



ASD Helping Hands Charity Wide Consultation 2019

A charity wide consultation held by ASD Helping Hands asking for service users input on services offered, their experiences and views on improvements to how we offer our services.



ASD Helping Hands Introduction

Charity Background

ASD Helping Hands started in the latter part of 2010, by Julie, who has over 30 years of experience of supporting with autistic children and adults. Julie has two sons and a husband who are diagnosed with Asperger's Syndrome and she found a distinct lack in support services for those with Autism Spectrum Disorders especially across Norfolk, UK.

ASD Helping Hands began with two support groups for families in Norfolk, we have now grown to be the biggest charity supporting those with Autism within Norfolk. We currently support over 1300 families across Norfolk and Suffolk and are supported by a small team of volunteers all who have a direct living experience of supporting someone with an Autism Spectrum Disorder.

Our Services

Our services include a Family support service, offering support on an individual basis to parents/carers, children and adults. Support groups providing ongoing support to those in need, as well as Residential Holidays and Activity days. We can also provide accredited training to parents/carers and professionals.

To access our service, we do not insist on a diagnosis, a certain age bracket or a specific location. We aim to be fully inclusive of all those who require our support.

We receive no statutory funding and are not funded by any governmental department, meaning we can provide independent and complete unbiased support and advice.

Governance

ASD Helping Hands is a registered charity (no. 1175729) with the UK Charity Commission.

We are constituted as a CIO (Charitable Incorporated Organisation) and are governed by a team of five Trustees all who either have Autism Spectrum Disorder themselves or a family member or children living with an Autism Spectrum Disorder.



Consultation Background

The 2019 consultation was carried out 12 months after the reshaping of some of our services and some changes to how we work including our Family Support service.

This consultation was put together to gather feedback from our service users, whether they are professionals, carers and parents or individuals with Autism themselves.

The Consultation focuses on each of our services within the last 12 months and we also ask about donations and the barriers that some of our service users have in making donations.

The Consultation

The consultation ran between 23rd September 2019 to 23rd October 2019 using an online survey creator (esurveycrator.co.uk) and was publicised via our social media pages of which we have a total of 1680 members. This was also sent out to our subscription list through our website which contains 1184 email addresses.

We had 75 respondents to our consultation, a reply rate of 3%. We offered a free prize draw for respondents as an incentive and they were able to either opt in or out for this draw.

The consultation consists of 43 questions (although not all would be applicable to every participant).

The following pages will show the results of each question. Questions 19 through to 25 will be omitted from the results due to one single participant and 42 and 43 will be omitted from the report as these were used to collect participant information to add to our mailing list and therefore have no effect on the outcomes of this report. We will then identify the actions we will take and recommendations to improve services based on the results given.

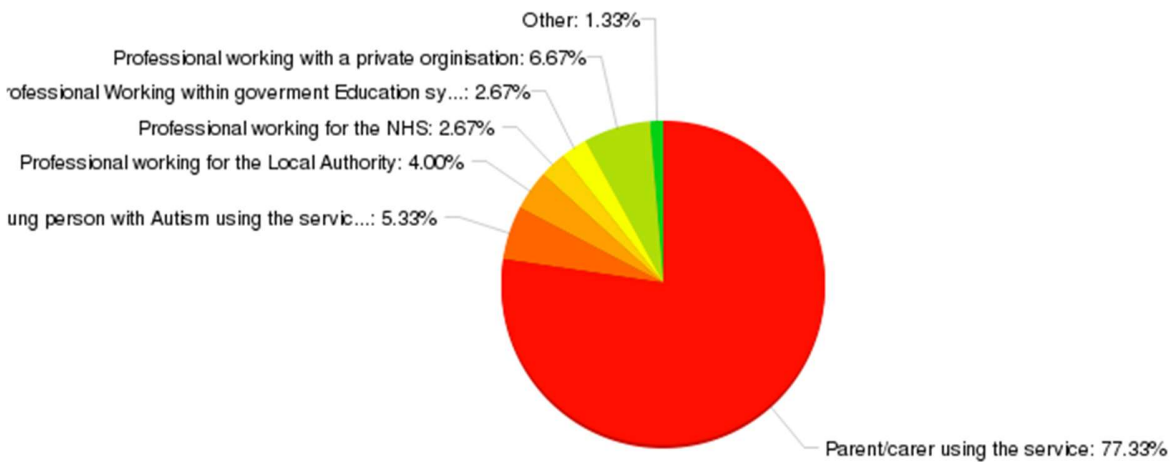
All answers will remain anonymous during the report.

Consultation results

1. Which best describes your relationship with ASD helping Hands?

Number of participants: 75

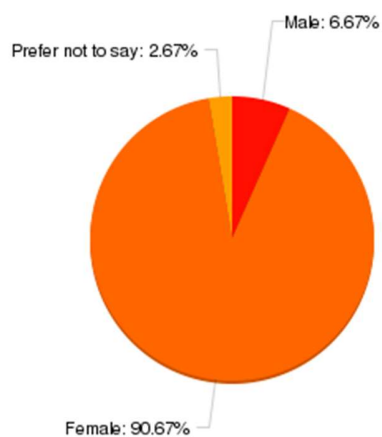
58 (77.3%): Parent/carer using the service
4 (5.3%): An adult/young person with Autism using the service
3 (4.0%): Professional working for the Local Authority
2 (2.7%): Professional working for the NHS
2 (2.7%): Professional Working within government Education system
(6.7%): Professional working with a private organisation
1 (1.3%): Other



2. I Am...?

Number of participants: 75

5 (6.7%): Male
68 (90.7%): Female
- (0.0%): Transgender
- (0.0%): Other
2 (2.7%): Prefer not to say



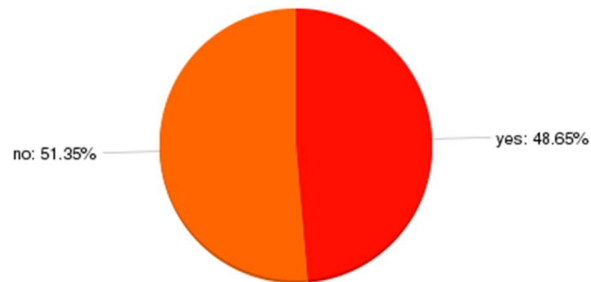


3. Have you used our Family Support service in the past 12 months?

Number of participants: 74

36 (48.6%): yes

38 (51.4%): no



4. Were you able to easily complete the online referral form?

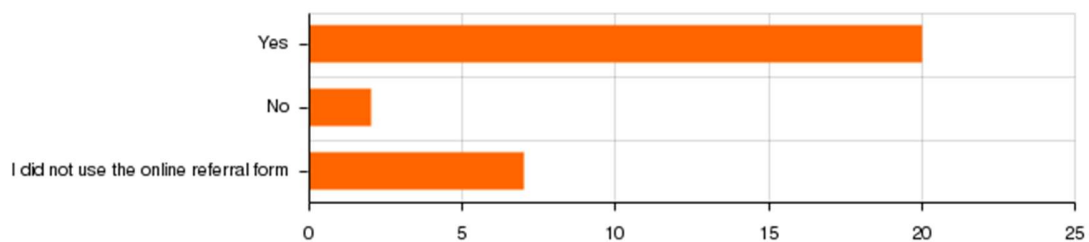
Number of participants: 29

20 (69.0%): Yes

2 (6.9%): No

- (0.0%): Someone completed it for me

7 (24.1%): I did not use the online referral form

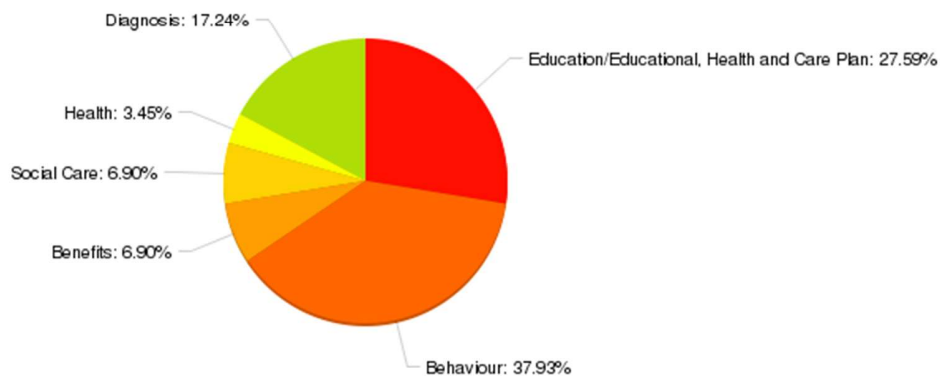




5. What was your main reason for contacting the Family Support Service?

Number of participants: 29

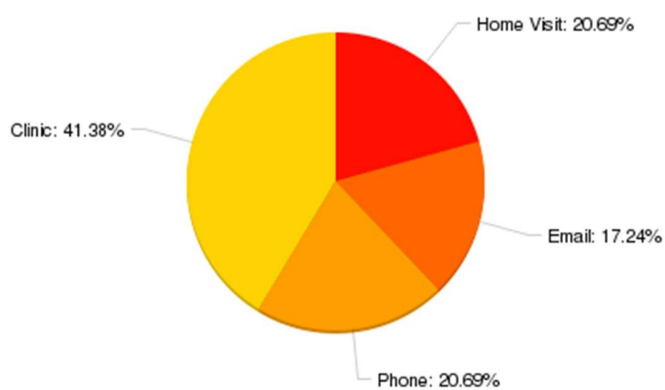
8 (27.6%): Education/Educational, Health and Care Plan
11 (37.9%): Behaviour
2 (6.9%): Benefits
2 (6.9%): Social Care
1 (3.4%): Health
5 (17.2%): Diagnosis



6. What method of contact did you select?

Number of participants: 29

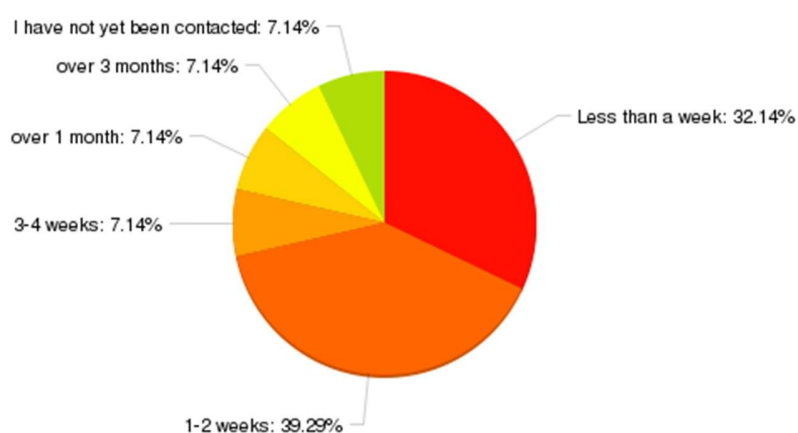
6 (20.7%): Home Visit
5 (17.2%): Email
6 (20.7%): Phone
12 (41.4%): Clinic Visit



7. How long did it take for one of our Family Support Volunteers to contact you?

Number of participants: 28

9 (32.1%): Less than a week
 11 (39.3%): 1-2 weeks
 2 (7.1%): 3-4 weeks
 2 (7.1%): over 1 month
 2 (7.1%): over 3 months
 - (0.0%): over 6 months
 2 (7.1%): I have not yet been contacted



8. How satisfied were you with...?

Number of participants: 28

- time taken to be contacted after your referral
- knowledge of the Family Support Volunteer
- information provided
- professionalism/manner of the Family Support Volunteer
- any follow up conversations or further work

	Very un-satisfied (1)		Un-satisfied (2)		Content (3)		Satisfied (4)		Very Satisfied (5)			
	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Ø	±
time taken to be contacted...	1x	3.57	2x	7.14	4x	14.29	9x	32.14	12x	42.86	4.04	1.10
knowledge of the Family S...	-	-	2x	7.41	1x	3.70	7x	25.93	17x	62.96	4.44	0.89
information provided	1x	3.70	1x	3.70	1x	3.70	9x	33.33	15x	55.56	4.33	1.00
professionalism/manner of...	1x	3.70	1x	3.70	-	-	8x	29.63	17x	62.96	4.44	0.97
any follow up conversation...	3x	11.11	-	-	3x	11.11	8x	29.63	13x	48.15	4.04	1.29

9. Please tell us about your experience with the Family Support Service

Number of Participants: 18

-I had an appointment at your Dereham office. I gave the lady all the information and never heard from you again. I was at my very lowest point and totally desperate for help. They came out to me and provided information and advice, we followed up with some visits to the Saturday play groups and we booked on 3 of the summer holidays days out, which were brilliant thank you

- I went and spoke with someone regarding a DLA form the person that i spoke to was very knowledgeable at the time and i left leaving my form there as the person said they would make notes on it and be in touch and I felt relieved that i was finally getting some help. However, the person never got back to me with the draft, although the person was going through a difficult time ow up was rubbish. Despite being reassured many times that the info had been passed on and the form was done it never turned up. Then it transpired that it had gone missing. A DLA form contains all my child's information, no form was ever received and i was left 2 days before the deadline having to try and get a new form and muddle through it. That said the online support and courses have been excellent

- They came out to visit me at home after a particularly difficult year. The advice was helpful, and we engaged with the Saturday play groups as well.

- This was my first visit regarding ASC and I wasn't quite sure of terms as it was all new to me but wanted more specific advise about using pecs to communicate... Everything they suggested we were doing anyway as instinctive but wanted more ideas on where to get pec cards but they weren't very knowledgeable or said go on Internet and print them off but that is a mine field so wanted specific information they couldn't give.

- Rebecca was lovely very helpful and understanding

- Always if answer not known they find out and get back to you ASAP. Non-judgmental and very supportive.

- One of your support workers came to a meeting to offer support with education
good knowledge was given to parents

- It was a lifeline for me, it helped me cope through a very difficult time. The most difficult for us. It was the understanding, kindness and caring attitude along with the knowledge and professionalism. The follow up was extensive and there as long as I needed.

- We booked our appointment through the school we were late because we couldn't find the venue for the meeting and when we arrived, we were told we were not even o. The list to be seen. However the lady to whom we thought we would be having our meeting with came and sat with us for five minutes between appointments and explained she would stay behind after and see us as she could see how long we had waited and how badly we wanted the help. We discussed many things during the time with her and she gave us some fantastic advice which has since led to us getting accepted to neurodevelopmental team at Norwich. Without the advice I would not have known who I needed to talk to and were to go for help she is a credit to your organisation and very caring for the people she works with. I have since messaged her on several occasions for advice and she has always responded within 24hours. I could not ask more.

- Found it very helpful. This is the first time that someone has said that they can help rather than just say we don't do that. Offered some really useful suggestions. Made me feel that myself and my family are normal.

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- We booked an appt. online (I can't remember how long it took for you to contact us- sorry); there was a wait of a few months to be seen; which compared to most ASD Services is short! We were then contacted to say that additional apps. Had been added and invited to book on one of them. The volunteer was supportive and caring.
- Advise was helpful length to wait for appointment was stressful
- I couldn't make the initial consult due to a family emergency then didn't get contacted again for a couple of months at least. I also attempted to make contact via Facebook which has still gone unanswered. I have tried to attend a family meet up and emailed before it took place to let them know I would be coming only to find out that they weren't holding one that day so I haven't actually had any support from helping hands to this day which is really sad as the need was and is still there
- I have previously had support from Emma Grimbly. I worked with 3 families who we asked for her support too. Emma had an amazing amount of knowledge and i found the information and advice she gave me for the families and with the families was absolutely outstanding. my responses above are about this service as I couldn't skip this part of survey. Since then the service has changed. I have rung on a few occasions and left messages and these can take a long time to be responded to. yesterday however I got through immediately and spoke with Lee who was very helpful. He said he would ask a volunteer to contact the family. I cannot therefore answer the questions above in relation to the new family service
- I went to the clinic to get information and help regarding my daughter who possibly has ASD. It was extremely helpful to know what the process would be and how long it would take. The person I saw seemed very knowledgeable and was able to answer any questions I had.
- Leading to diagnosis support staff were helpful, kind and very willing to offer support and advice! My daughter myself and younger sister attended summer picnic my daughters first contact with any autism groups and we all enjoyed it and welcomed the chance to meet families with similar issues
- Great service - I only had brief involvement with the service, but the counsellor was lovely, really went the extra mile to help, understand and support.

10.How can we improve the Family Support Service?

Number of Participants: 14

- To come back to people with answers!
- We would probably have benefited from some more follow-on support for our biggest current issue which is toileting
- follow up
- We could probably have done with more follow up support for the main issue that we're facing which is toilet refusal
- We were referred from the diagnosing clinic and asked them to refer us to you but was never contacted so ended up ringing anyway. I appreciate they are volunteers but a few more evening /weekend courses and appointments I think would benefit as my husband and I both work full time, so I had to take time off work to visit.
- Getting back to people quicker who are distressed and need support.

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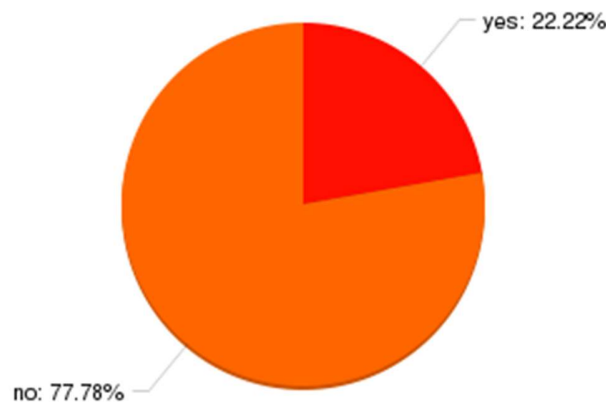


- It took me over a year to realise I needed to book an appointment online as whenever I called it was an answer machine. I was in crisis and was stressed. My fault but I could have done with the help much sooner.
 - The telephone system that we used to let people know we were running late was not answered on any of the six phone calls I left that day. I understand this is a volunteer-based operation however if I'd have been cancelling someone else then could have taken my spot and I know that plenty of people would want them so that may be something to consider
 - I went to the Dereham office. It was a bit challenging to navigate getting access to the office. Some direction /instruction as to how to gain access would be useful.
 - If you had more resources, then more than a one-off appt. would be very useful.
 - Better communication and faster turnaround on replies to messages across all media. Also, up to date website showing if and when events are to take place in real time would be really helpful.
 - As this is a new service I have yet to receive feedback from families I work with. one recommendation would be to have someone answering phones and a quicker response to messages left. I do understand however that there have been various changes and you are a charity.
 - Follow up service a few weeks/ months after initial clinic or home appointment. So there is a chance to discuss where things are at now and how to proceed in the future.
 - All good so far from our experience
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11. Have you accessed one of our Family Support Groups in the last 12 months?

Number of participants: 63

14 (22.2%): yes
49 (77.8%): no

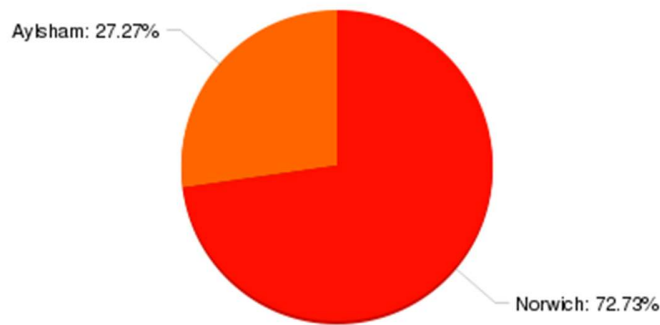




12. Which Family Support Group do you typically attend?

Number of participants: 11

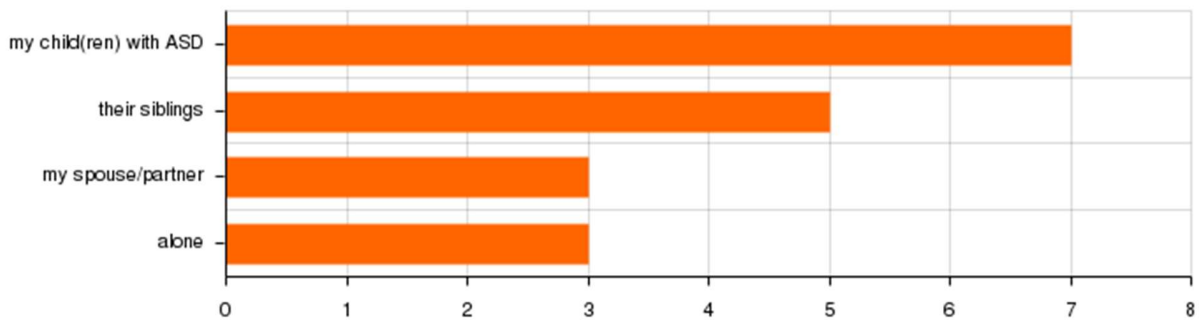
8 (72.7%): Norwich
3 (27.3%): Aylsham
- (0.0%): Thetford



13. I typically attend Family Support Groups with...

Number of participants: 11

7 (63.6%): my child(ren) with ASD
5 (45.5%): their siblings
3 (27.3%): my spouse/partner
- (0.0%): other family members
3 (27.3%): alone

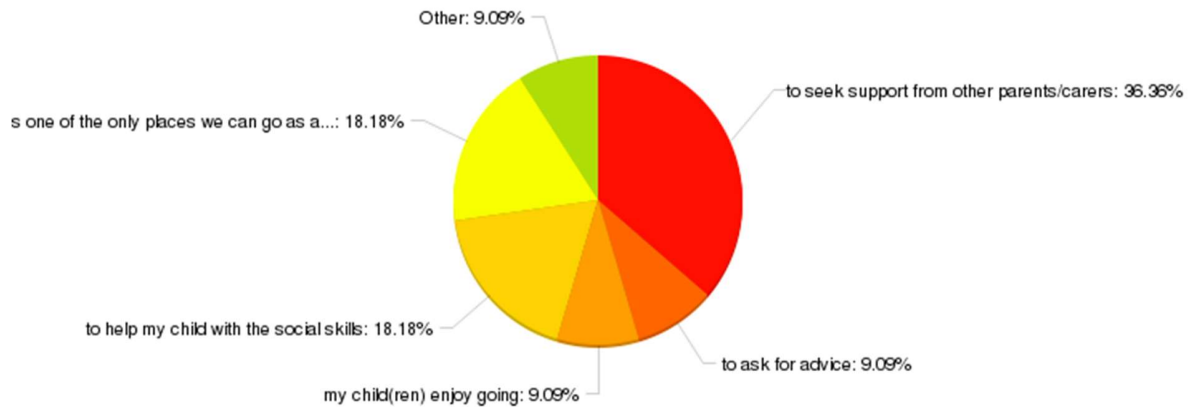




14. My main reason for attending the Family Support Groups is...

Number of participants: 11

- (0.0%): to socialise
- 4 (36.4%): to seek support from other parents/carers
- 1 (9.1%): to ask for advice
- 1 (9.1%): my child(ren) enjoy going
- 2 (18.2%): to help my child with the social skills
- 2 (18.2%): I feel it is one of the only places we can go as a family
- 1 (9.1%): Other





15. How satisfied are you with the following areas?

Number of participants: 11

- Price
- Location/Venue
- Time of day
- Activities Offered
- Group Leaders/volunteer involvement
- Support Available

	Very un-satisfied (1)		Un-satisfied (2)		Content (3)		Somewhat satisfied (4)		Very satisfied (5)			
	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Ø	±
Price	1x	9.09	1x	9.09	3x	27.27	1x	9.09	5x	45.45	3.73	1.42
Location/Venue	1x	9.09	-	-	3x	27.27	3x	27.27	4x	36.36	3.82	1.25
Time of day	1x	9.09	1x	9.09	1x	9.09	3x	27.27	5x	45.45	3.91	1.38
Activities Offered	1x	9.09	-	-	2x	18.18	3x	27.27	5x	45.45	4.00	1.26
Group Leaders/volunteer i...	1x	9.09	-	-	3x	27.27	-	-	7x	63.64	4.09	1.38
Support Available	1x	9.09	1x	9.09	3x	27.27	1x	9.09	5x	45.45	3.73	1.42

16. Please tell us what you enjoy most about the Family Support Groups?

Number of participants: 6

-The opportunity for the kids to play together and for them to try a variety of sensory activities

- You realise you are not alone; many have walked the path before and can help you along your way. No one judges anyone and everyone is caring and helpful.

- able to have a coffee and know I'm not alone

- I enjoy the chance for my children to get to socialise and know that they won't be judged for their behaviour or choices in the group. It's a chance for her to just be herself.

- it seems everyone understands your problems

- Being able to meet people in the same situation

- it was a lovely day, weather warm, and for once I didn't feel different from everyone else



- Really helpful to be able to talk to others and know that I'm not alone with what is happening at home and knowing that everything we try isn't always going to be the same

17. What do you enjoy least about the Family Support Groups?

Number of participants: 2

- Nowhere private to go.
- I've only been to one support group. There didn't feel like there was a chance to get support or ask questions regarding my child with ASD. Which I was hoping to do but didn't feel able to.

18. How could we improve the Family Support Groups?

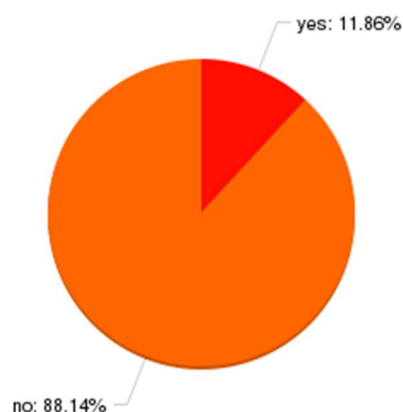
Number of participants: 2

- Maybe have more signposting to support services
- More sign posting as to where to go. On my first visit it was extremely difficult to find where the room was in the school.

26. Have you attended any of the training sessions (including the Ageing with Autism Information Day) in the last 12 months?

Number of participants: 59

7 (11.9%): yes
52 (88.1%): no

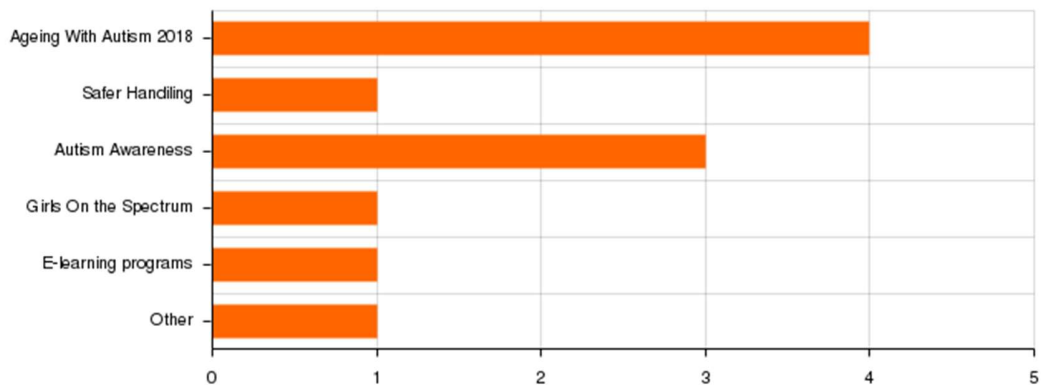




27. What events or training have you been on in the last 12 months?

Number of participants: 59

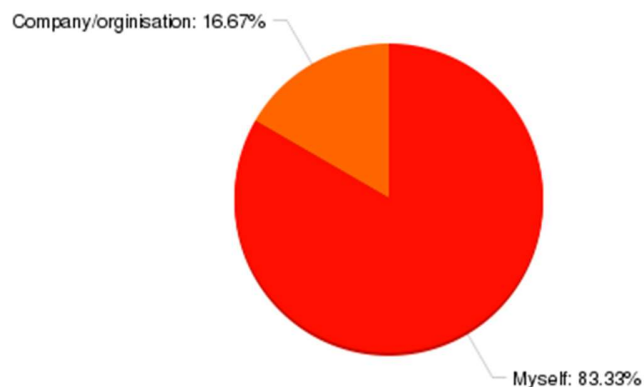
- (0.0%): Just Diagnosed?
- 4 (66.7%): Ageing with Autism 2018
- 1 (16.7%): Safer Handling
- 3 (50.0%): Autism Awareness
- 1 (16.7%): Girls on the Spectrum
- 1 (16.7%): E-learning programs
- (0.0%): Level 3 Autism (Gateway qualification)
- 1 (16.7%): Other



28. Who pays for you to access out training and events?

Number of participants: 6

- 5 (83.3%): Myself
- (0.0%): Family
- 1 (16.7%): Company/Organisation



29. How satisfied were you with the Event/Training you attended?

Number of participants: 6

- Just Diagnosed?
- Ageing with Autism 2018
- Safer Handling
- Autism Awareness
- Girls on the Spectrum
- E-learning programs
- Level 3 Autism (Gateway qualification)
- Other

	Very unsatisfied				Content satisfied				Very Satisfied				Did not attend			
	(1)		(2)		(3)		(4)		(5)		(0)					
	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Σ	Ø	±	
Just Diagnosed?	-	-	-	-	-	-	1x	16.67	-	-	5x		4.00	0.00		
Ageing With Autism 2018	-	-	-	-	-	-	2x	33.33	2x	33.33	2x		4.50	0.58		
Safer Handling	-	-	-	-	-	-	-	-	1x	16.67	5x		5.00	0.00		
Autism Awareness	-	-	-	-	-	-	1x	16.67	2x	33.33	3x		4.67	0.58		
Girls On the Spectrum	-	-	-	-	-	-	1x	16.67	-	-	5x		4.00	0.00		
E-learning programs	-	-	-	-	-	-	-	-	1x	16.67	5x		5.00	0.00		
Level 3 Autism (Gateway q...	-	-	-	-	-	-	-	-	-	-	6x		-	-		
Other	-	-	-	-	-	-	1x	16.67	-	-	5x		4.00	0.00		



30. How satisfied were you with the following elements of the Event/Training?

Number of participants: 6

- Venue
- Time
- Knowledge of speaker/trainer
- Catering
- Price
- Information provided before training

	Very unsatisfied		unsatisfied		Content		satisfied		Very Satisfied		N/A	
	(1)		(2)		(3)		(4)		(5)		(0)	
	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Σ	±
Venue	-	-	-	-	-	-	1x	16.67	4x	66.67	1x	4.80 0.45
Time	-	-	-	-	1x	16.67	1x	16.67	3x	50.00	1x	4.40 0.89
Knowledge of speaker/trai...	-	-	-	-	-	-	1x	16.67	4x	66.67	1x	4.80 0.45
Catering	-	-	-	-	-	-	1x	16.67	2x	33.33	3x	4.67 0.58
Price	-	-	1x	16.67	1x	16.67	1x	16.67	2x	33.33	1x	3.80 1.30
Infomation provided befor...	-	-	-	-	1x	16.67	1x	16.67	3x	50.00	1x	4.40 0.89

31. What other training/events would you like to see organised?

Number of participants :4

-de-escalation training similar to that done with step on, Positive behaviour, Dealing with anxiety, Sleep

- Autism shows in Norwich

- More about autism in adults and something around them as parents as this is particular to me. The support needed simply isn't there

- more about mental health and autism including what support available but also ideas and strategies for professionals and schools.

-many of the young people I work with are struggling with school, yet schools don't appear to be able to meet their needs. it's often the teachers not the SENCO who has no idea about autism.



32. Any other comments on the training events that we offer?

Number of participants :1

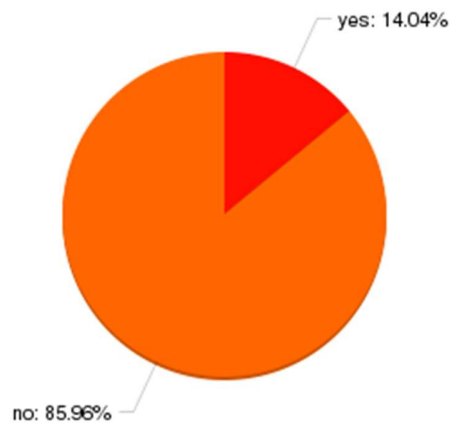
- I think the emails we receive are a good way to let us know about upcoming events and much appreciated

33. Have you attended any of our Activity days or Residential holidays in the past 12 months?

Number of participants :57

8 (14.0%): yes

49 (86.0%): no

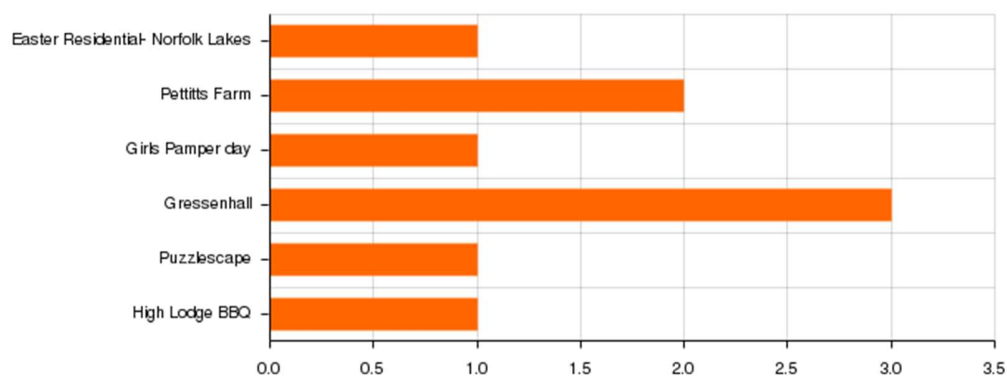




34. Which Activity Days/Residential Breaks have you or your young person attended?

Number of participants :7

1 (14.3%): Easter Residential- Norfolk Lakes
 - (0.0%): Christmas at Butlins
 2 (28.6%): Pettitts Farm
 - (0.0%): Teen Bowling
 - (0.0%): Laser Quest
 1 (14.3%): Girls Pamper day
 3 (42.9%): Gressenhall
 1 (14.3%): Puzzlescape
 - (0.0%): Family Bowling and Pizza
 1 (14.3%): High Lodge BBQ





35. How satisfied were you or your young person with the following elements of the Activity Day/ Residential Break?

Number of participants :7

- Venue
- Time
- Catering
- Price
- Support provided by ASD helping Hands
- Information provided before event

	Very Unsatisfied				Content				Very Satisfied				N/A			
	(1)		(2)		(3)		(4)		(5)		(0)					
	Σ	%	Σ	%	Σ	%	Σ	%	Σ	%	Σ	Ø	±			
Venue	-	-	-	-	-	-	2x	28.57	5x	71.43	-	4.71	0.49			
Time	-	-	-	-	-	-	2x	28.57	5x	71.43	-	4.71	0.49			
Catering	-	-	-	-	-	-	3x	42.86	1x	14.29	3x	4.25	0.50			
Price	-	-	-	-	-	-	2x	28.57	4x	57.14	1x	4.67	0.52			
Support provided by ASD ...	-	-	-	-	-	-	3x	42.86	4x	57.14	-	4.57	0.53			
Infromation provided befor...	-	-	-	-	1x	14.29	2x	28.57	4x	57.14	-	4.43	0.79			

36. What other Activity days/ Residential Breaks would you like to see offered?

Number of participants :2

- Short holidays like Butlins are great we will do this next and only missed the BBQ because we were away at Disneyland Paris.

- Any adventure, nature activities suitable for 11yr olds as not able to attend camping weekend as my daughters too young

37. How could we improve the Activity Days/ Residential Holidays we provide?

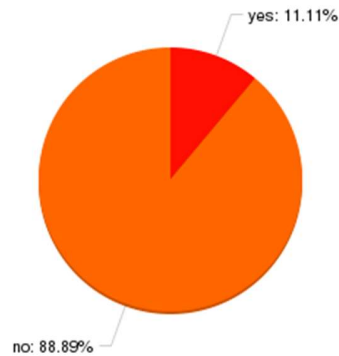
No answers provided



38. Have you ever made a monetary donation to ASD Helping Hands?

Number of participants: 54

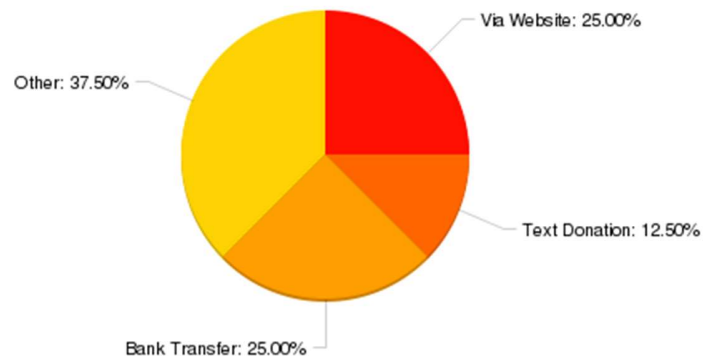
6 (11.1%): yes
48 (88.9%): no



39. If yes, how did you do this?

Number of participants: 8

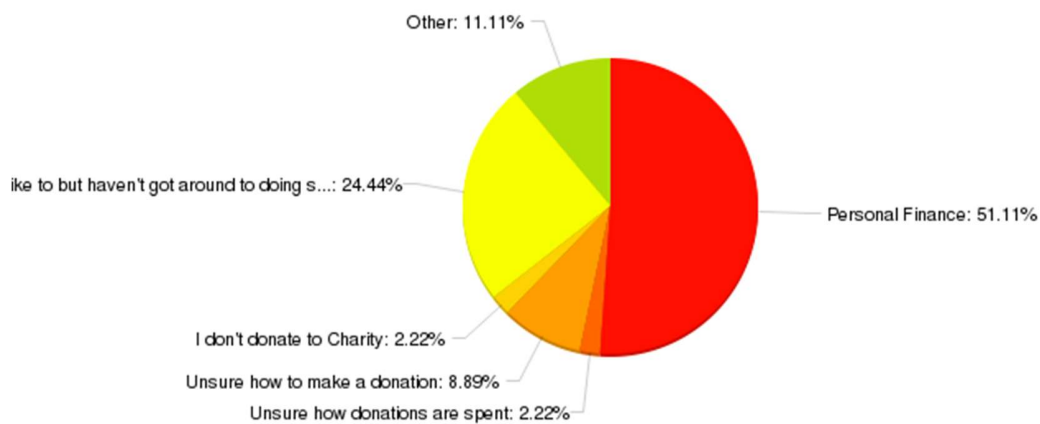
- (0.0%): In person
2 (25.0%): Via Website
1 (12.5%): Text Donation
2 (25.0%): Bank Transfer
3 (37.5%): Other



40.If no, is there a barrier to you making a donation?

Number of participants: 8

23 (51.1%): Personal Finance
1 (2.2%): Unsure how donations are spent
4 (8.9%): Unsure how to make a donation
1 (2.2%): I don't donate to Charity
11 (24.4%): I would like to but haven't got around to doing so yet
5 (11.1%): Other



41. We would love to hear any other comments you have about ASD helping Hands and the services we offer.

Number of participants: 25

- We have previously accessed your services and help but the survey only asks in the last 12 months, it was prior to this. We have accessed resources previously available and these have been very beneficial in supporting our son as too the individual support we received which we accessed through the Family Voice annual event.
- Despite one negative experience i wouldn't hesitate to recommend the charity to anyone affected by autism.
- Just over a year ago I contacted the organisation as we were at crisis point with our daughter. She was school refusing and had very violent and self-harming behaviour. We had no diagnosis and had only just started the referral process. A member of staff came out to see me to discuss our situation and wrote a letter to Director of Children's Services demanding an assessment of needs. It was the first person I spoke to who 'got it' and did something positive to help. The only way this could have been improved was if there had been some follow up contact.
- Helped me when fighting for son's needs at school before EHCP. Will be attending ageing with autism this year.

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- ASD helping hands seems a brilliant charity, I wish it could expand to support people I Suffolk, Bury St Edmunds where my son and I live.
 - I have met members of your team at the Family Voice Conference and the SEND March in May. Such a lovely group of people offering a lot for our children.
 - Very good support network
 - Too many of your events are during the working week - I would love to come but I need to earn money.
 - I was well supported in the past (over 12 months ago) when my son's school were not supporting him appropriately. ASD helping hands wrote a letter to school to outline what needed to be put on place.
 - I am very new to the world of ASD especially with a diagnosis, so I am still learning a lot about what is out there to support my son and ourselves
 - lifeline. Thank you
 - I'd like to say a massive thank you to Rebecca who works at the Norwich centre. She is by far the most incredible person I have met.
 - We are booked on the 'Safer handling' course in a few weeks' time, so can't comment on it yet.
 - A lifesaving service for parent's mental wellbeing.
 - Set up a system whereby I can help raise funds for ASD (coffee mornings with a collection tin etc)
 - I have been to the last conference you held in Norwich. It was very well attended. Unfortunately, due to the level of people and small venue rooms this has put me off attending this year's conference. I don't cope well in crowded rooms without access to fresh air or feeling I can't leave the room. It'd be nice to see photos of the event for future reference, so it gives me an idea of what to expect. Thank you
 - Something for autistic parents
 - The service offered by Emma Grimbly supported the families I work with immensely. She also supported my learning and development so that I can help in my parent support role in a much more effective way. I am hoping this service will continue but I really couldn't fault it.
- the training has also been very useful for learning but also networking.
thank you
- Whilst the residential events and conference are clear, it is less clear what other support the charity provide and how to access it. It would be useful for the charity to provide things like the cygnet's programme which there is a long waiting list for on the NHS even if families have to contribute towards this. It might also be useful if a peer support programme could be established to help support young people as they become independent who might not otherwise wish to join in typical activities for children their age without support.
 - I can't thank them enough for the help and information they offered in clinic. So we feel more prepared and know the stages we will have to go through for a diagnosis.

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- I still feel very alone and the recent attempts I tried to make contact was when you had some issues with your service. It has had a negative effect on me to feel I am just one in a long line of people to process.

- I took my son to one of the summer events held at Pettitt's Adventure Park in Norfolk. Lee from ASD Helping Hands did a great job of organising it and we were able to get in straight away without queuing. We had a lovely day. I have also been to the Ageing with Autism conference and found it a very informative day. I was impressed with the communication leading up to the event.

- The main problem in Yarmouth seems to be that there is very little help for parents to help them negotiate with schools on how to get the support their child needs, so there are more exclusions due to kids reacting to not getting help they need to stay in mainstream education

- Thank you for your approach of extending support to family members, and not requiring a diagnosis to be able to access the service - invaluable for me in trying to support a child with autistic traits who hadn't been formally 'diagnosed'. I have recommended your service to a GP I know who was seeking sources of support for a family members of an autistic patient, who were struggling - he wasn't aware of the service, and I wonder if it is worth doing some work raising the profile of your service with health professionals/GP practices?

- It's hard to access services

Conclusion and Further Actions

Family Support

Overall in the past 12 months we have met with our timeframes of contacting those who refer with the average waiting period from 1 – 2 weeks, with the majority of people opting to visit clinics as their initial contact point. Clinics have since been stopped as we had on average 60% of appointments either cancelled at the last minute or not attended. We have now resorted to initial contact either via phone or email. This seems to be going well and allows us to contact people quicker, reducing waiting times and offering the advice and supported need sooner.

The online referral process seems to be a fast and efficient way for parents/carers and professionals to contact us and means that less referrals get lost in the process. The main reasons for contacting the Family Support service still seem to be around education and behavior, although when we begin to support these often lead into other areas such as health and social care. Housing support is becoming a common thing that we are being contacted for.

Many people value the support and advice we offer, and many see it as a lifeline and the only source of support they receive. It is also positive to hear about service users' experiences with our volunteers and are happy to refer family and friends to us.

That being said there are some things that need improvement on. We need to ensure that we have processes in place to follow up on conversations and check on the status of the situation. There also appears to be some gaps in the volunteer's knowledge when offering support.

Action points:

- Put into place systems to ensure that follow ups are made and families are continued to be contacted in a reasonable timeframe.
- Look at ways for service e users to contact while we are out of the office (in relation to the phone calls)
- Re evaluate the training that the volunteers receive and organise educational resources to fill these gaps.
- Evaluate and update the relevant webpages to be clearer on what support the Family Support service can offer.
- The introduction of a resource and sign posting page on the website, allowing signposting to other organisation's that may be able to help, providing information and support while the referral is being processed.
- Re write the family support policy to update on changes to the service

Family Support Groups

The family support groups continue to be well attended and meet their purpose of providing on going support via introducing those in similar situations to each other. It is also good to see that people attend these groups for a variety of reasons such as peer to peer support, inclusive environments and that their children enjoy attending.

Although the majority of answers very positive, there have been some concerns raised around some areas in the support group such as price, time of the groups and the support available.

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Action Points:

- Look at the possibility of offering 30 minute 1:1 session's during the groups for parents/carers to book onto to talk about specific difficulties and receive support.
- The creation of a resource box for each group, with relevant information about the services in the near by areas and events that may be of interest. These boxes could also include copies of our resources for those attending to read.
- Update all promotional materials for the groups
- Put together a timetable of activities for each group and link these on the website.
- Look at the possibility of live updates on website in case groups have to be cancelled at short notice. The individual Facebook groups already do this.

Training and Events

Many people enjoy our events and training and find them beneficial and like the way we notify you of these (via our email shout outs).

Those who have attended find the majority of areas questioned on content – very satisfied. Although the attendance of these events could be vastly approved,

Action Points:

- Look at ways of promoting training and events to those who are not on our mailing list or social media.
- Look at increasing the number of courses we offer covering different subjects as requested.
- Seek sources of funding to increase the training offered and reduce attendance fees.
- Increase the number of E-learning courses offered
- Look at the possibility of transferring some of our courses to e-learning formats

Activity Days and Residential Holidays

We have received some very positive feedback on our Residential Holidays and Activity days. For specific details on the Easter Residential please see the associated report which can be found at : https://5679bac1-5543-4ce3-bc6d-0a9c8bb61289.filesusr.com/ugd/1ea20f_5d26adb5f1154223a612bb0d60b3c0c2.pdf.

We will continue to offer one day activities as well as shorter breaks however these are all subject to funding which isn't something we can control.

Action Points:

- Plan further residential holidays and look for sources of funding for these
- Plan program of summer activity holidays for 2020, focusing on visiting venues such as Pettitt's or LaserQuest as these were highly attended.

Donations

ASD Helping Hands, like many other smaller non-profit organisation's continues to struggle to secure funding to carry out our charitable processes. We have not received a large funding point (bar the health Lottery) in 3 years. We therefore request donations from our service users and smaller companies to finance the day tot day running of the charity.

The biggest barrier to making a donation seems to be personal finance, followed by those who would like to but haven't had a chance to as of yet.

Action Points:

- Look at ways that service users and third parties can make regular donations which do not require a manual process from the donor
- Implement a tool on the website to draw attention to the donation panel and ways to donate to the charity
- Plan fundraising events for the year in advance.
- Continue to look at and apply for funding pots

We would like to thank everyone who participated in the Charity Wide Consultation and we value your input. We will be looking at these actions points and implementing those we are able to over the coming months. Be sure to keep up to date on all our activities by visiting our website www.asdhelpinghands.org.uk or our social media on Facebook and Twitter.

Consultation and report overseen by



Lee Gibbons
Operations Manger ASD Helping Hands