

PERTH AUTISM SUPPORT

Family and Education Service Consultation November 2022

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EXECUTIVE SUMMARY

Parents and carers were invited to engage in consultation in a range of ways, including a paper questionnaire, an online Survey Monkey, voting polls within a closed Facebook group, and both in-person and online focus groups.

Questions focused on parents' and carers' knowledge and experience of the current Family and Education Service, gaps in service and ideas for new ways to improve accessibility. Results have been collated from all sources to form answers to the questions.

Results show the awareness and experience of the Family and Education Services and suggest areas of development that should be considered.

CONSULTATION SNAPSHOT

48

Total Respondents
(Paper Questionnaire
and Survey Monkey)

506

Responses Cast Within
Facebook Polls

3 mins 47 secs

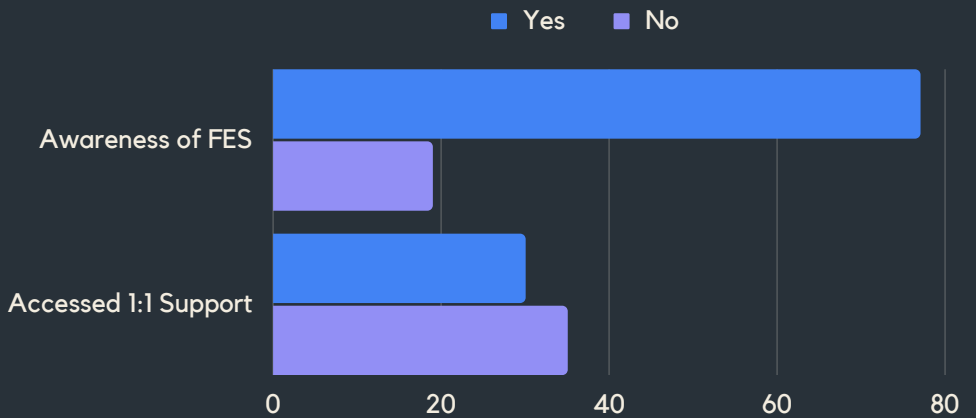
Average Time to
Complete Survey
(Survey Monkey)



GENERAL AWARENESS OF THE FAMILY AND EDUCATION SERVICE

All participants answered the first question, with the majority demonstrating awareness of Family and Education Services at Perth Autism Support - 80% (77 participants).

30 people indicated that they had accessed Family and Education Services and 35 had not. This might indicate that they did not need the service, were able to get support if needed from other sources or it might indicate that there is a difficulty in accessing the service.



14 people provided further details on how they would access the service, with the vast majority stating they would phone or email reception for further details.

Only 3 participants mentioned contacting the service or Line Manager directly.

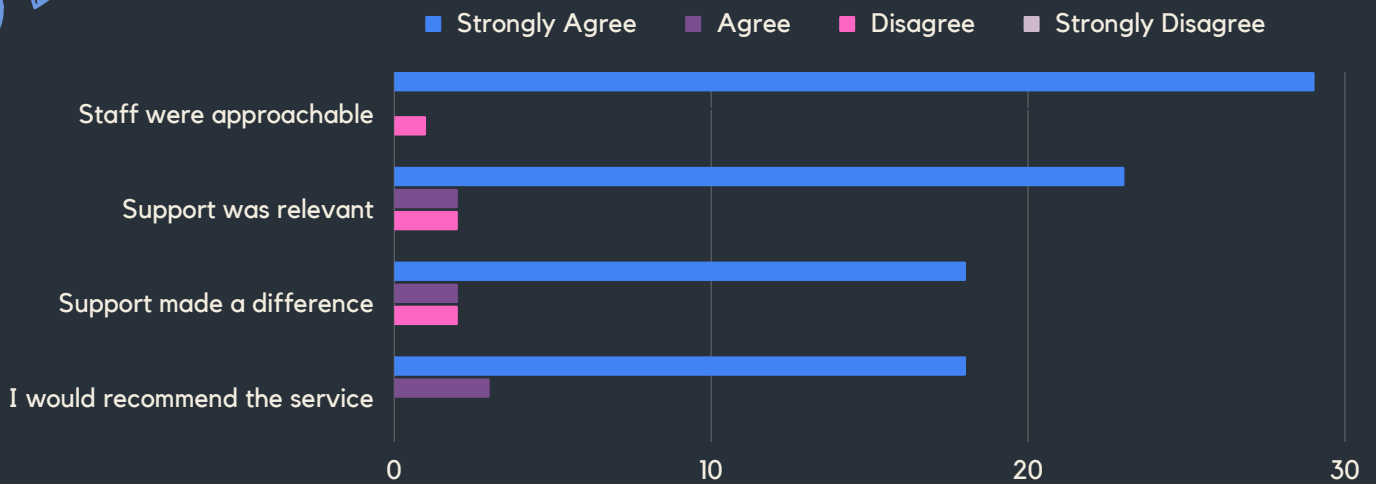
4 participants were aware of the requirement to complete a referral form.

Six people indicated whether or not they had problems accessing the service. Three people had no issues, the other two are outlined below:

PARTICIPANT	DETAILS	ANALYSIS
One	Phoned Children's Services and they arranged for the Family and Education Service to get in contact.	<ul style="list-style-type: none"> Shows joined up working internally.
Two	Lots of staff changes - when your allocated person leaves, the support stops.	<ul style="list-style-type: none"> Participant stated they accessed service in 2000 - this is an error as Perth Autism Support was not started until 2011. In rating of service, participant disagreed that staff were approachable, support was relevant/made a difference, but would still recommend service. Highlights possible improvements to be made at handover points.



EXPERIENCES OF PARENTS WHO HAVE USED THE FAMILY AND EDUCATION SERVICE

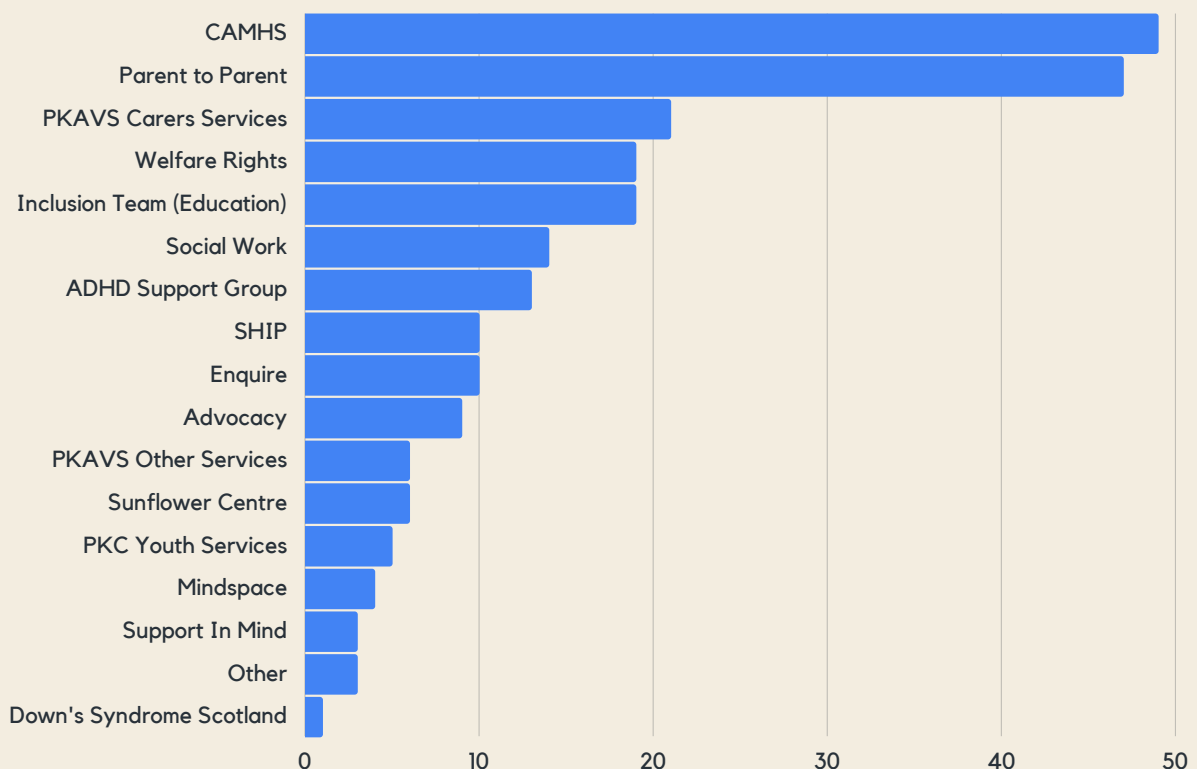


- No one "Strongly Disagreed" with anything.
- Everyone would recommend the service.
- Two respondents "Disagreed" that staff were approachable, and that the support was relevant/made a difference.
- All other respondents marked "Agree" or "Strongly Agree".

ACCESS OF EXTERNAL SUPPORTS

23 participants answered and 27 skipped this question via the Survey Monkey. On Facebook, 171 responses were recorded.

Three respondents noted other services they had used: Private Sensory Integration OT assessment, Early Bird and FASD Support Hub. One of these respondents was previously unaware of the Family and Education Service in Perth Autism Support. Most respondents had accessed Child and Adolescents Mental Health Services (CAMHS) - 49 respondents.



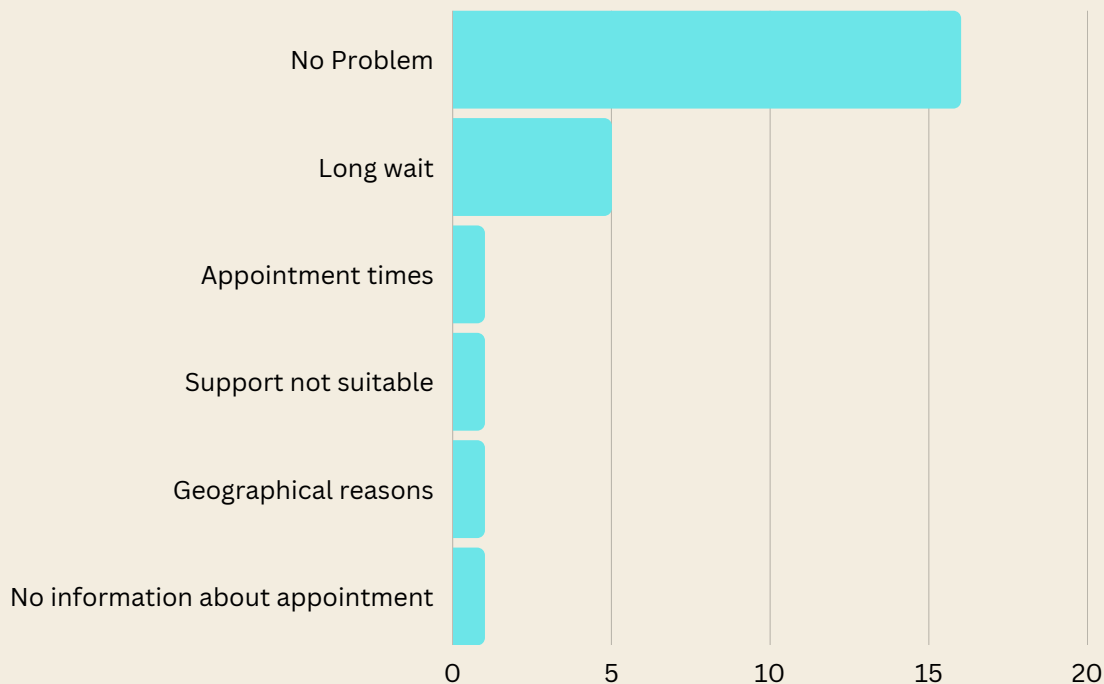


BARRIERS TO ACCESSING FAMILY AND EDUCATION SERVICES

This was a question specific to the Facebook page.

"If you accessed Family and Education Services, did you have any problems in accessing the service?"

There were 25 responses in total, and feedback was mostly positive.



The majority of the respondents said there was no problem to accessing support. The main problem respondents highlighted was the long wait times in accessing Family and Education Services, which accounted for 20% of total responses. The Family and Education Services have seen an increase in demand for the service since 2020 and the Covid19 pandemic. As of November, 2022, there are currently 34 families waiting for support and the longest wait time is 11 months.

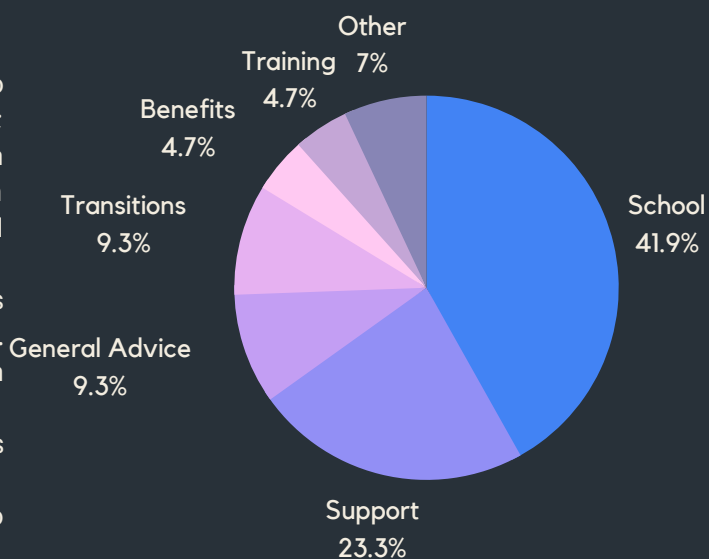
All other problems in accessing the service accounted for 16% of the total votes, with no obvious pattern of significant barriers. It should be noted, however, that this question was directed only to families who had previously accessed the service. It therefore may not have identified any barriers to general access of the service.



WHAT SHOULD A FAMILY AND EDUCATION SERVICE PROVIDE?

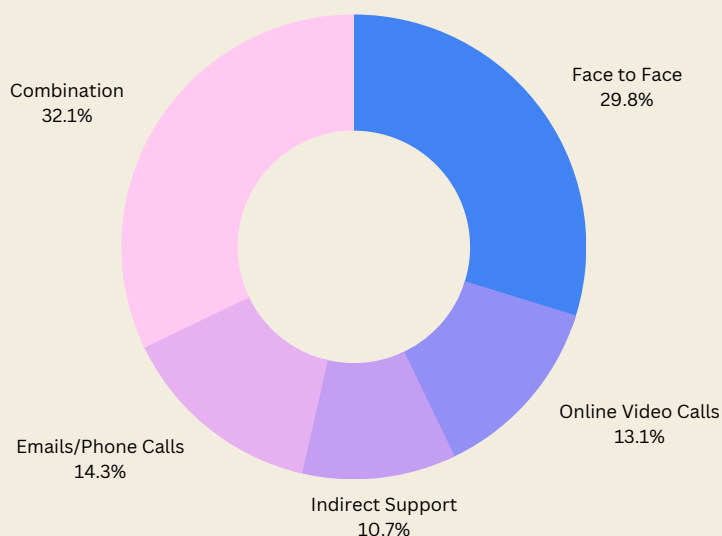
Answers fell into six main categories:

1. School - general advice and support for school problems; info on how to access alternatives to mainstream education; attending school meetings with parents; info for older children when starting high school or college; online support from schools to assessment and liaison between school and parents.
2. Support - both for the family as a unit and as individuals (specific mention for mothers), including extended family i.e. grandparents; general support for situations at home/in school/general parenting.
3. General Advice - strategies and how to understand situations and difficulties.
4. Transitions - to high school, to college, from Primary to Secondary, and how families can support this.
5. Benefits - what is available and can be applied for, i.e. Blue Badge, Carers support
6. Training - suggestions were for training to be provided externally to schools and Education and Children Services.
7. Other - suggestions included: practical support such as help to complete forms; careers advice; lunch clubs for autistic students; and support to attend groups.



All respondents were asked this question; 22 answered via the Survey Monkey questionnaire, two of whom had no suggestions. 6 respondents answered this question via the paper questionnaire. No responses were collated from Facebook, where this was posed as an open question, to which no participants responded.

HOW DO PARENTS PREFER TO ACCESS SUPPORT?

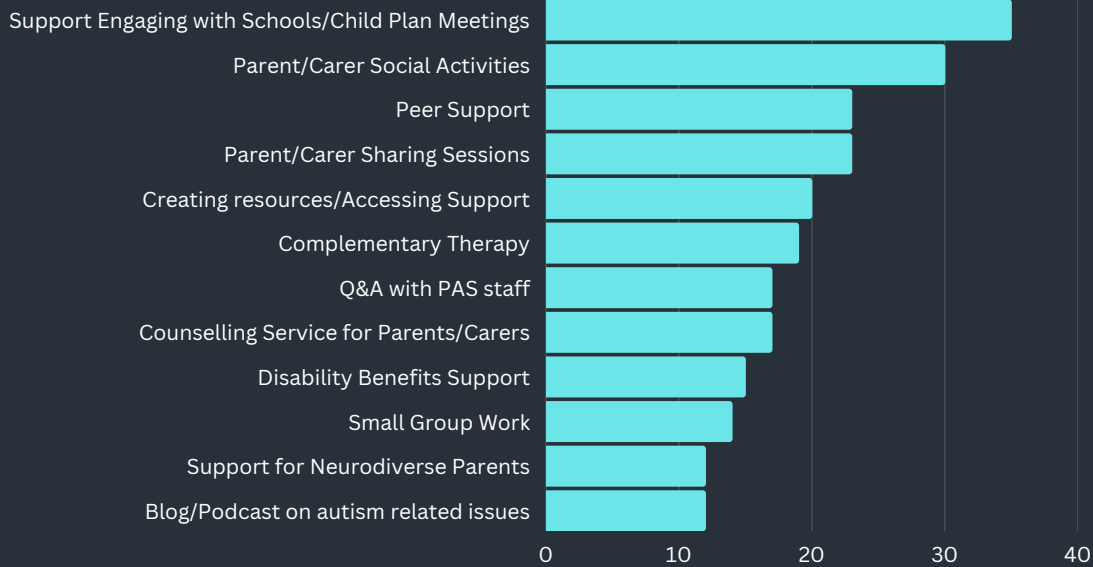


All respondents were asked this question; 84 responses were recorded.

Most respondents were happy to receive a combination of support, although face to face support was also strongly indicated as a preference.

One parent suggested that online training sessions would also be useful.

ARE ANY OF THE FOLLOWING SUPPORTS OF INTEREST?



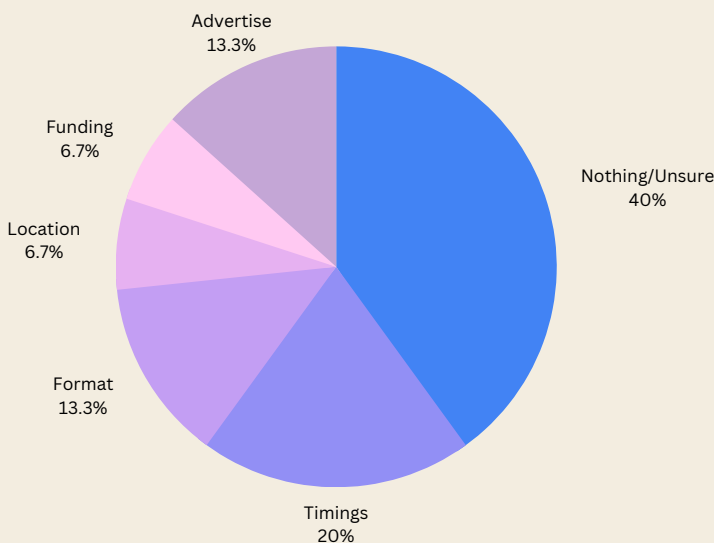
All respondents were asked this question; and there was a high level of engagement in this question across Facebook, the paper survey and Survey Monkey. Parent and carers were most interested in support when engaging with schools or attending Child Plan Meetings. Parents and carers were also interested in gaining support from other parents whether that is through less structured social events, peer support sessions or information sessions on specific topics.

One respondent had their own suggestion: "someone to chat with the sibling of autistic child, probably just once, he won't come to social group as he wants to be off with his friends not inside, he says he'd come if it was a more exciting thing!"

HOW ACCESSIBILITY OF SUPPORT CAN BE IMPROVED?

Respondents were only asked this question via Survey Monkey and the paper based questionnaire.

Answers fell into 6 main categories:

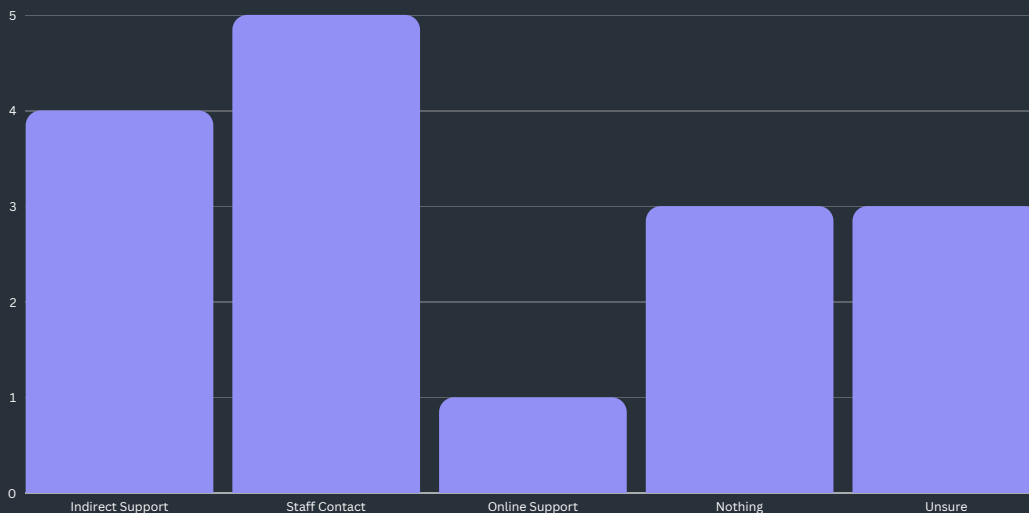


- Timings - suggestions of extended opening hours/more availability to accommodate working parents; another suggested shorter waiting times, but clarified this depended on funding and out with Perth Autism Support's control.
- Format - emails and small group sessions.
- Advertising - one respondent was unaware they could access PAS without a diagnosis until CAMHS passed info on. Another wanted "more available knowledge about all services offered"
- Location - Outreach areas and Kinross in particular
- Funding - As above, respondent mentioned this was dependent on providers, not Perth Autism Support.

Two respondents were either not sure what Perth Autism Support could do to improve accessibility and four other respondents thought PAS was already doing a good job.

One further response was difficult to categorise: "Actually offer support to families?" This respondent was unaware that Perth Autism Support offered a Family and Education Service, but also mentions: "Since my son was first seen, diagnosed and referred to all these services, we had had no support at all, we have been left to work it all out ourselves."

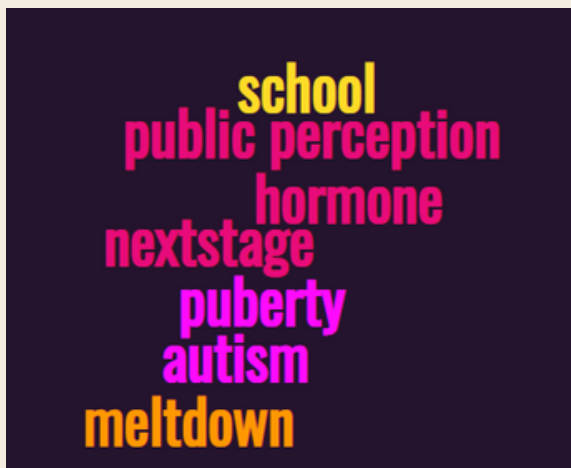
SUPPORT WHILST ON WAITING LIST



All respondents were asked this question. Respondents were most interested in staff contact while they were waiting. In the email response to accept an application for Family and Education Services, we do encourage families to access other Perth Autism Support services while they are waiting but currently we do not have dedicated times for parents to access support. The second highest response was Indirect Support, such as a list of Frequently Asked Questions; General Ideas to Support Their Child; Guidance on Topical Subjects (e.g. meltdowns and coping strategies); and an Easy Access Library of Support and Information.

Some respondents felt they didn't currently need support or Perth Autism Support was already doing enough. The Facebook Parent group was noted as a positive. Other respondents were unsure what else could be put in place. Some other suggestions of other supports were suggested and included: an online support group with other parents, an emergency option for families that were really struggling.

IMPROVEMENTS TO CURRENT TRAINING SESSIONS



All respondents were asked this question.

Other areas requested for training support were as follows:

1. Puberty, hormones and autism
2. Next stage for those in their last year of school
3. Working with schools
4. Dealing with meltdowns in public
5. Public Perceptions
6. Discovering own neurodiversity as a parent
7. Co-occurring conditions and other additional needs (e.g. OT, Speech and Language)
8. Diagnosis Pathway
9. Differences in autistic presentations in girls versus boys
10. Training for the autistic young people themselves

A third of respondents had no further suggestions for the current training programme and one respondent stating: "Already offer a great range! Thanks."

These responses show we need to ensure we have a rolling program of training with wide access to a range of sessions in order to meet the wide needs of registered families. Most of the topics highlighted have previously been offered or are currently available. This suggests that we need to improve our communication about the training we offer with descriptors of what is included in the sessions.

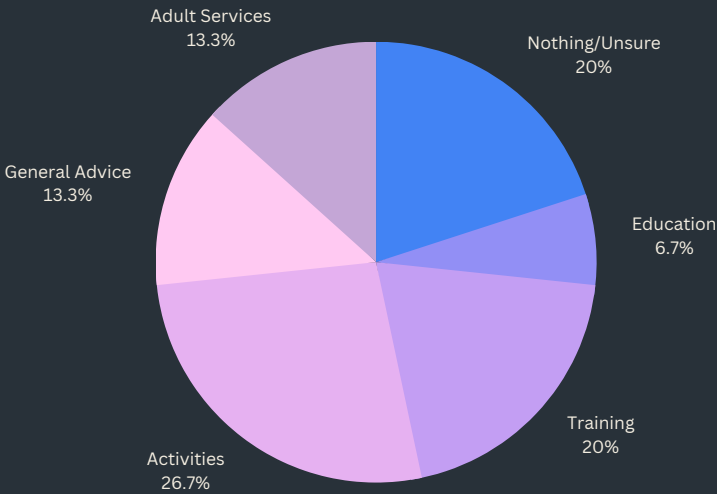
Other comments focused on improvements to current training offers. One respondent felt the timings could be improved, as early evening sessions did not work for them as a working parent, with a child requiring routine at bedtimes. Another suggested the sessions were repetitive, and new examples were needed. This respondent also questioned how one young person felt being the source of so many of the examples used in training sessions.

Finally, one respondent mentioned that any support at all would be great. This respondent was previously unaware of Family and Education Services, and has mentioned that they have had no support since being referred to all the different services following diagnosis.

WHAT OTHER SERVICES PAS COULD PROVIDE?



All respondents were asked this question. Answers fell into 6 main categories:



- Education - one respondent wanted more support in Primary schools to educate teachers and to work alongside education staff, as well as providing a link for health and social care.
- Training - two respondents wanted training sessions for family members, i.e. grandparents and siblings. Another respondent felt more online training would be helpful, as well as other trainings offered at different times of day - they were aware this already happens for some training.
- Activities - one respondent suggested siblings support for older children/teens; one suggested Outreach activities during the holidays; and one suggested a 1:1 befriending service for those who can't access groups. One respondent suggested parent socials at the end of activity blocks. One parent just wanted respite and felt like this couldn't happen anywhere else unless social services are involved.
- General advice - one respondent suggested an obvious point of contact for advice; one suggested support for parents around the support available, especially when very young or newly diagnosed.
- Adult services - one felt it was sad the support stopped at 18. And another thought a service bridging the gap between the end of PAS and transfer to adult services would be a good compromise.

Two further responses were difficult to categorise:

- "Since first seen, diagnosed and referred to all these service, we have had no support at all and been left to work it all out ourselves."
- "Like all service, there is not enough support for demand. I felt palmed off."

The results suggest that further clarity is required around who is able to access the PAS training sessions, as well as changing the format, particularly in regards to delivery and timings. The results also suggest that more clarity is required around the staffing structure and contact points for Perth Autism Support staff, or perhaps a more general FAQ document when first referred to the service. Finally, the results suggest that families may not be aware of the support on offer in Perth and Kinross Council for adult services, suggesting Perth Autism Support could improve its signposting.

FINAL COMMENTS

This section also provided a chance for respondents to make any further comments. Some parents shared some positive feedback including:

"Supportive service already."

"You do a fantastic job"





CONCLUSIONS

As a result of the consultation we will feedback to parents about the outcomes of the consultation, what we have learnt and what we will do as a result of this information.

The survey suggests a number of quick fixes that Perth Autism Support can provide:

- New Referral FAQ document around Perth Autism Support services and points of contact to help with access to Perth Autism Support in general.
- Family and Education Services to continue to offer a combination of ways of engaging with parents but to also consider increasing the days/hours we do this.
- More advertising of who can access Parent/Carer Training and of Parent Support Facebook Group

The survey also suggested a number of more medium term fixes:

- General FAQs document for those accessing Family and Education Services.
- Increase support while waiting for 1:1 support by identifying dedicate slots when parents could access staff for advice and advertise this service.
- Start new peer support groups and information sharing sessions in order to widen the support to more families.

And longer term fixes:

- Recruit staff in order to increase the capacity of the team.
- To work collaboratively with Children and Education Services in Perth and Kinross Council in order to address the high need of support needed for parents to help with education issues.

The Family and Education Service at Perth Autism Support would like to thank all the parents and carers who took time to engage in the consultation and telling us about their experiences.