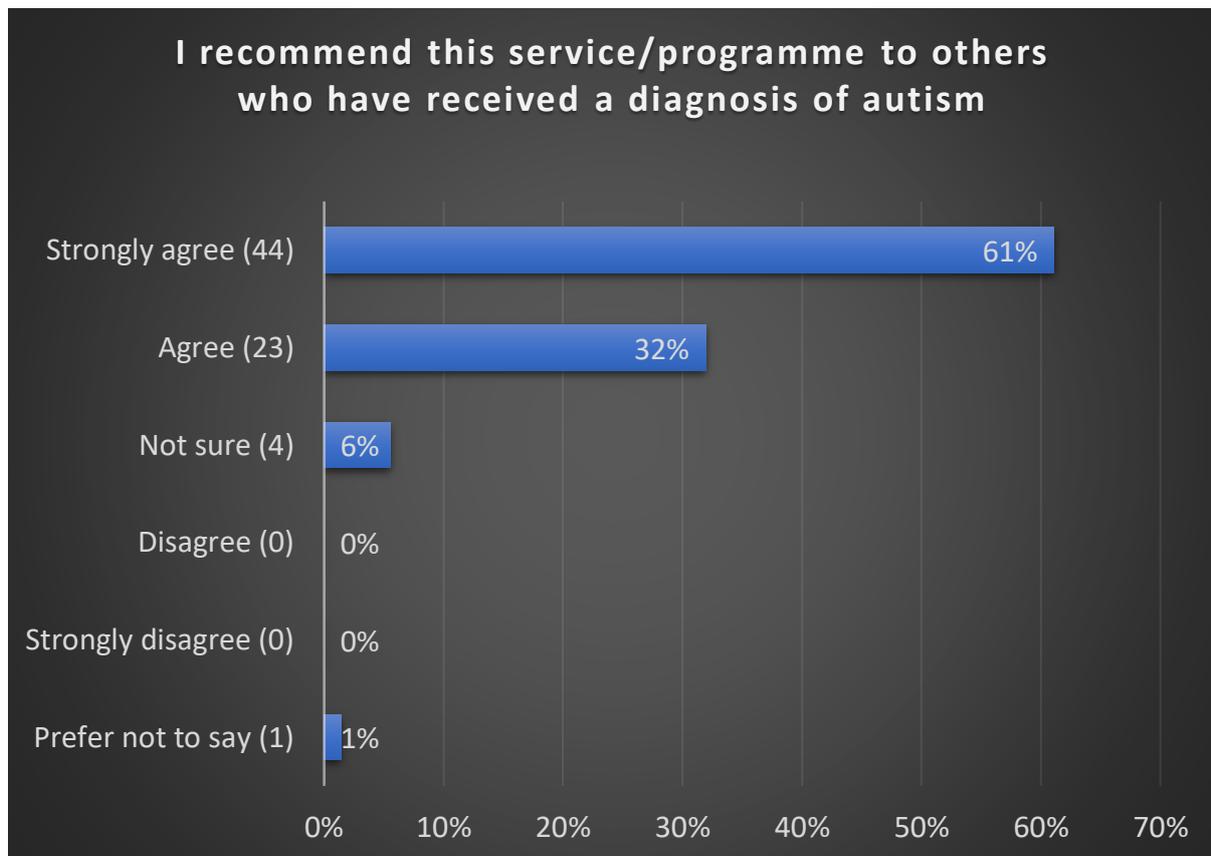
Since my involvement with the service/programme, I feel more positive about myself (e.g. my self- esteem)



Since my involvement with the service/programme, I feel confident when dealing with professionals (e.g. from health/employment, education/government agencies)



I recommend this service/programme to others who have received a diagnosis of autism

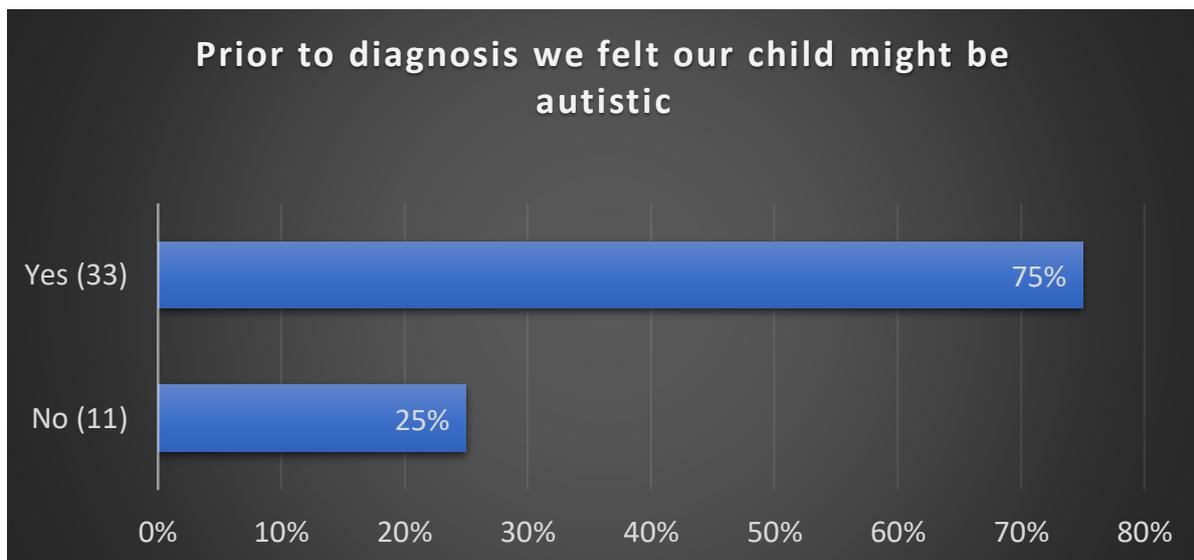


Responses for Families: A family of an autistic child (16 and under)

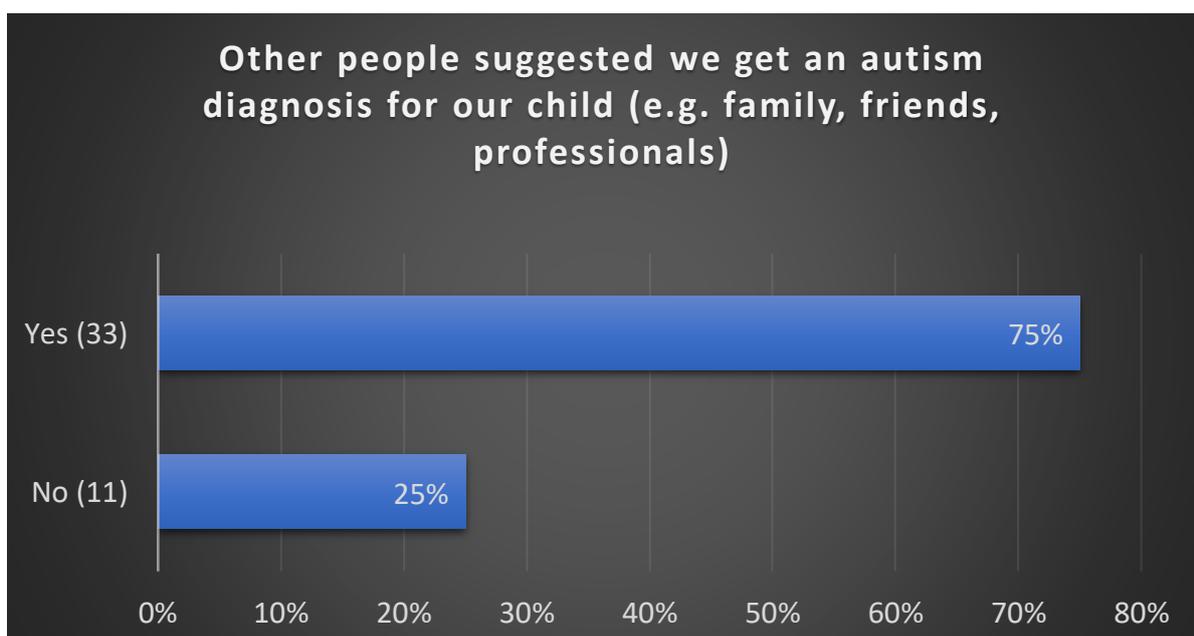
It was noted above, that of the 50 respondents who are 'A family of an autistic child (16 and under)', 44 had received a diagnosis. Responses for these are given as follows.

Regarding an autism diagnosis

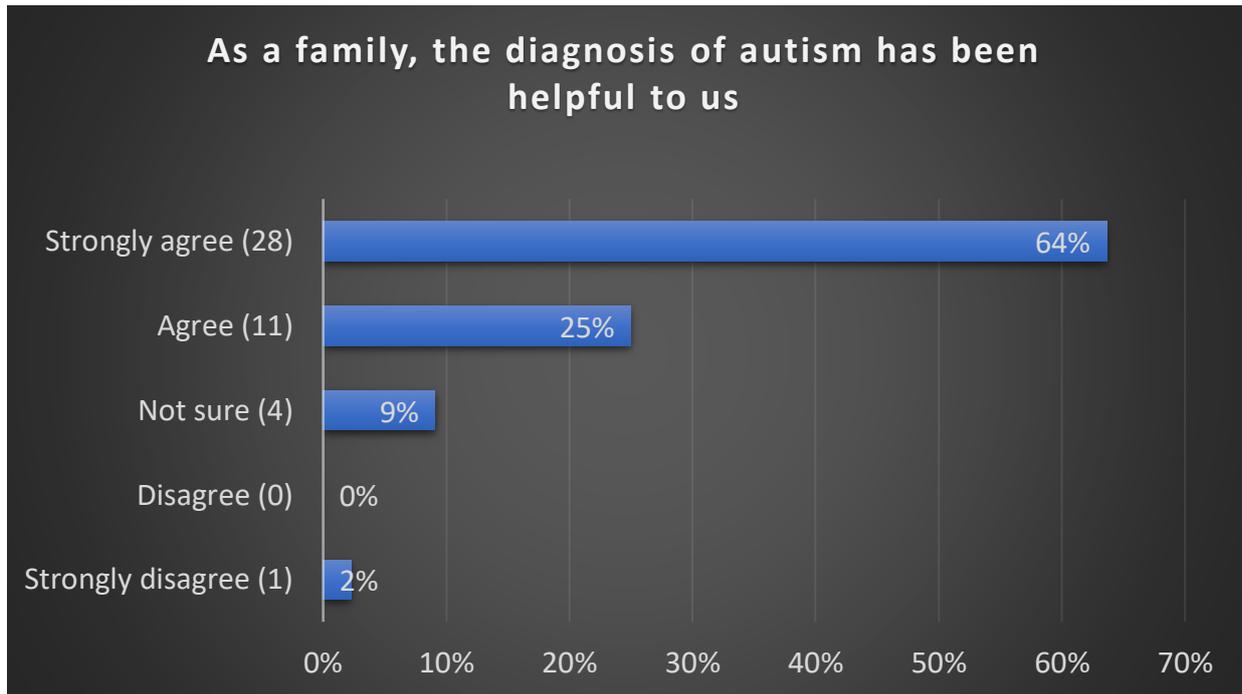
Prior to diagnosis we felt our child might be autistic



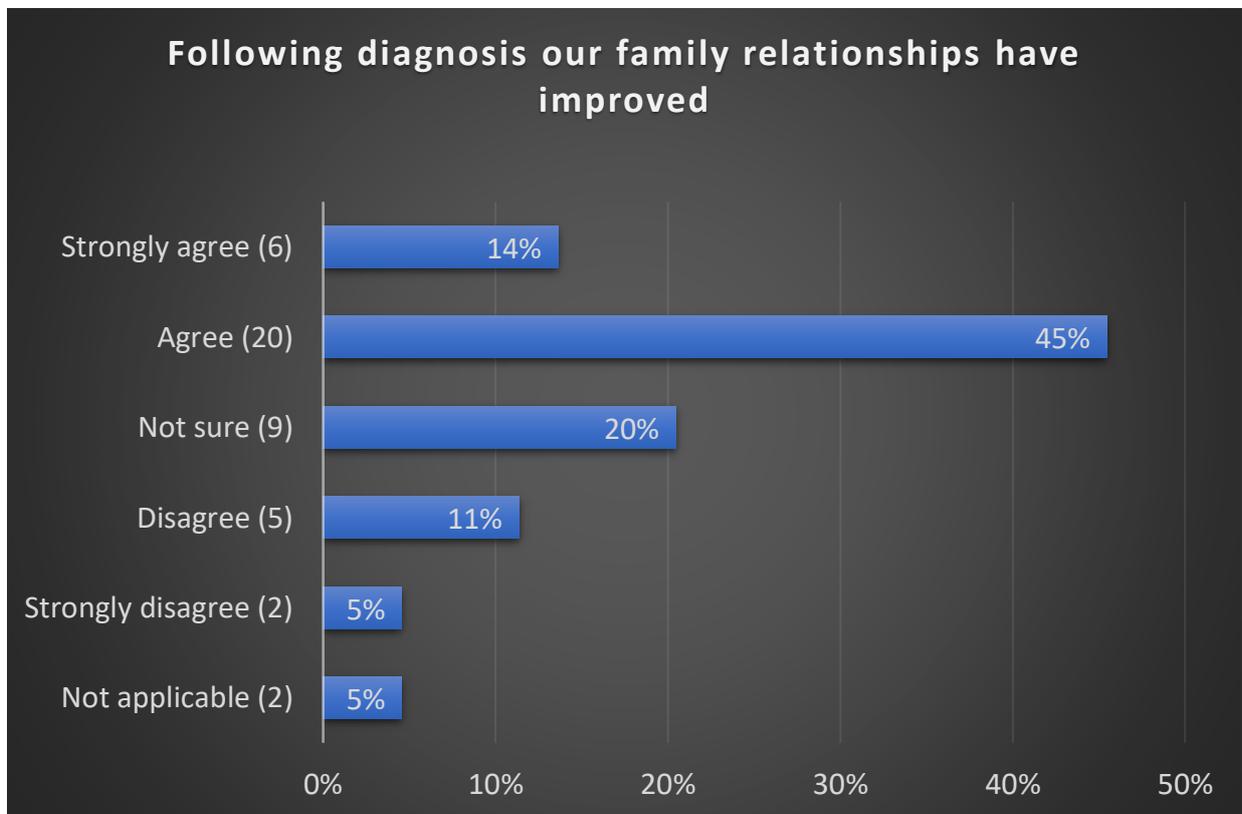
Other people suggested we get an autism diagnosis for our child (e.g. family, friends, professionals)



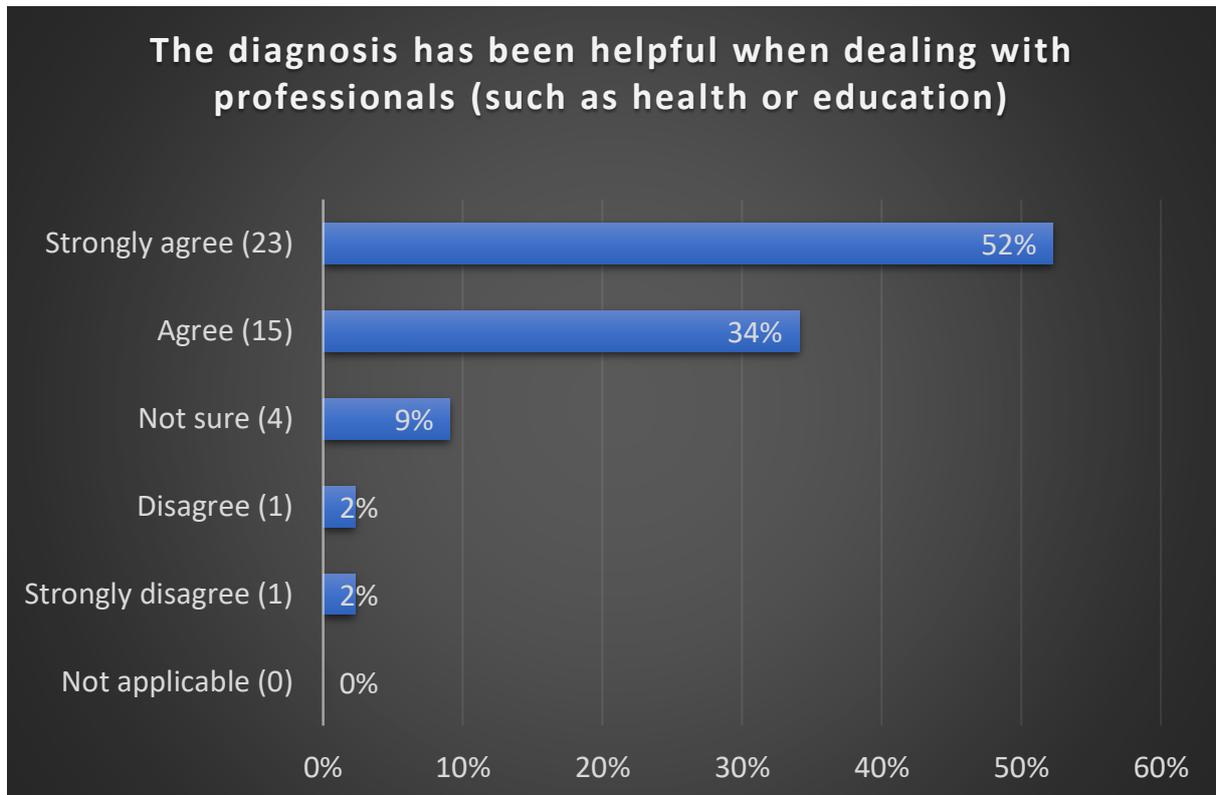
As a family, the diagnosis of autism has been helpful to us



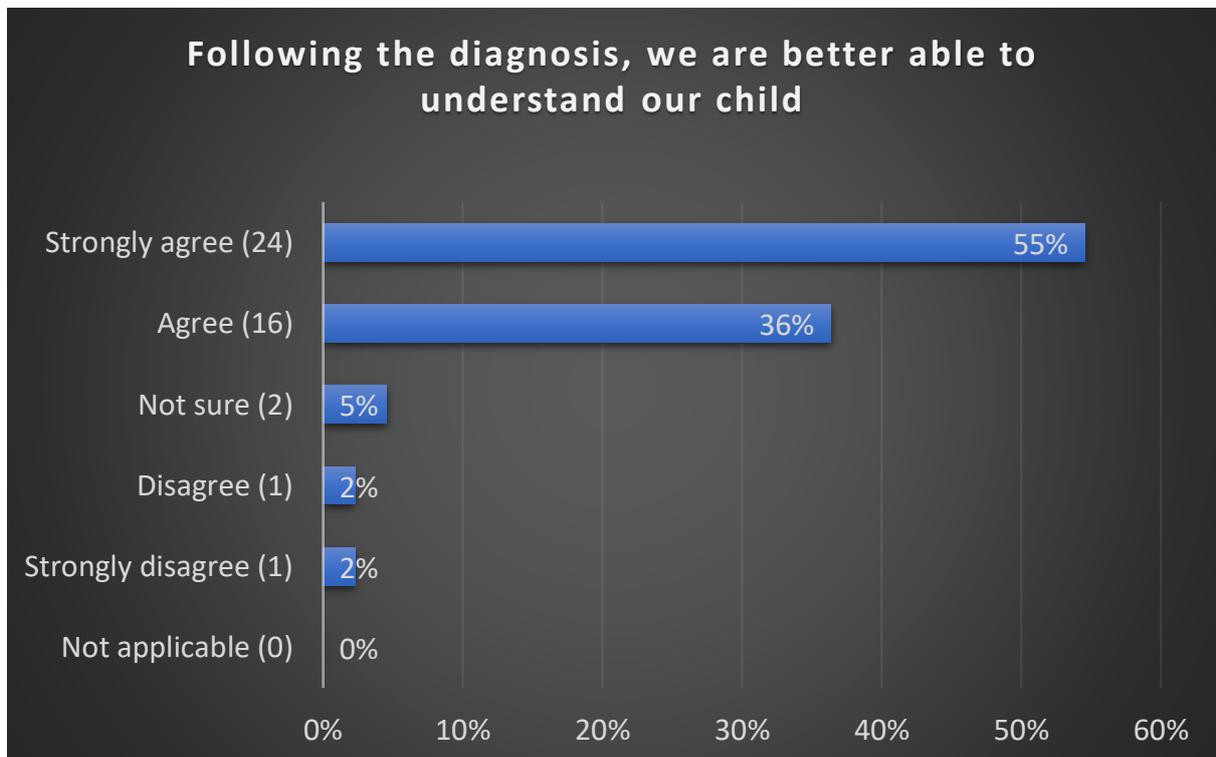
Following diagnosis our family relationships have improved



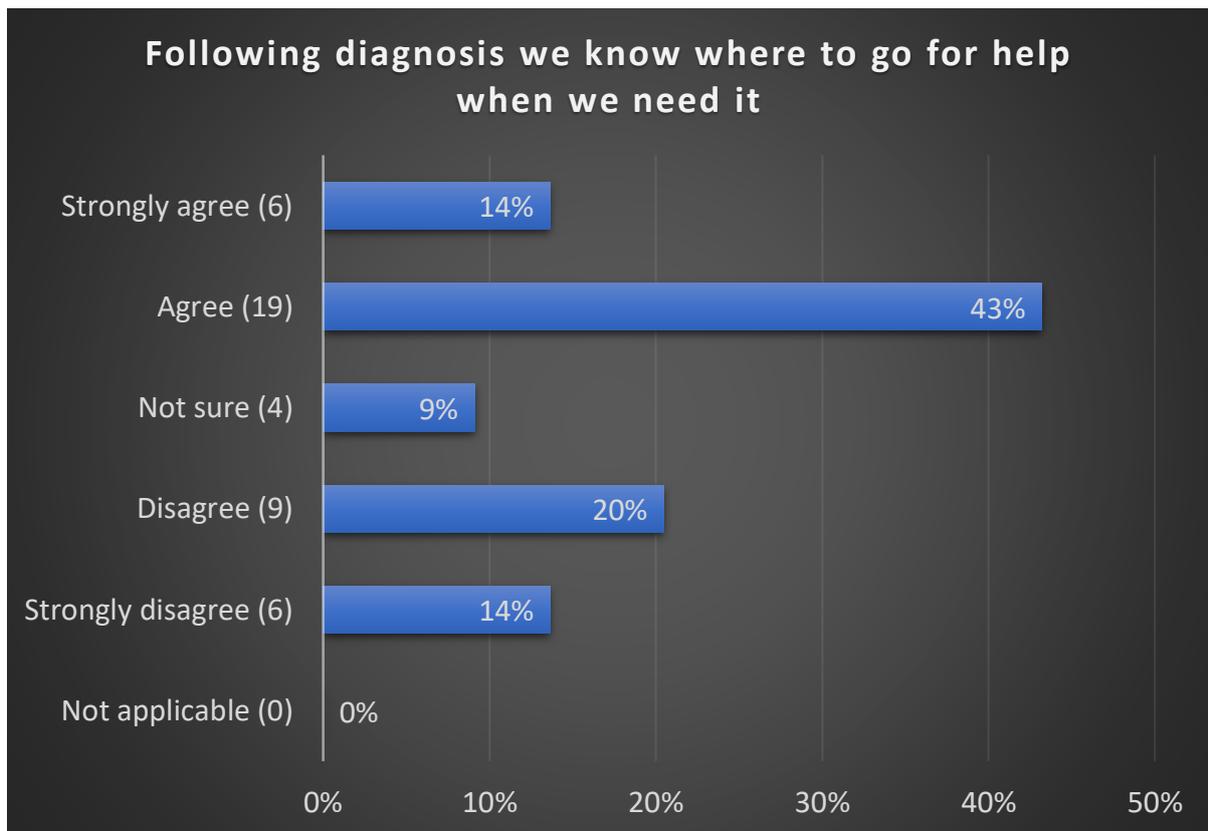
The diagnosis has been helpful when dealing with professionals (such as health or education)



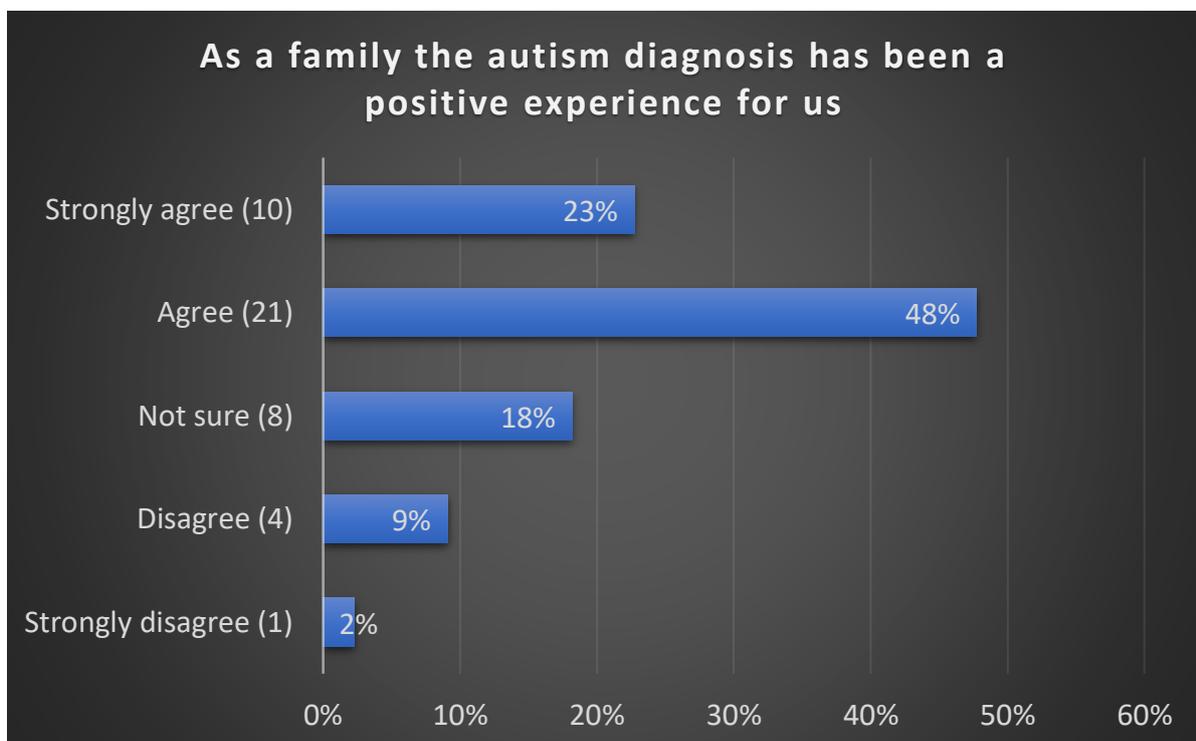
Following the diagnosis, we are better able to understand our child



Following diagnosis we know where to go for help when we need it

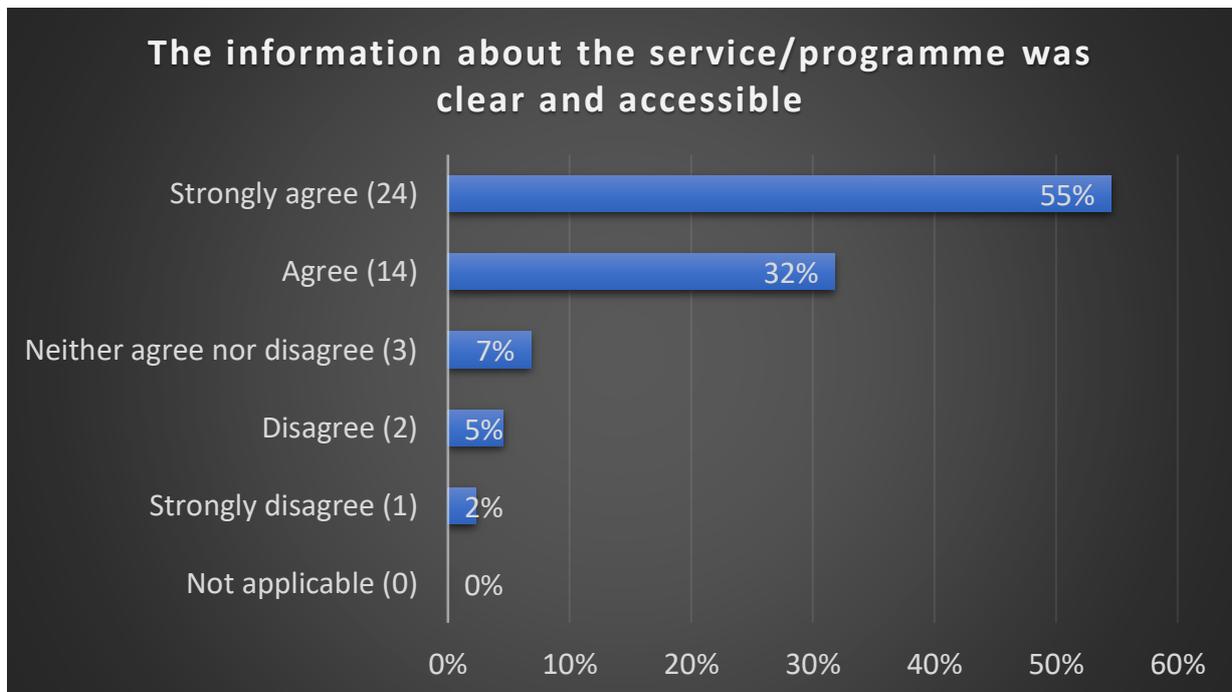


As a family the autism diagnosis has been a positive experience for us

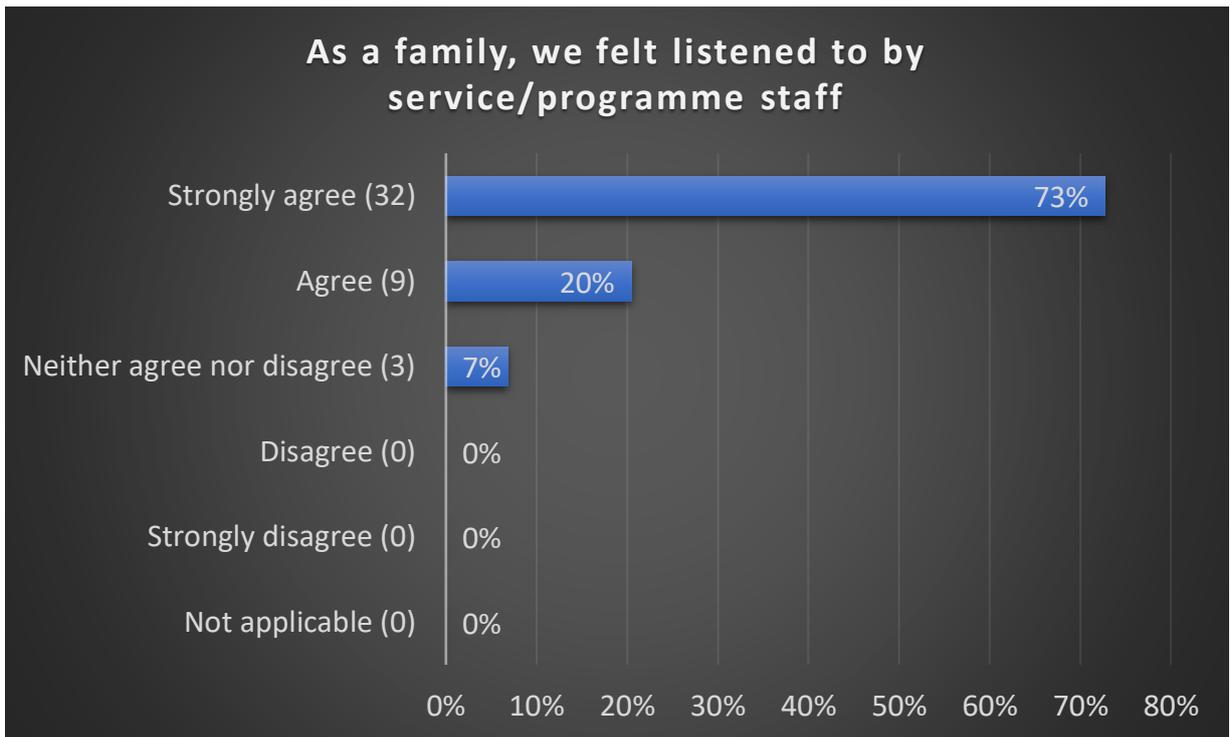


Regarding the service/programme

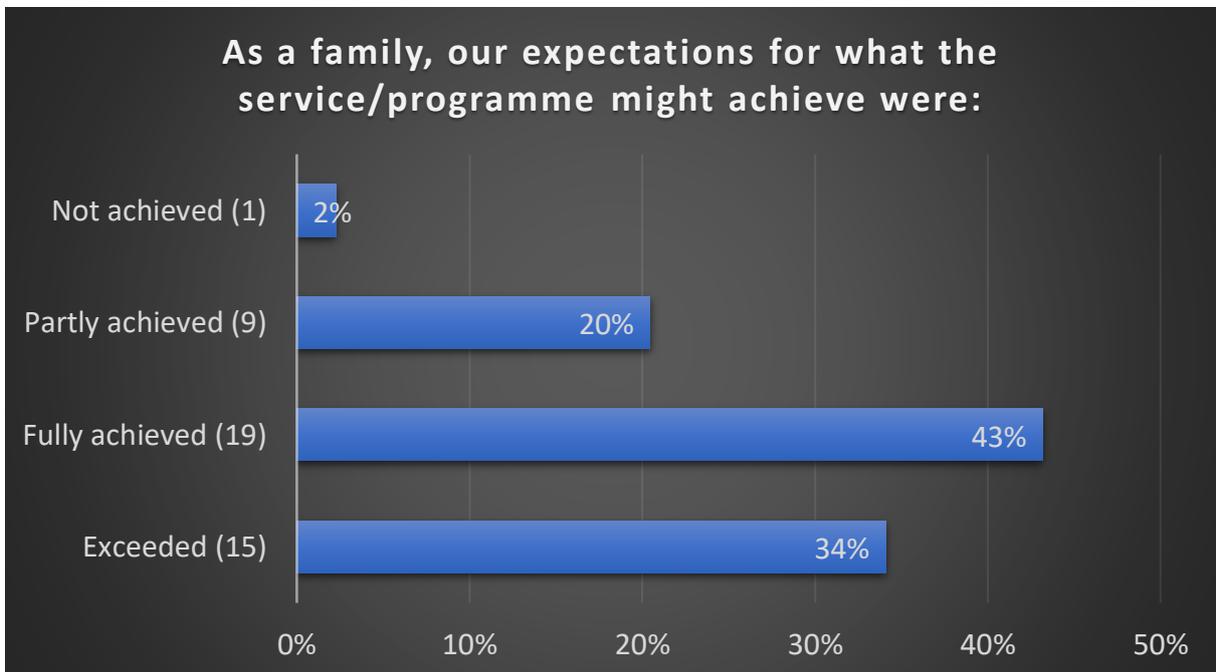
The information about the service/programme was clear and accessible



As a family, we felt listened to by service/programme staff

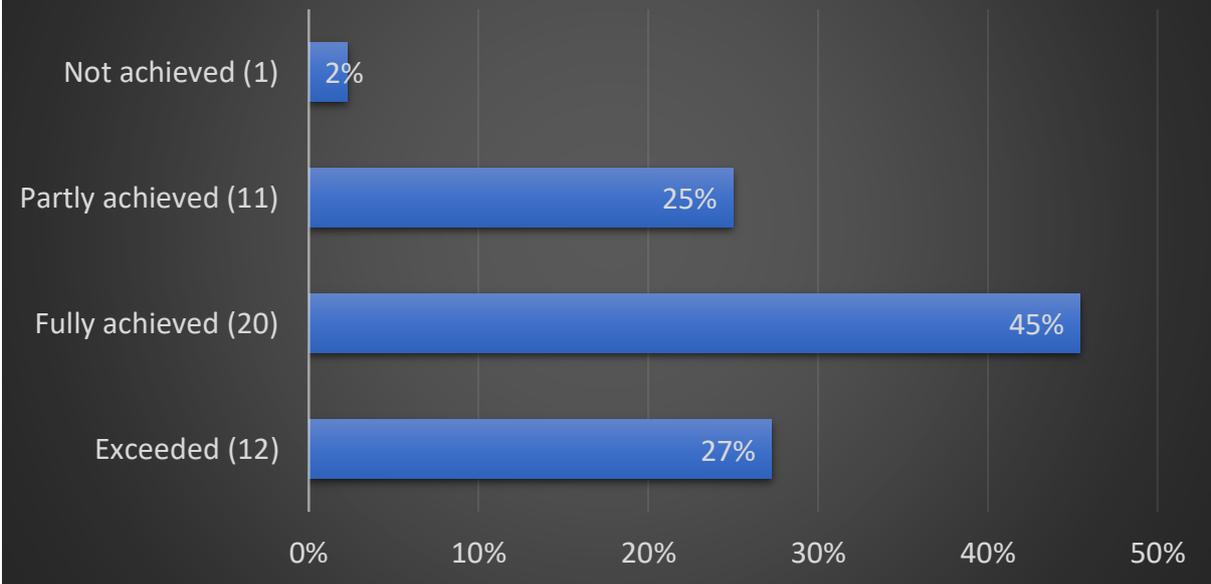


As a family, our expectations for what the service/programme might achieve were:

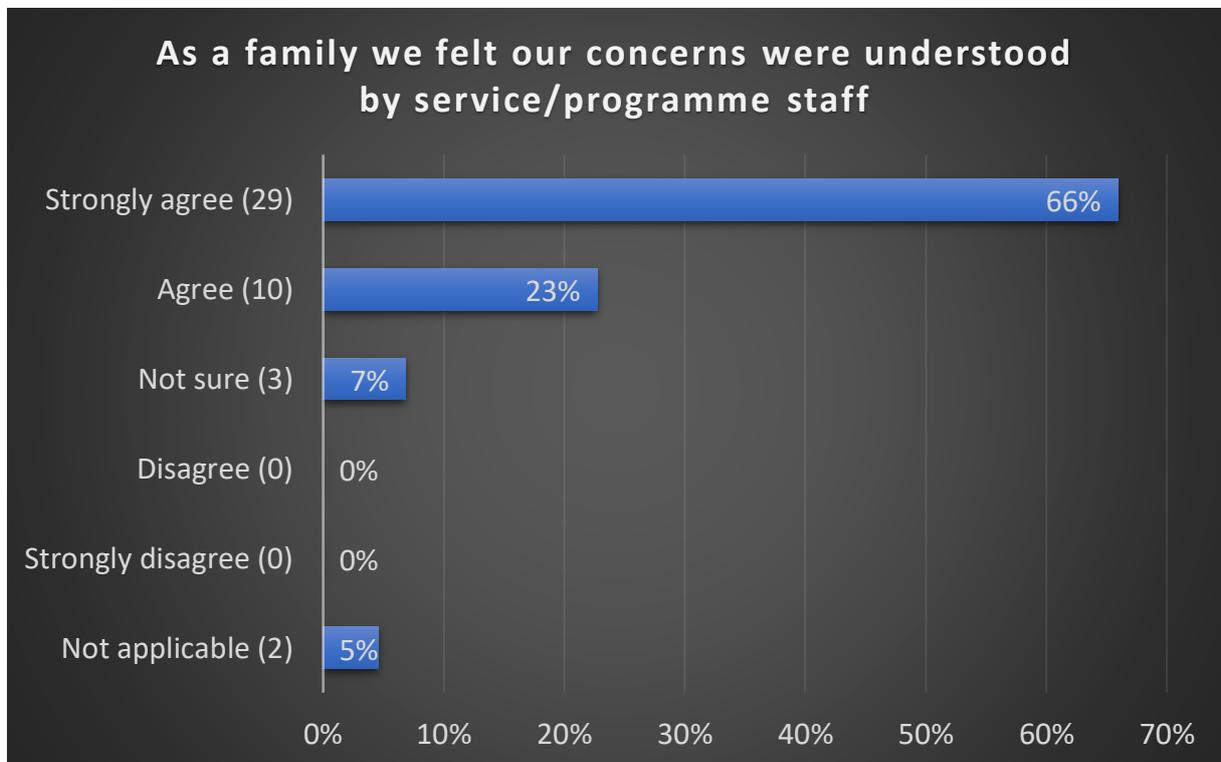


As a family, our goals for what the service/programme might achieve were:

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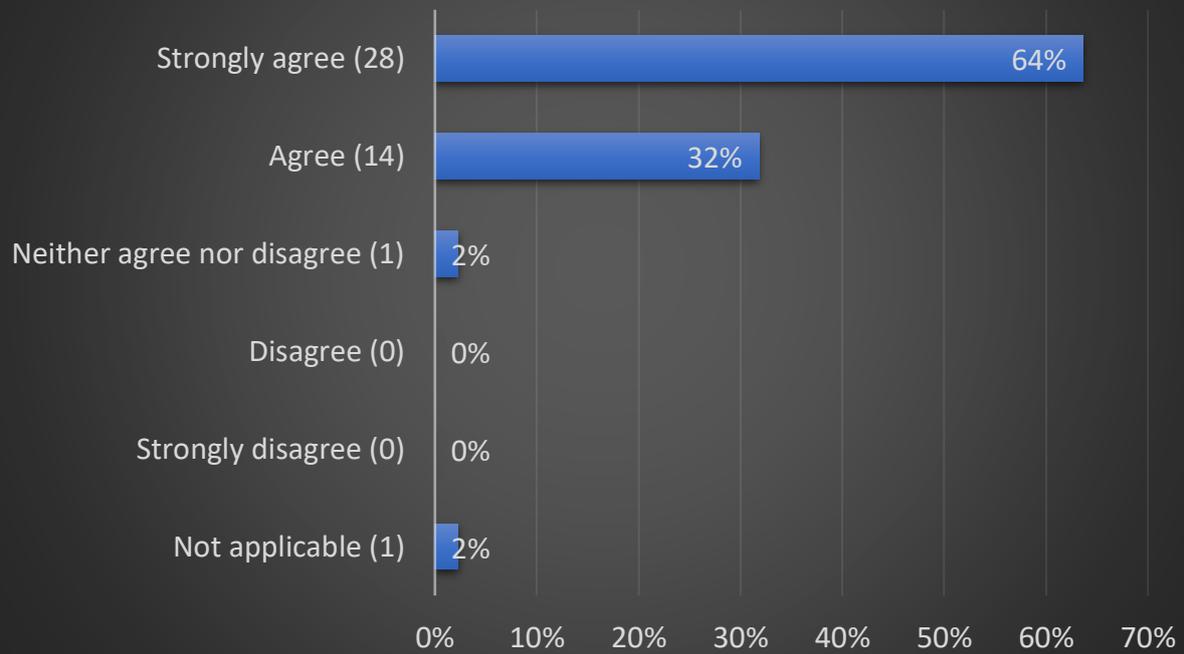


As a family we felt our concerns were understood by service/programme staff

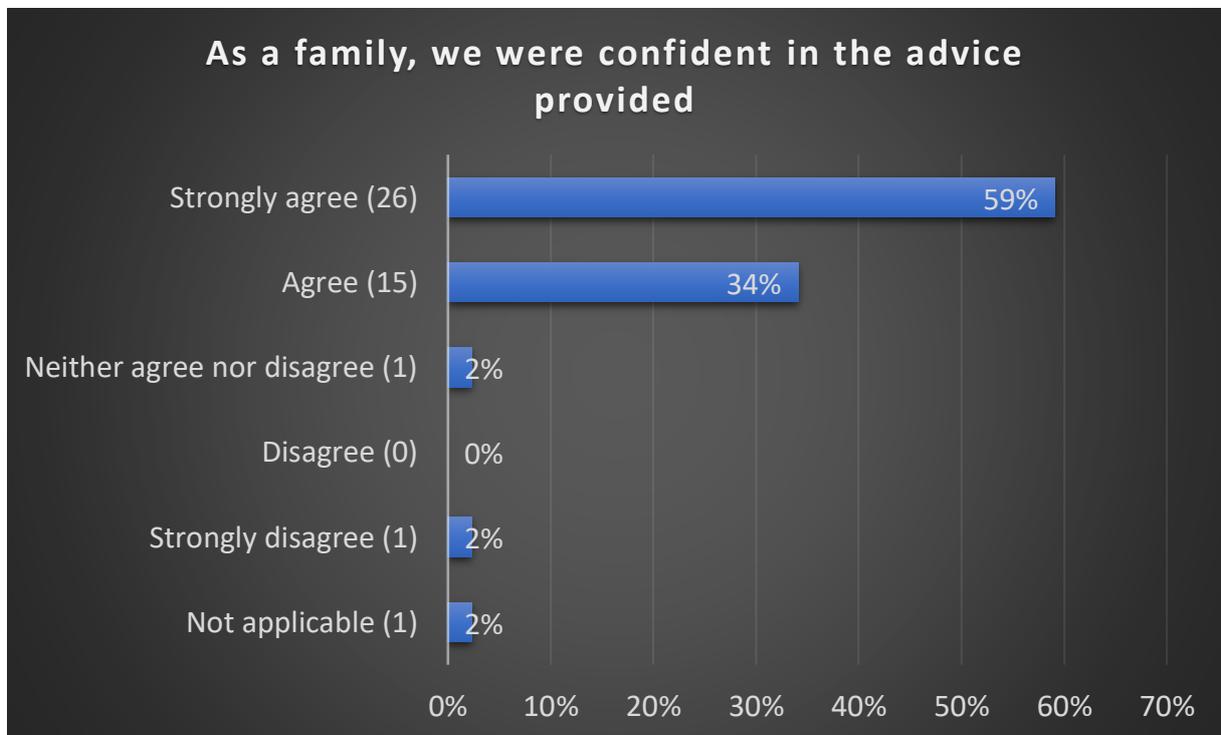


The information about autism was relevant to our child

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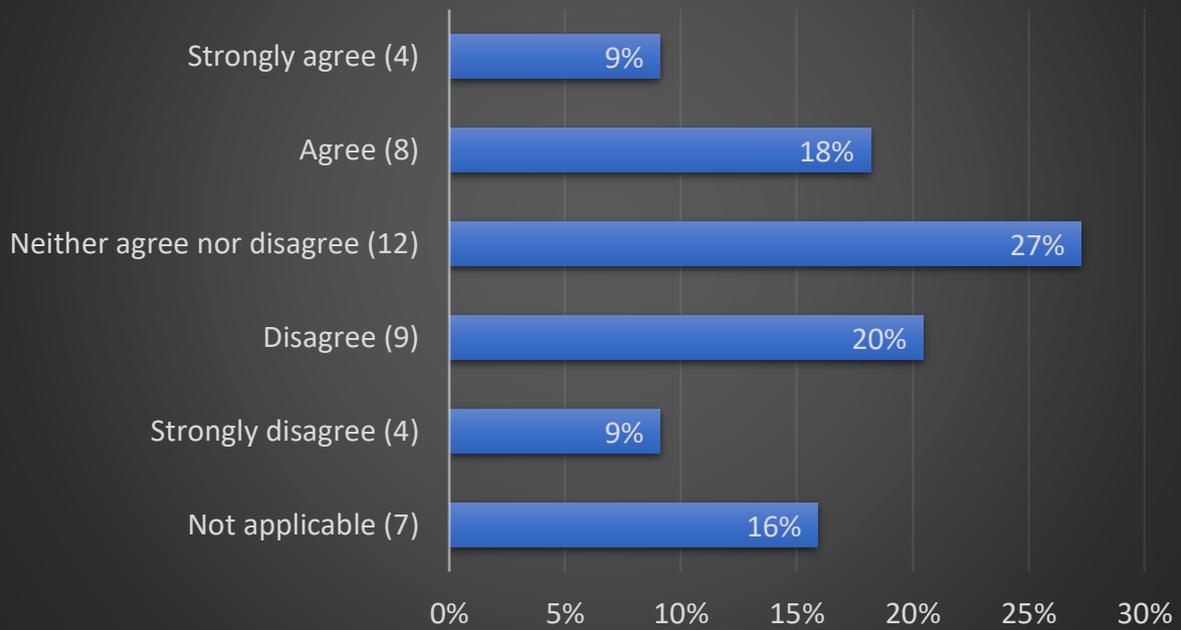


As a family, we were confident in the advice provided



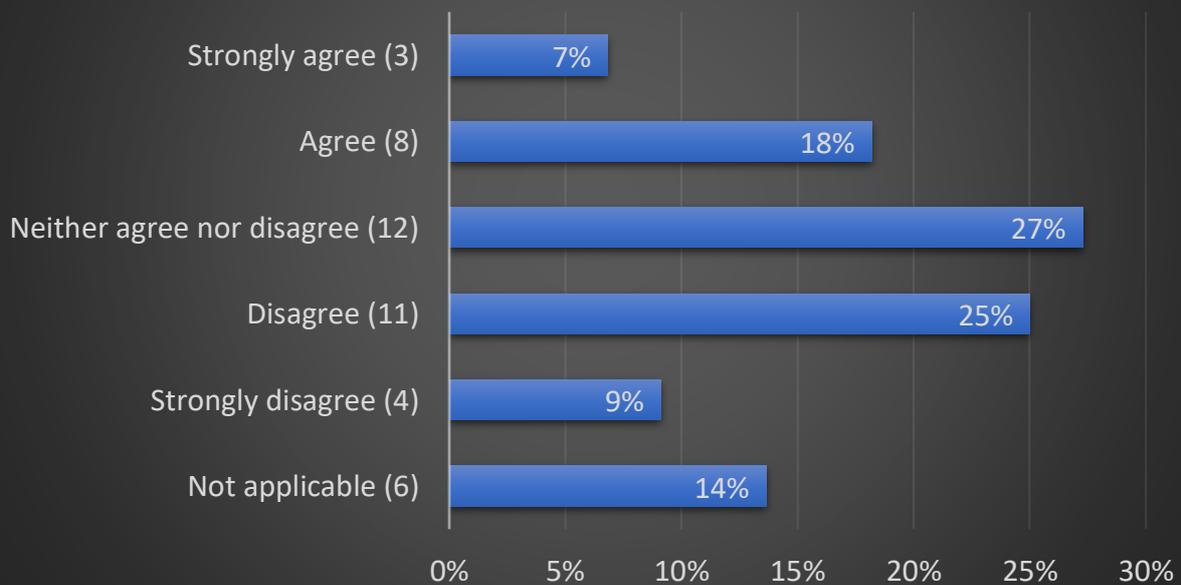
Since our involvement with the service/programme, we now have a connection with other families with an autistic child

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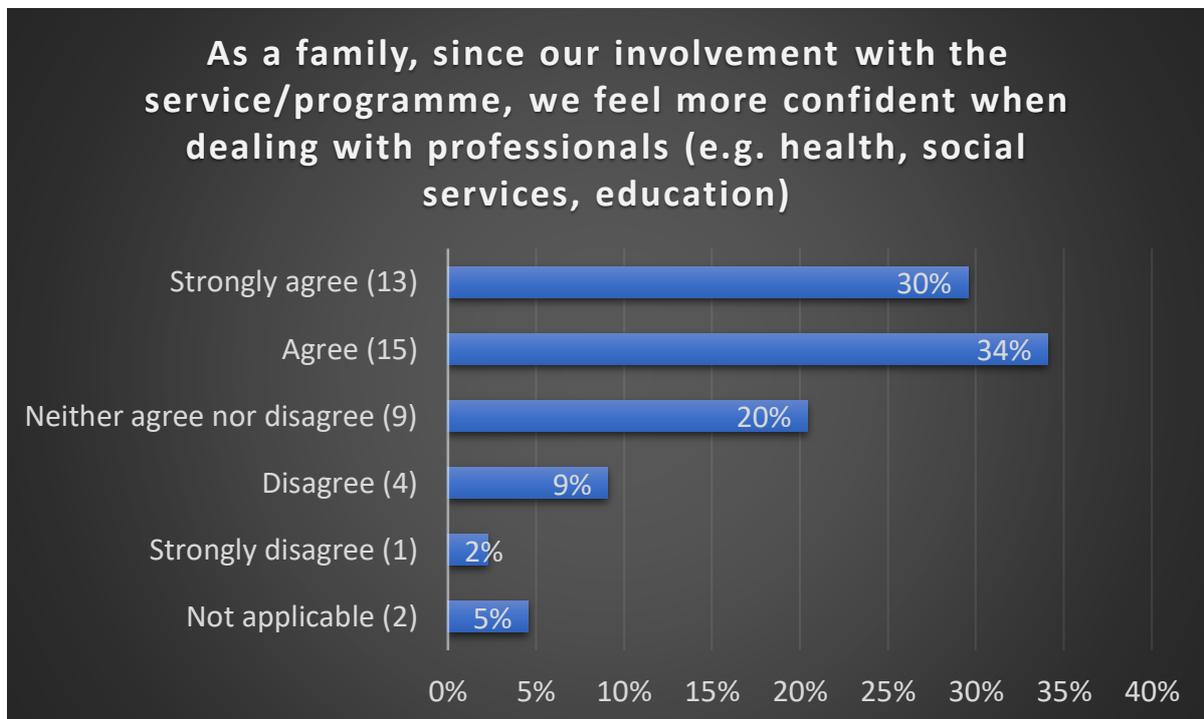


As a family we already had a connection to other families, but this has increased since our involvement with the service/programme

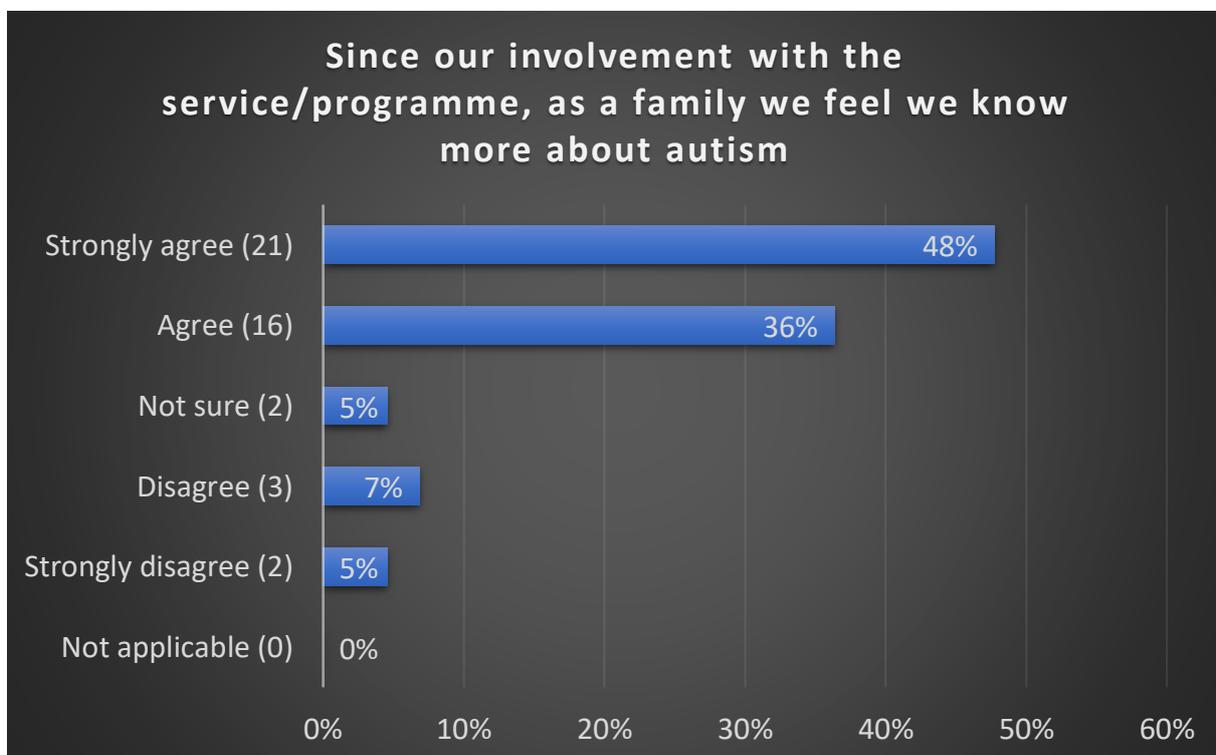
As a family we already had a connection to other families, but this has increased since our involvement with the service/programme



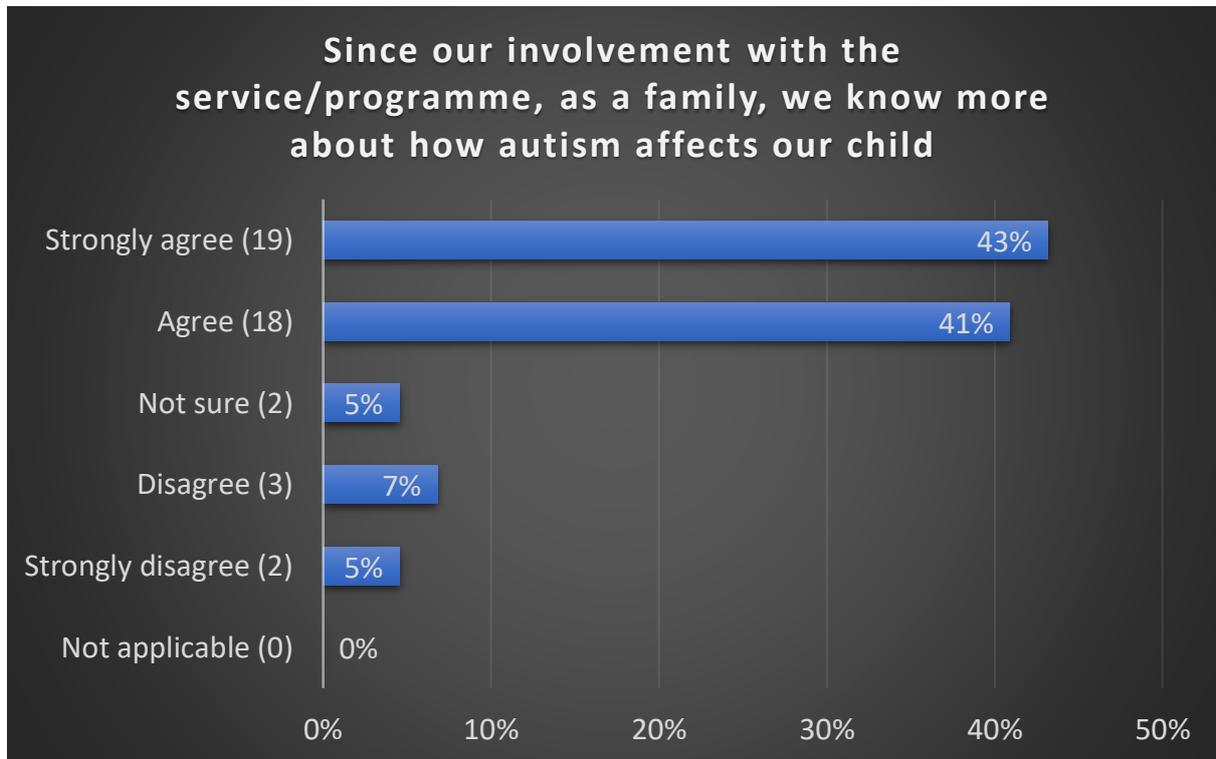
As a family, since our involvement with the service/programme, we feel more confident when dealing with professionals (e.g. health, social services, education)



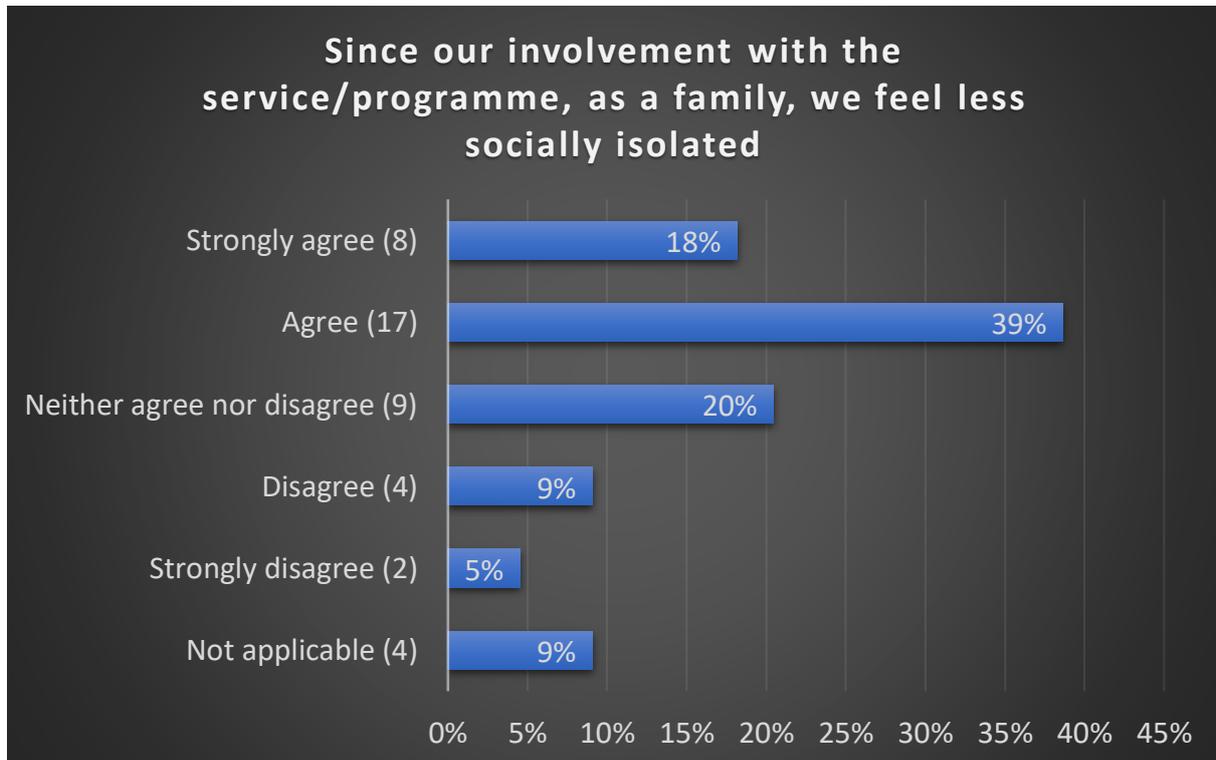
Since our involvement with the service/programme, as a family we feel we know more about autism



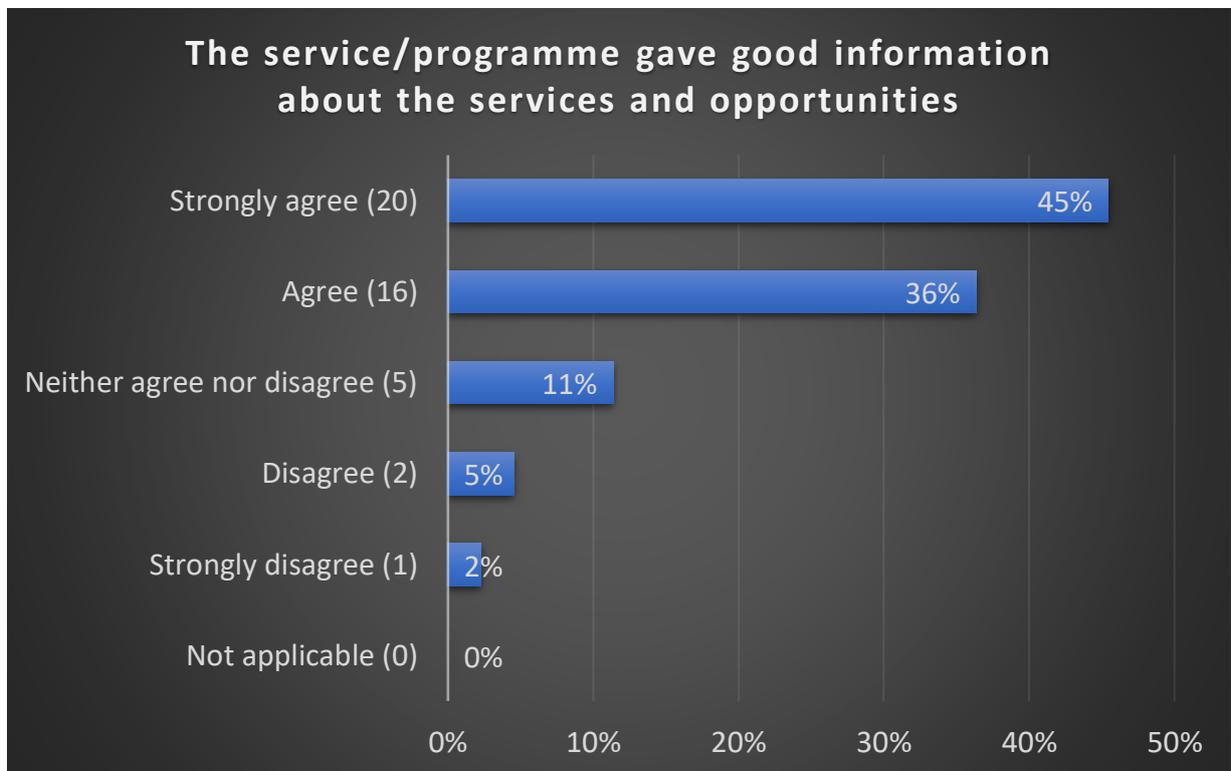
Since our involvement with the service/programme, as a family, we know more about how autism affects our child



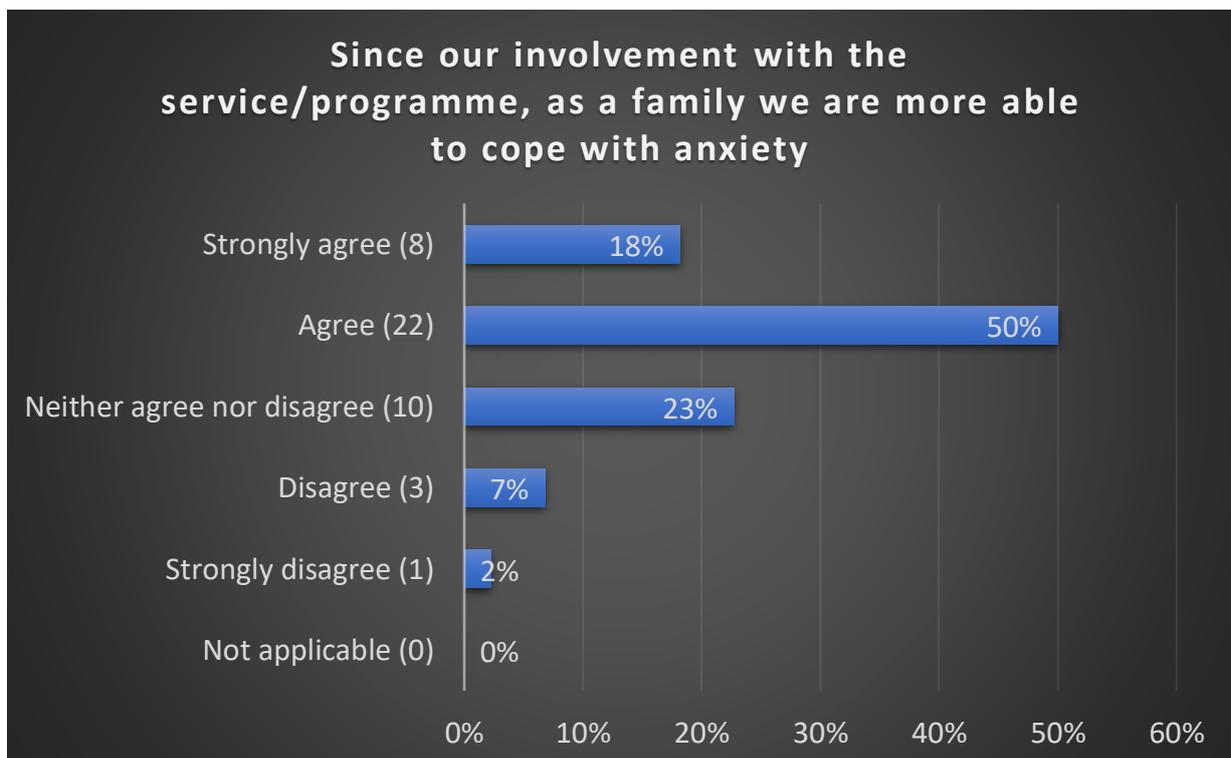
Since our involvement with the service/programme, as a family, we feel less socially isolated



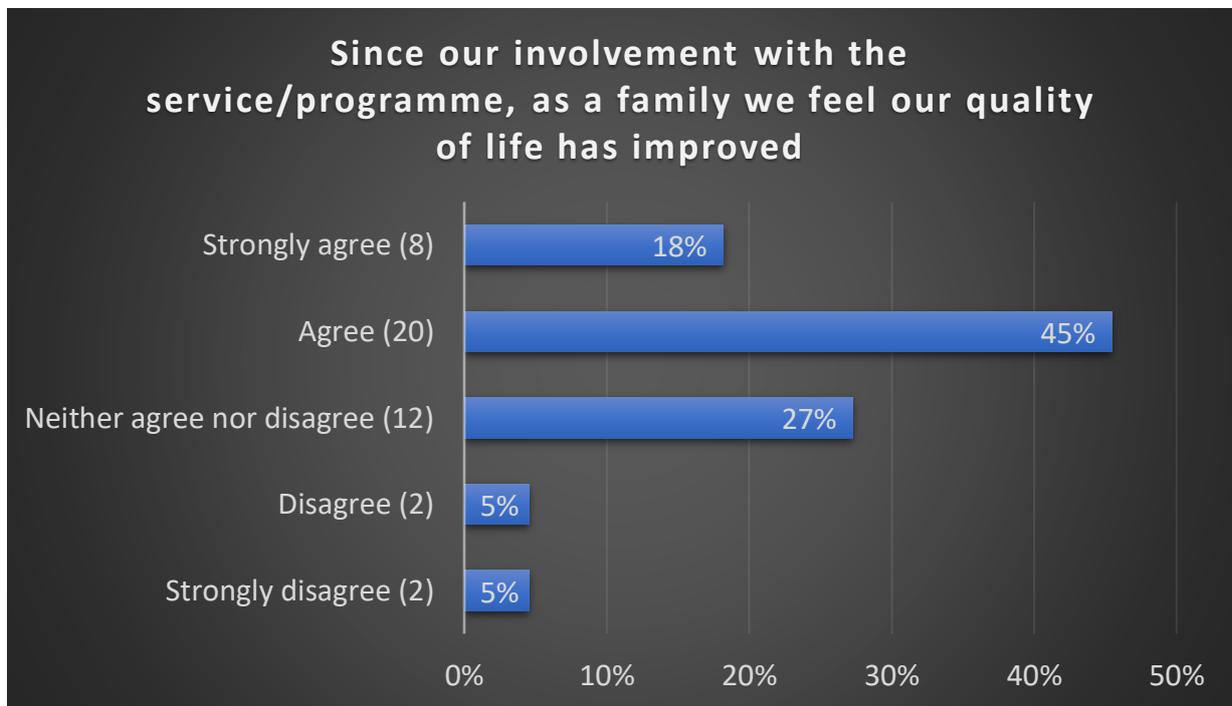
The service/programme gave good information about the services and opportunities



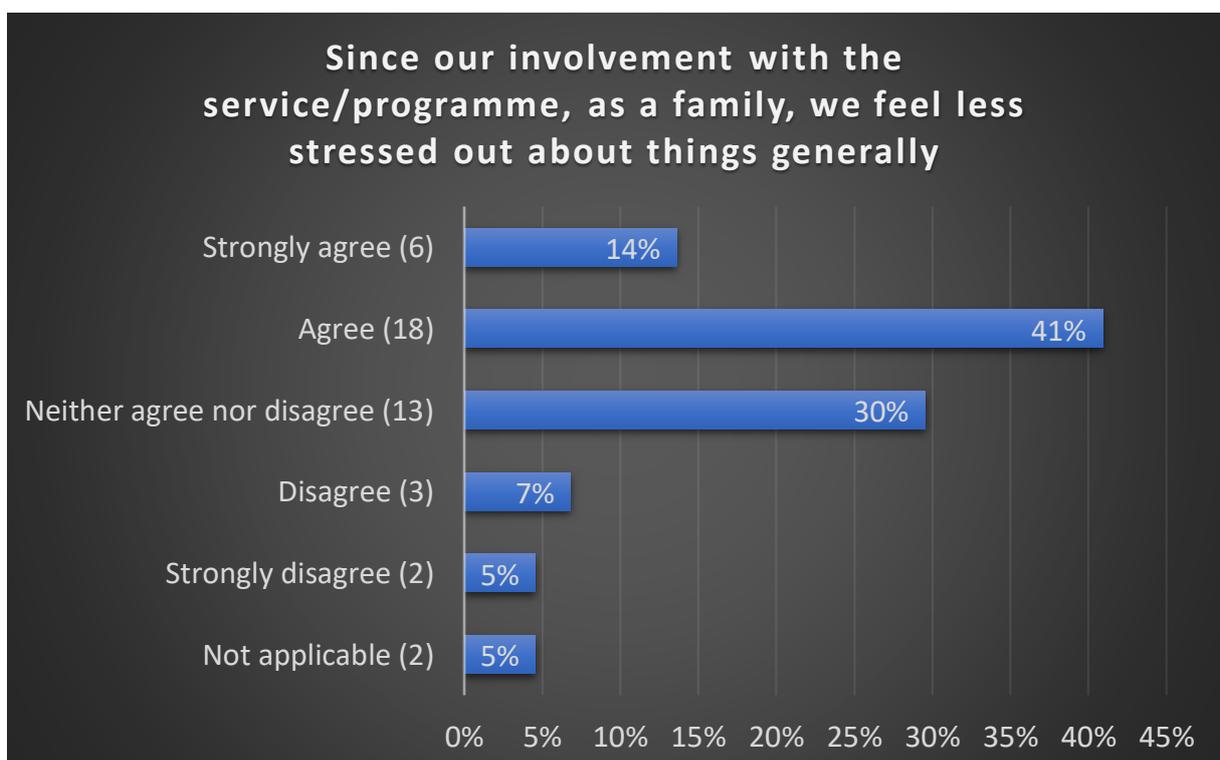
Since our involvement with the service/programme, as a family we are more able to cope with anxiety



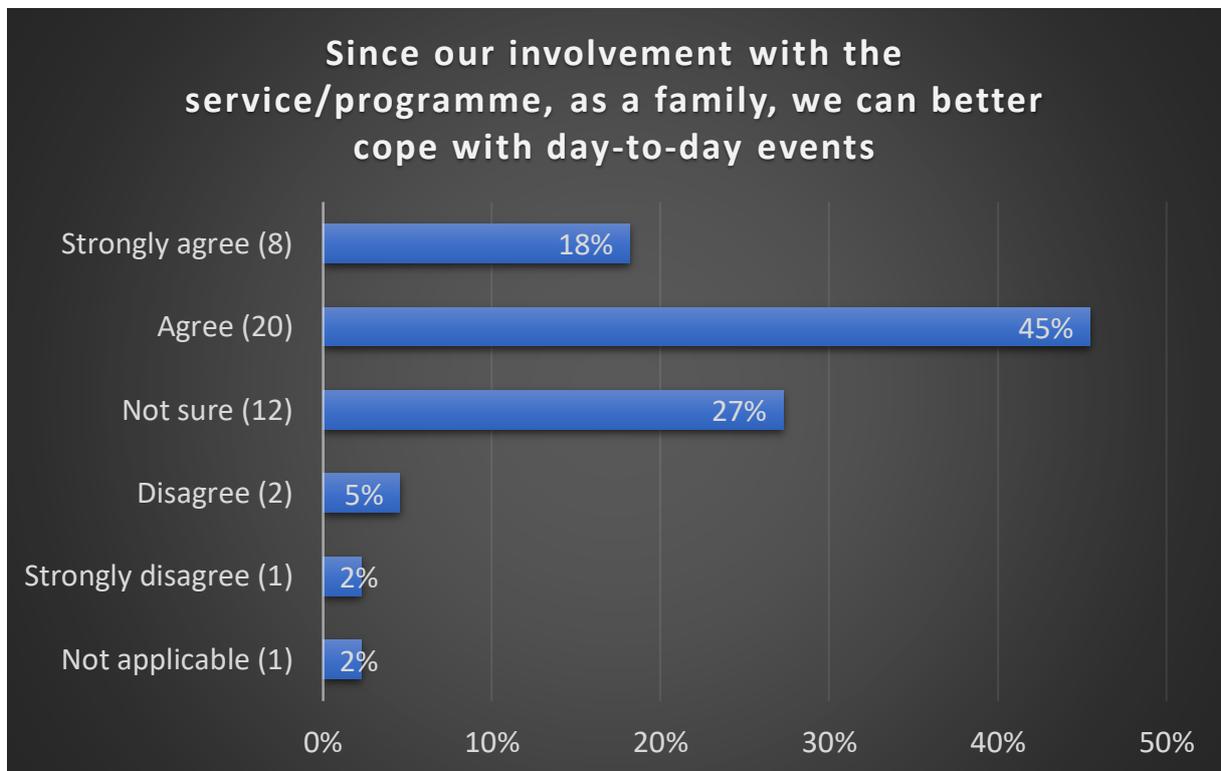
Since our involvement with the service/programme, as a family we feel our quality of life has improved



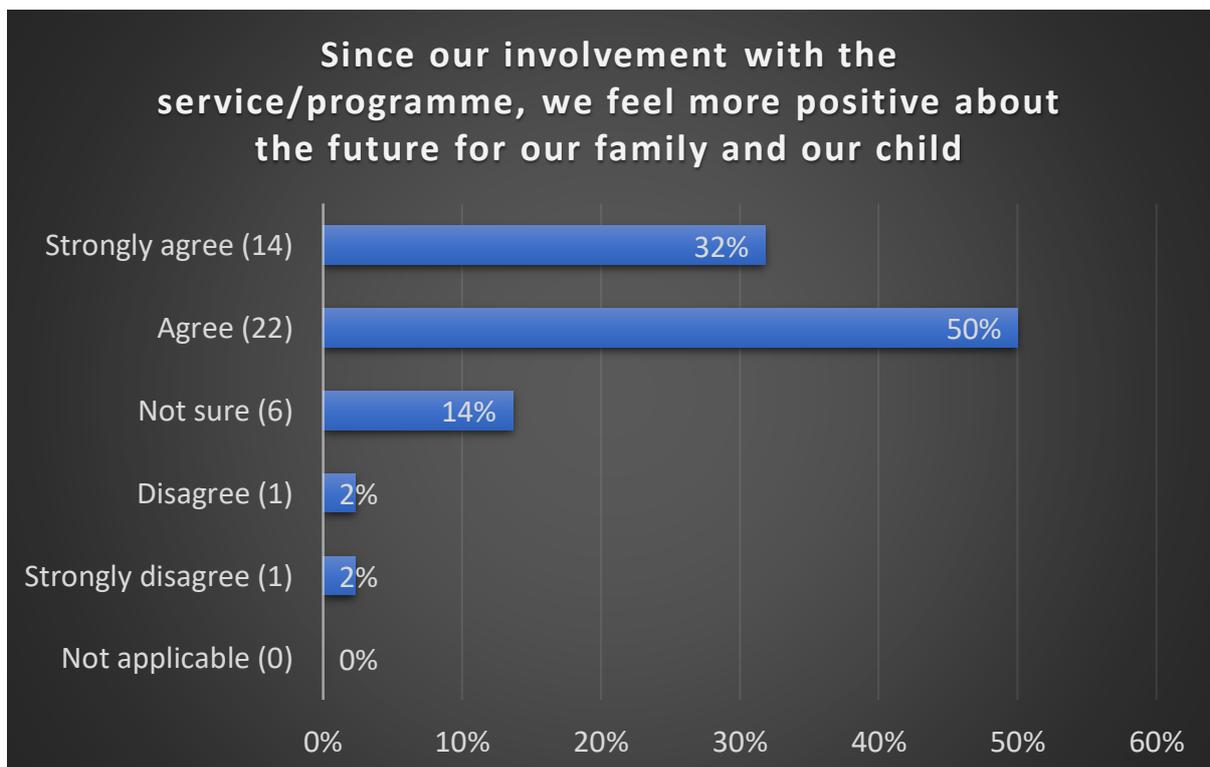
Since our involvement with the service/programme, as a family, we feel less stressed about things generally



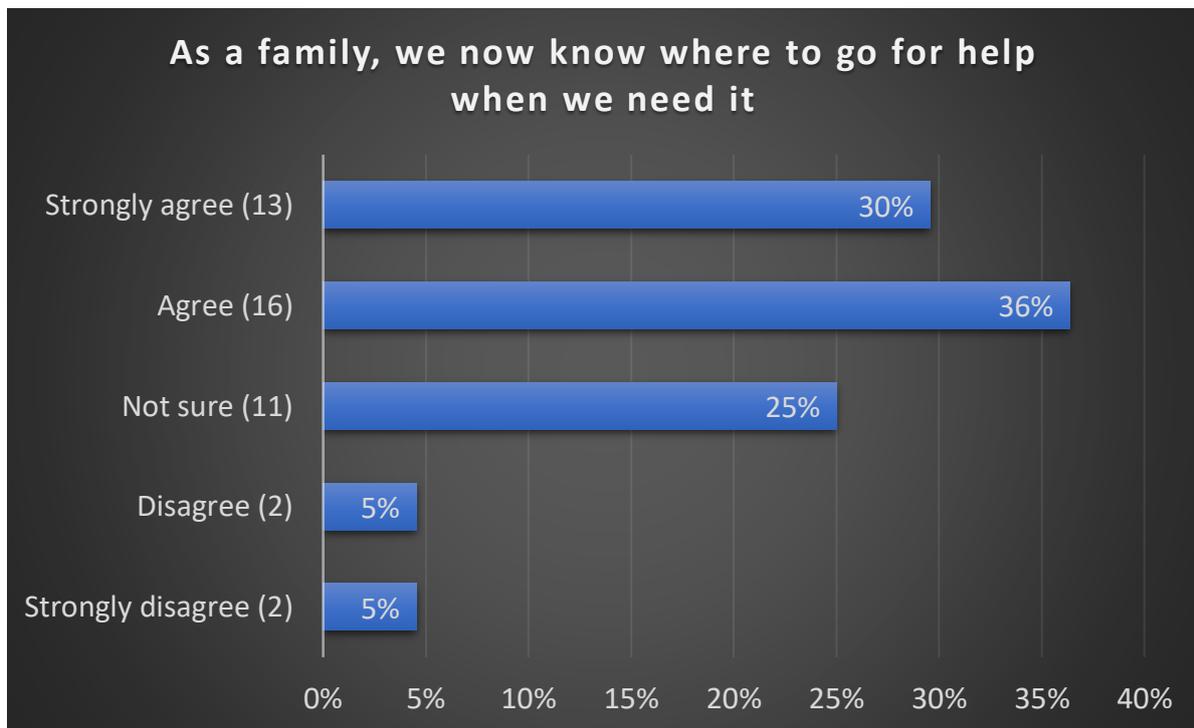
Since our involvement with the service/programme, as a family, we can better cope with day-to-day events



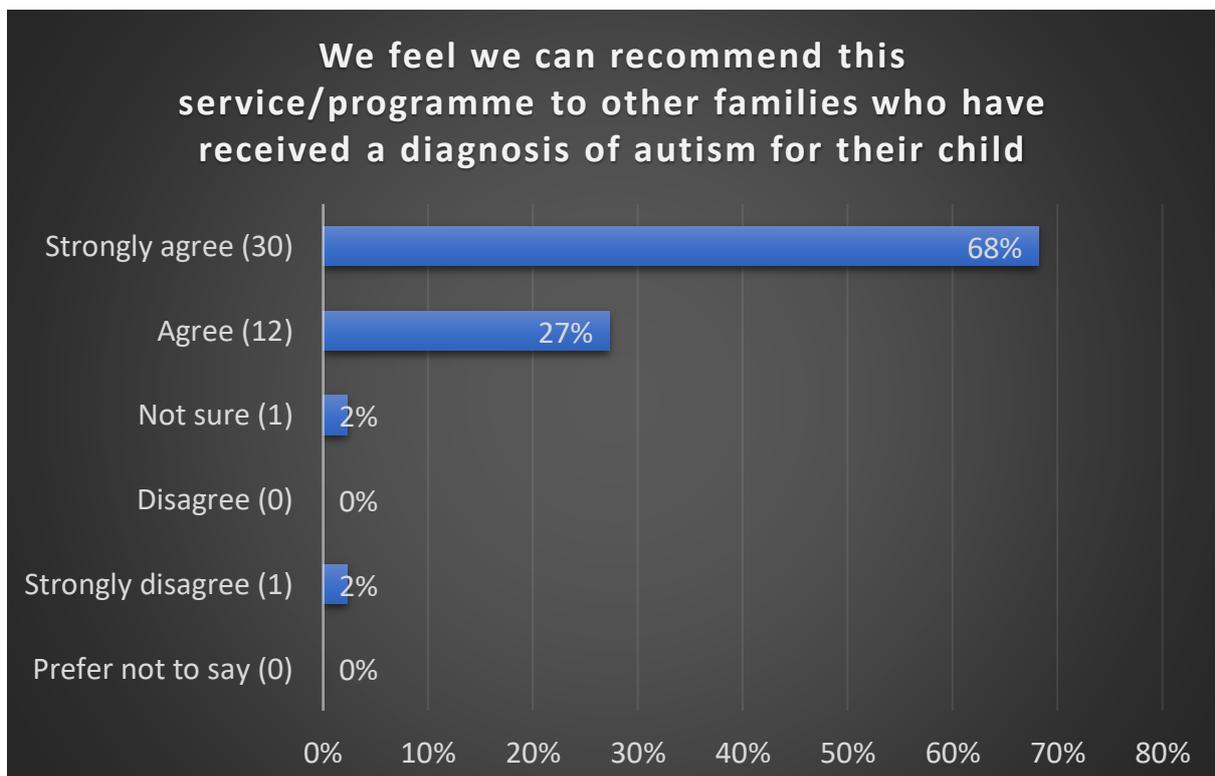
Since our involvement with the service/programme, we feel more positive about the future for our family and our child



As a family, we now know where to go for help when we need it



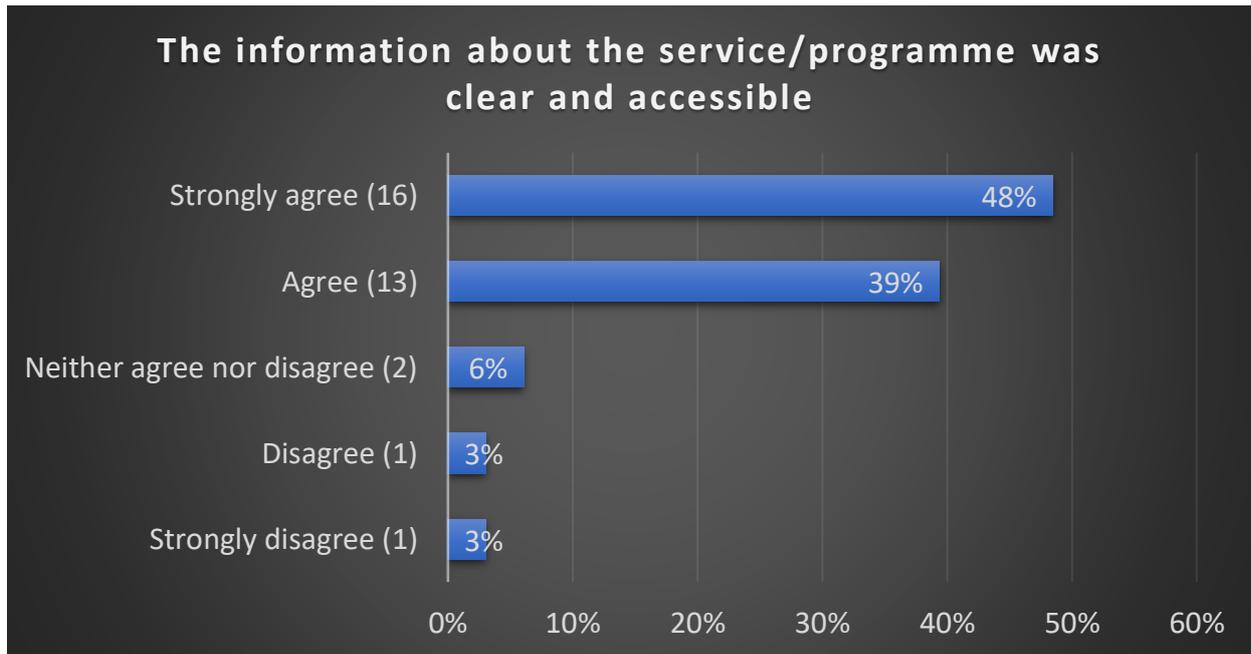
We feel we can recommend this service/programme to other families who have received a diagnosis of autism for their child



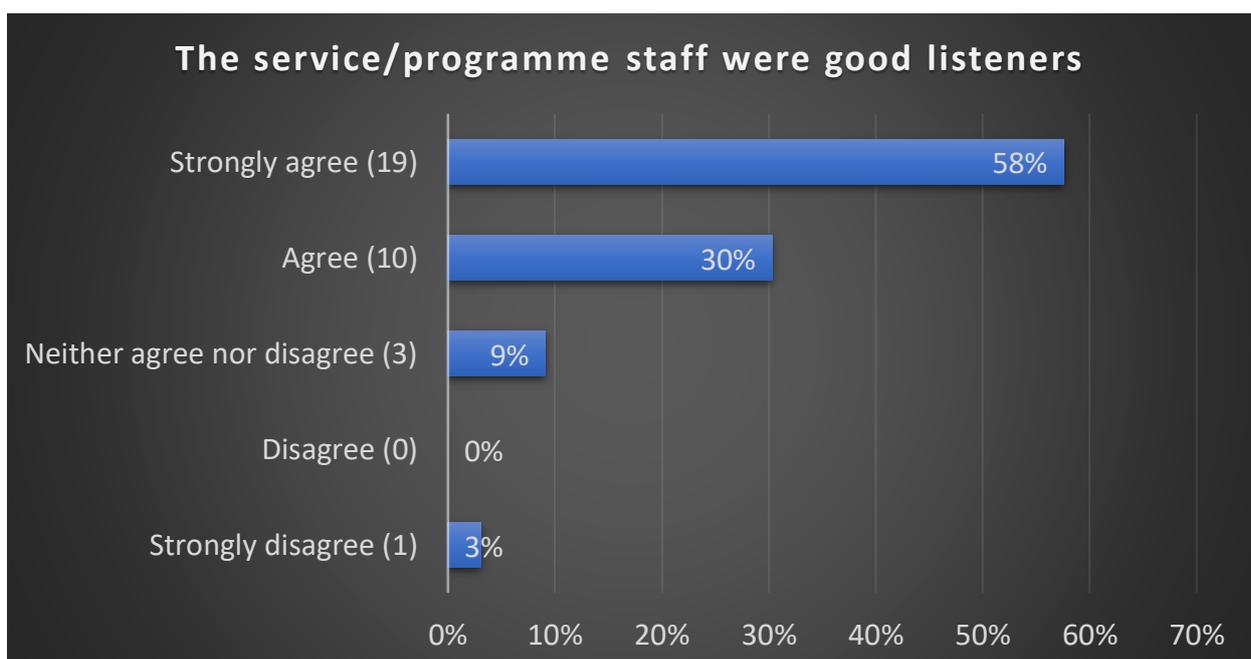
Responses where neither Individuals (Autistic person (over 16 years)), nor the family of an autistic child (16 and under) has received a diagnosis of autism in the last three years

As noted above, there are 27 individuals and 6 families of an autistic child who have not received a diagnosis of autism in the last 3 years.

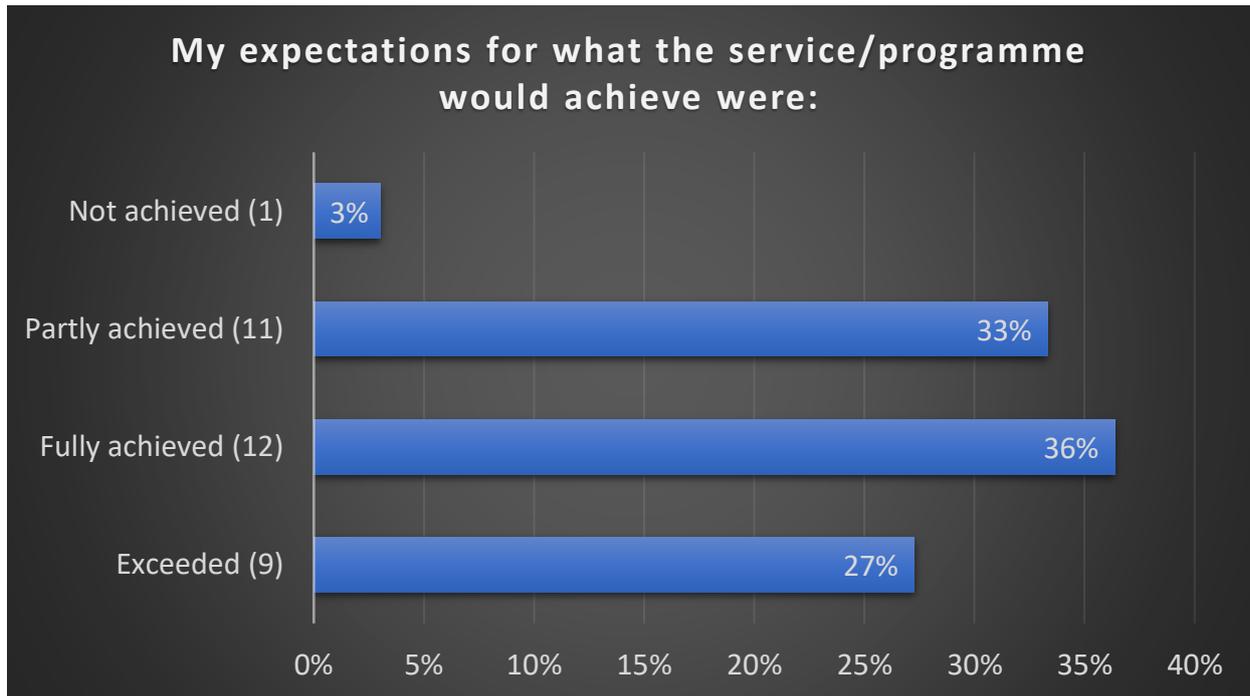
The information about the service/programme was clear and accessible



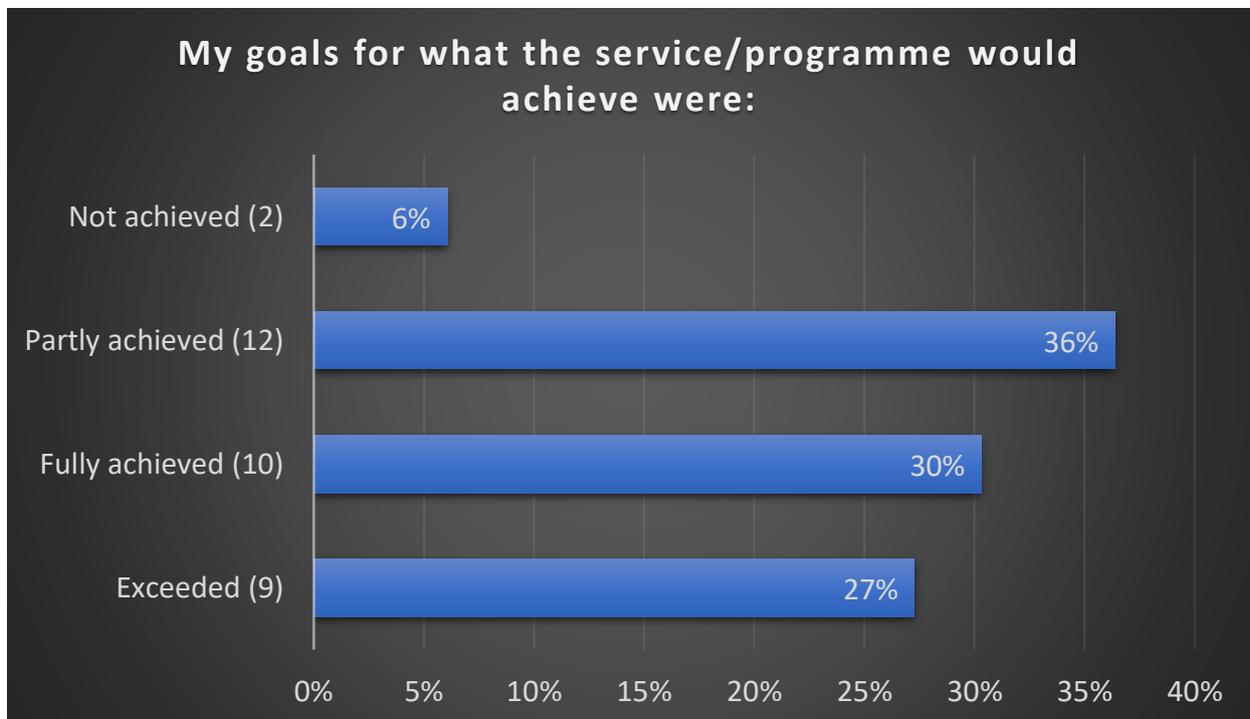
The service/programme staff were good listeners



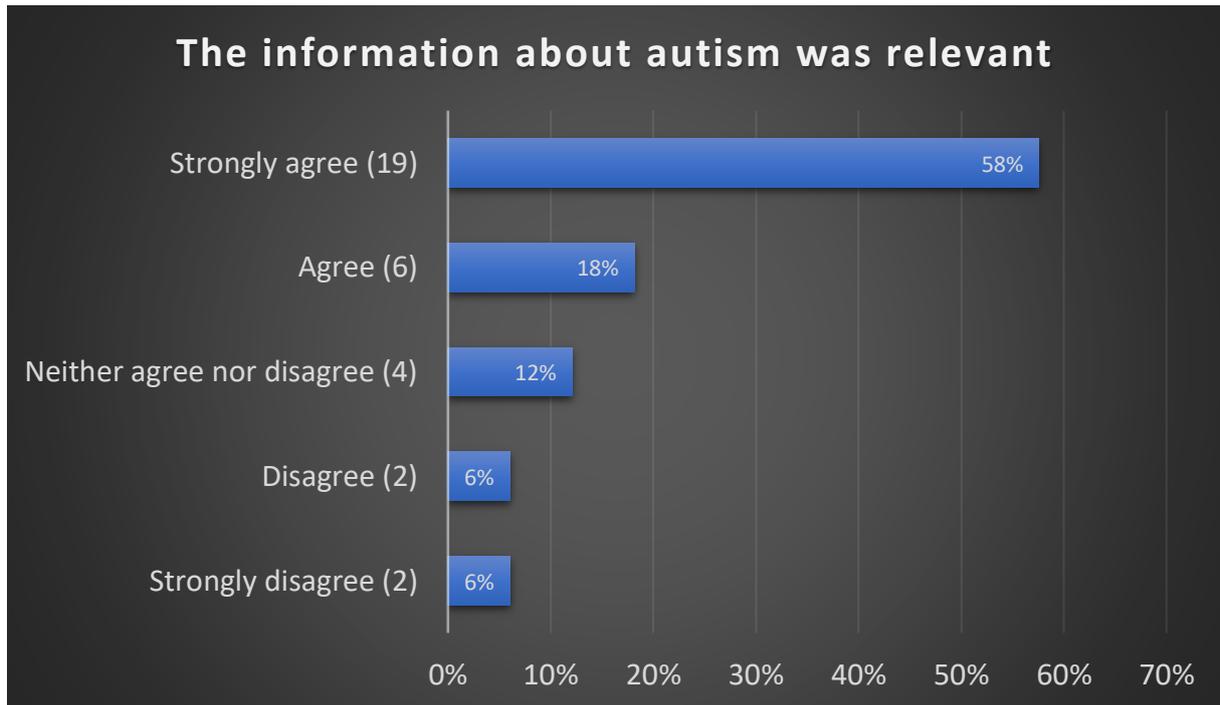
My expectations for what the service/programme would achieve were:



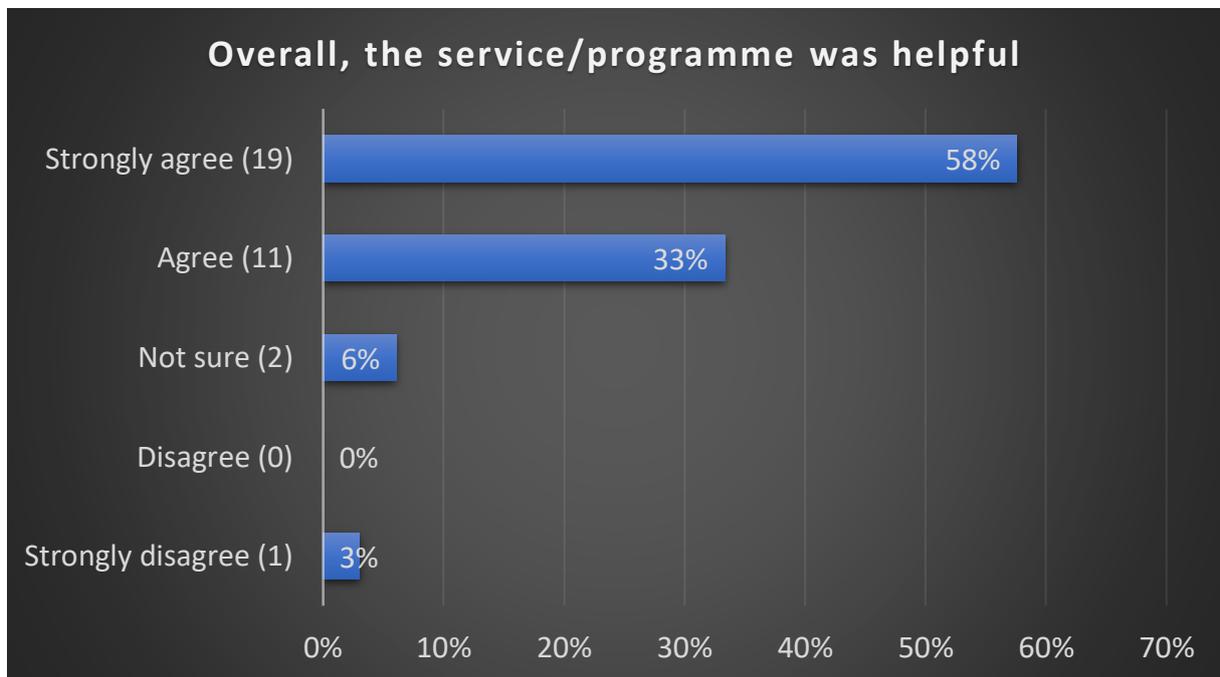
My goals for what the service/programme would achieve were:



The information about autism was relevant



Overall, the service/programme was helpful





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