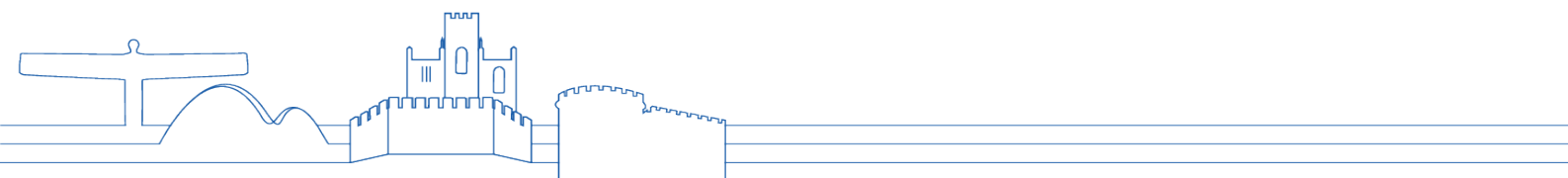


Stakeholder views of Autism services in Gateshead: A report to inform service commissioning

January 2023





This report was produced by Involve North East on behalf of North East and North Cumbria Integrated Care Board. We are an independent organisation who specialises in involvement and engagement. We work with integrity, ensuring people's voices influence the design of services they receive.

We have vast experience and expertise in gathering the views and opinions of patients, carers and the general public in relation to health services. For example:

- service evaluations
- changes to care pathways
- locating new services

We employ quantitative and qualitative data collection techniques including:

- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face and telephone interviews
- Focus groups
- Informal group discussions

For more information about the services we can provide please contact Andrew White on 0191 226 3450 or email andrew@involve.org.uk. Visit our website at: www.involve.org.uk

Charity number: 1116182
Company number: 5899382

Contents

Introduction	1
Views of parents and carers	2
Views of autistic adults	13
Views of Autism Information Hub volunteers	20
Views of professionals	24
Conclusions	36
Recommendations	41
Appendices	45

Introduction

- Gateshead Cares is made up of health and care organisations including the Council, local NHS organisations and voluntary and community sector who are all working together to improve the health and wellbeing of local people.
- As part of their Learning Disability and Autism Programme Gateshead Cares want to ensure that autism services are working for people and that they are receiving the support and information they need and as part of this are also reviewing the use of Gateshead Autism Information Hub.
 - The Autism Information Hub is available to anyone with an interest in autism - parents/carers/family members, professionals, practitioners, or individuals with autism, with or without a diagnosis.
 - It provides monthly drop-ins at its base in at the Elgin Centre offering opportunities to speak with professionals about related issues such as sleep, feeding, occupational therapy and education. professionally trained autism specialist, seek advice about concerns, guidance on assessments and diagnosis and a range of resources. Two monthly support groups for parents and carers of autistic children and young people.
- Between October 2022 and December 2022 Involve North East spoke to a range of stakeholders to understand:
 - What is working within autism services?
 - Are there any areas where improvements could be made?
 - Specific to the Hub:
 - What impact does the Hub have?
 - What gaps exist within the Hub provision?
 - What barriers prevent people from using the Hub?
 - How does/can the Hub support autistic adults?
- The findings of this exercise will be used to help inform the future commissioning of autism services.
- We spoke to the following groups, engaging with them in a variety of different ways as informed by people who work closely with them:

Stakeholder group	Techniques used	People engaged
○ Parents/carers of autistic children and young people (see Appendix 1 for participant profile)	○ Online/face-to-face questionnaires	○ 75
○ Autistic adults	○ Focus groups	○ 10
○ Gateshead Autism Information Hub volunteers	○ Semi-structured questionnaires	○ 3
○ Professionals (working for the NHS, Gateshead Council or within the VCS) working with autistic children, young people and adults	○ Teams/face-to-face interviews	○ 13

- The project was widely publicised with relevant statutory and voluntary, community and social enterprise organisations (VCSE) in Gateshead. The parent/carer survey was also promoted through relevant Facebook groups for residents of Gateshead.
- The following is a summary of the findings with recommendations.

Views of parents and carers

- Through interviewer-administered and online questionnaires, parents/carers of autistic children and young people shared their views on local information provision around autism and their awareness and use of Gateshead Autism Information Hub (the Hub) as well as suggestions for improvements to the service.
 - 75 people shared their views:
 - 59 people described themselves as a Carer/Parent of an autistic child
 - 12 people described themselves as a Carer/Parent of an autistic adult
 - 12 people described themselves as autistic

Key themes

Use of local information and support

- Parents/carers named their first port of call for professional support around autism, with face-to-face support via their GP practice, the Hub and their child's schools being mentioned most frequently. Facebook groups and the North East Autism Society were also used.
- When considering satisfaction with local support and information, the Hub in particular was highlighted positively.
- One quarter of parents/carers stated that they had never accessed any local information about autism.

Awareness of local support

- There is a lack of awareness of local support. When asked where they would go first for professional support around autism a minority of people were unable to identify any services and when providing reasons for their dissatisfaction with local support, one quarter reported that they were simply not aware of any local information and support.

Demand for local information and support

- There is demand for more local information and support. Half of parents/carers were dissatisfied with the amount of local information and support available to them. They feel it is too limited, they are offered little support post diagnosis and provision is not always accessible in terms of location and operating hours.

Gateshead Autism Information Hub

- Awareness and use of the Hub is not far reaching; just over half of parent/carer respondents were aware of the resource and half of those had used it. Most had used the Hub more than once with more than four in five accessing the Elgin Centre physically.
- The Hub is used to access information and peer support in particular, by at least half of users.
- Those who had not used the Hub cited accessibility as a barrier – inaccessible operating times, locations and a lack of childcare facilities - followed by a lack of awareness of the service. When considering services they would like the Hub to provide, support to help them look after their loved ones with autism, help with navigating services and support for young adults were mentioned most frequently.
- Users of the Hub made a range of suggestions when considering what information and support could be offered in the future.

- Information on mental health, healthy relationships and parenting advice were highlighted most frequently.
- Support suggestions included Talking Therapies, greater access to professionals on site, having more than one site and increased frequency of drop-in sessions.
- Parents/carers appreciate having access to the Hub both online and in person, and would prefer it if there was a website available. There was less support for a telephone resource.

Summary of findings

Accessing support and information

To understand where parents/carers currently go for information and support about autism they were asked about their first 'port of call' for professional support, and the local and national resources they access.

When you need professional support around Autism, where is the first place/who is the first person you would go to?

First place or person	No. of respondents	Percentage of respondents (%)
GP	15	26.8
Gateshead Autism Information Hub	10	17.9
School	10	17.9
Online	6	10.7
Children Young People's Service	4	7.1
Friends and peers	4	7.1
Consultant	3	5.4
Gateshead Council	3	5.4
Children and adolescent mental health services (CAMHS)	2	3.6
North East Autistic Society	2	3.6
Portage Team	2	3.6
ADHD clinic	1	1.8
Adult social care	1	1.8
Children North East	1	1.8
Health Visitor	1	1.8
National Autistic Society	1	1.8

No. of respondents – 56
Several respondents gave more than one answer

- Parents/carers would be most likely to visit their GP if they need support around autism (26.8%). The Gateshead Autism Information Hub and their child's school were mentioned by 17.9% of parents/carers, respectively.
- However, 11 (15.0%) parent/carers stated that they did not know where to go for support and six (8.2%) reported that there was no support available to them.

“As a parent who works plus having three children and not driving, I find it hard to get access to any help or support.”

“None. We have exhausted medical support, social services. Early years no longer offers support.”

“I get no support since diagnosis in March.”

Where do you access local information about Autism?

Parents/carers could choose from a list of organisations/resources and provide their own answers.

Local resource	No. of respondents	Percentage of respondents (%)
Gateshead Autism Information Hub	23	41.1
School	22	39.3
Gateshead autism Facebook groups	15	26.8
North East Autism Society	14	25.0
GP	11	19.6
Autism North East	7	12.5
Health Visitor	7	12.5
Gateshead Council website	6	10.7
Local NHS autism services	5	8.9
Atypical Support	2	3.6
Child Adolescent Mental Health Service	1	1.8
Children and Young People's Service	1	1.8
Online resources	1	1.8
Other Facebook groups	1	1.8
Parent Carer Forum	1	1.8
Portage Team	1	1.8
Peer support groups	0	0.0

No. of respondents – 56
Respondents could give more than one answer

- Parents/carers are most likely to access local information via the Autism Information Hub (41.1%) and through their children’s school (39.3%). Over one quarter of parents/carers access information via social media (26.8%). The North East Autism Society is also well used (25.0%).
- No parent/carers had accessed Autism in Mind or Peer Support Groups.
- Furthermore, one quarter of parents/carers (25.3%) stated that they had never accessed any local information about autism.

Where do you access national information about Autism?

Parents/carers could choose from a list of organisations/resources and provide their own answers.

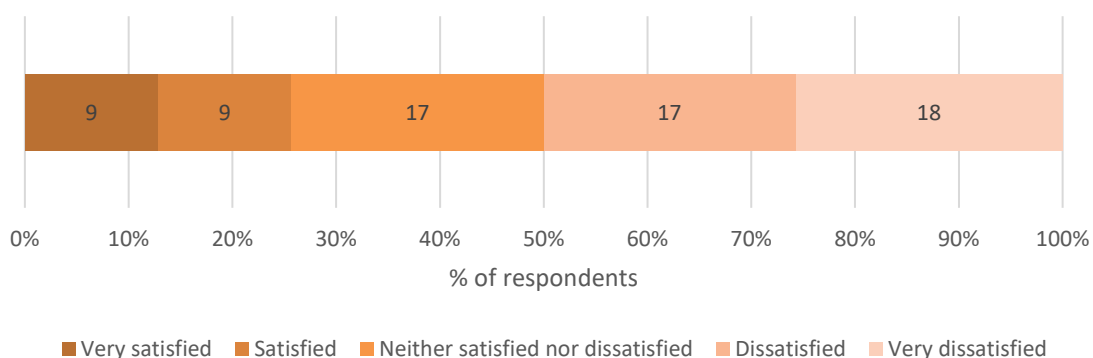
- Over half (51.4%) of parents/carers stated that they had never accessed any national resources when seeking information about autism.
- Those who did, used the following:

National resource	No. of respondents	Percentage of respondents (%)
National Autistic Society	15	44.1
National Autism Facebook Groups	11	32.4
Child Autism UK	5	14.7
National Peer Support Groups	3	8.8
Online resources	2	5.9
Ambitious About Autism	1	2.9
Autism West Midlands	1	2.9
Books	1	2.9
Published academic research	1	2.9

No. of respondents – 34
Respondents could give more than one answer

How satisfied are you with the amount of local information and support available?

How satisfied are you with the amount of local information and support available?



No. of respondents – 70

- Half of parents/carers are dissatisfied or very dissatisfied with the amount of local information and support available to them
- A further 24.3% are neither satisfied nor dissatisfied.
- One quarter (25.7%) of parents/carers are satisfied or very satisfied.

Those stating that they were dissatisfied or very dissatisfied gave the following reasons:

Reason for rating	No. of respondents	Percentage of respondents (%)
Limited information and support available	10	28.6
Not aware of any local information and support	9	25.7
No support after diagnosis	8	22.9
Provision is not accessible	5	14.3
Waiting times are too long	3	8.6
Lack of information around support for young adults	2	5.7
Provision lacks quality	2	5.7
Lack of joined up working between local authority and school	1	2.9
Lack of support for autistic adults	1	2.9
Lack of support for carers	1	2.9
Poor advertising of information and support available	1	2.9

No. of respondents – 35. Respondents could give more than one answer

- One quarter (25.7%) of parent/carers stated that they were not aware of any local information or support.
- Those who were aware of local resources found them to be limited and this was particularly evident immediately after diagnosis. The accessibility of the limited support available was also highlighted with location and operating hours mentioned.

“Since my son was diagnosed, I feel we were given a few leaflets then he was discharged from the health service. He had some counselling for a while but that’s it. I did my own research and have had to do my own critical reflection to work out how to manage my son's difficulties.”

“On diagnosis I was handed some leaflets and that was it. I’ve never felt like the support was for families like ours.”

“Every avenue of support you go down has an expiry date with x amounts of sessions and then you are back to square one.”

“Once you get a diagnosis you don’t get any help towards anything.”

“There is nothing in Gateshead, no support groups for young adults or playgroups for young children. I travel to Howdon to access a playgroup.”

Seventeen people who stated that they were neither satisfied nor dissatisfied gave the following reasons:

Reason for rating	No. of respondents	Percentage of respondents (%)
Not aware of any local information and support	5	33.3
Limited information and support available	3	20.0
Not used information/support	3	20.0
Provision is not accessible	2	13.3
Autism Hub provides good information/support	1	6.7
Do not require support	1	6.7
Provision lacks quality	1	6.7

No. of respondents – 15
Respondents could give more than one answer

- One third (33.3%) of parent/carers answering in this way cited a lack of awareness of any local information and support.
- Those who were aware of it felt it was limited and for one, this was around understanding typical behaviours.
- For two people accessibility in terms of opening times and a lack of childcare was an issue.

“We have not had any support and only dealt with professionals through the school when sorting our education plan.”

“We have never felt part of anything in regard to our children’s autism. It’s a very lonely world for all of us.”

“I was able to access support but now I'm home educating both of my autistic children full time I can no longer access as children can't attend and I'm a lone parent so can't access the evening session either.”

Those stating that they were very satisfied or satisfied gave the following reasons:

Reason for rating	No. of respondents	Percentage of respondents (%)
Autism Information Hub provides good information/support	11	64.7
Limited information and support available	4	23.5
Adult services good	1	5.9
GP provided information	1	5.9
More information and support than there used to be	1	5.9
Services try hard	1	5.9

No. of respondents – 17
 Respondents could give more than one answer

- They particularly appreciate the support provided by the Autism Information Hub.
- Despite this resource, there is still a feeling that local information and support is limited, particularly for those with younger children or those children with higher level needs.

“There is such a wealth of knowledge at the Hub and they offer excellent advice.”

“The Autism Hub is my first contact due to long GP and NHS waiting lists. It is a valuable and essential resource for parent and carers - however it is very busy and I feel the resource is really stretched.”

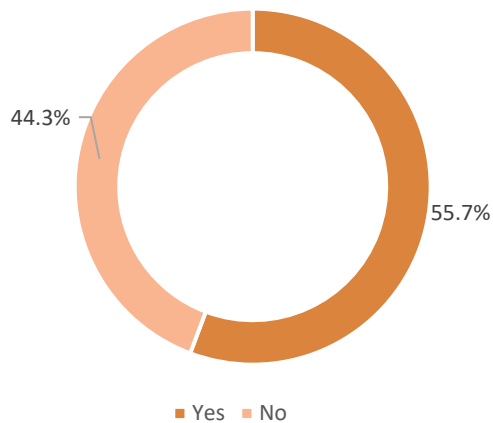
“I have never had a question that hasn't been answered by [main volunteer] and the Hub it's a fantastic lifeline for parents.”

“Information from the Hub is great, but the professionals don't deliver as much by law as they should, especially those in the Local Authority.”

Awareness and use of Gateshead Autism Information Hub

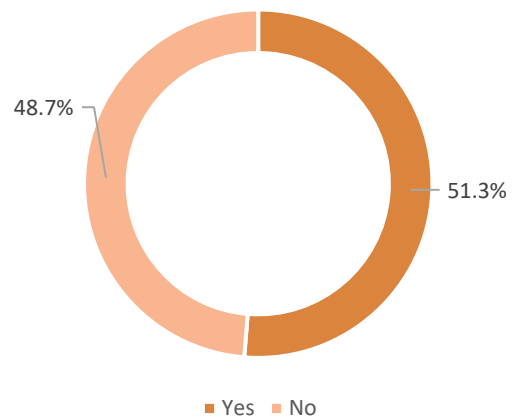
We also wanted to gauge awareness of the Gateshead Autism Information Hub.

Have you heard of the Autism Information Hub?



No. of respondents – 70

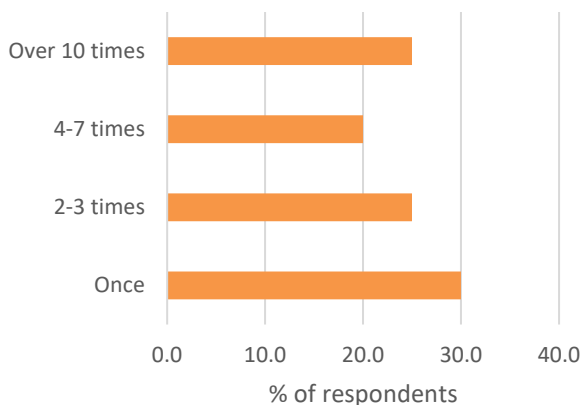
Have you ever used the Hub?



No. of respondents – 39

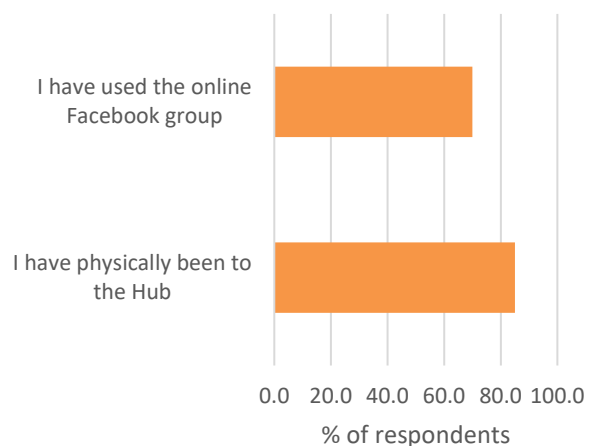
- 39 parents/carers had heard of the Hub.
- Of these, 20 had used it; they shared their experiences and offered suggestions for its improvement.

How many times have you visited the Hub?



No. of respondents – 20

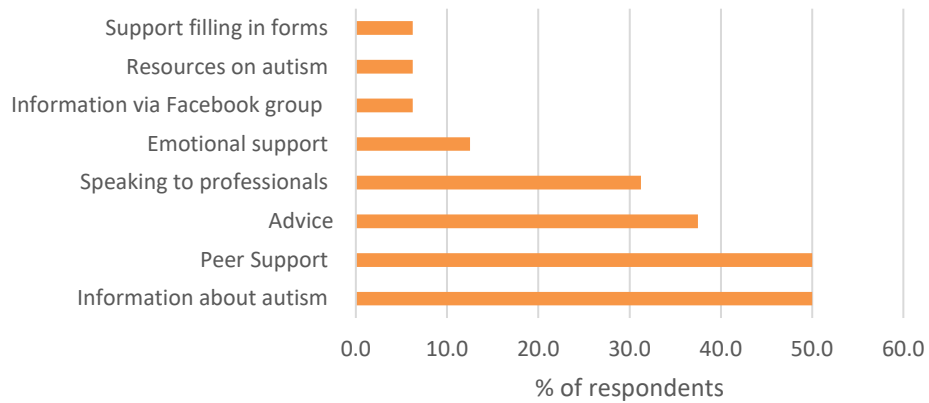
How have you used the Hub?



No. of respondents – 20
Respondents could give more than one answer

- Frequency of use varied between one occasion and more than 10 times.
- More than 4 in 5 (85.0%) parents/carers had visited the Hub building and over two-thirds (70.0%) had visited the Facebook group.

What support did you receive from the Hub?



No. of respondents – 20
Respondents could give more than one answer

- Parents/carers use the Hub to access information about autism (50.0%) and peer support (50.0%) in particular.
- The Hub also provides advice (37.5%) and the opportunity to speak to professionals (31.3%).

“Great advice, numerous handouts, fantastic support from others in the 'same boat' and excellent food.”

“Lots of informative articles that we can read to help understand and manage our son’s issues. Someone with the ability to point us towards relevant help/groups.”

“Amazing support from peers and professionals. Sometimes at the hardest points of my life.”

“Written information, guidance, peer support, an ear, friendship, understanding.”

Reasons for not using the Hub

19 people had heard of the Hub and never used it. They gave the following reasons why:

Reasons for not using the Hub	No. of respondents	Percentage of respondents (%)
Times do not fit	6	33.3
Too far to travel	4	22.2
No child care	3	16.7
Unaware of their offering	3	16.7
Not relevant/children focussed	2	11.1
Just found out about it	1	5.6
No need to use it	1	5.6

No. of respondents – 18
Respondents could give more than one answer

- Most frequently mentioned was that the times support is available is not accessible (33.3%), particularly for working parents.

- Others said the Hub building was simply too far for them to travel to.
- A lack of childcare was also a barrier (16.7%).
- Several people were unaware of what the Hub could offer them (16.7%).

“Times not practical for working parents. Even the evening support group is right on my child’s bedtime. Might work for those with older children who stay up later.”

“I have a job and 3 kids so no possible way to manage it.”

“Because you cannot take a child with you. Which I find very strange when the group is there to support. Not everyone can find childcare for their children.”

“I feel like I don't fit the criteria for it to be useful having a teen with autism. It has always appeared to be aimed at younger children and parents who struggle whereas I simply want a safe space for my son to go to that is more of a youth club feel so he can make friends and interact with peers.”

Future use

Parents/carers who had not heard of or had not used the Hub were asked if they were to use the Hub in the future what services and support, they would like it to provide. They suggested the following:

Information and support	No. of respondents	Percentage of respondents (%)
Help with supporting loved ones with autism	11	36.7
Help with navigating services	4	13.3
Support for young adults	4	13.3
Behaviour management strategies	3	10.0
Emotional support for carers	3	10.0
Provide up to date broad range of information	3	10.0
Support for children during holidays	3	10.0
Different operating times	2	6.7
Peer support	2	6.7
Play group for children	2	6.7
Closer to my home	1	3.3
Family support	1	3.3
Online support	1	3.3
Outreach	1	3.3
Support for autistic adults	1	3.3

No. of respondents – 30
Respondents could give more than one answer

Suggestions for improvements to the Hub

Parents/carers who had used the Hub were asked a series of questions to understand whether the Hub was meeting their information and support needs.

Is there any other information you would like to see provided by the Hub?

Parents/carers could choose from a list of information and provide their own answers.

Information topics	No. of respondents	Percentage of respondents (%)
Mental health	10	66.7
Healthy relationships	7	46.7
Parenting advice	5	33.3
Carer support available e.g. counselling	3	20.0
Gender identity	2	13.3
Housing	2	13.3
Schools/education services/home schooling	2	13.3
Debt management	1	6.7
Drug & alcohol advice	1	6.7
Estrangement	1	6.7
Grief support	1	6.7
Health (related to autism)	1	6.7
Self-esteem	1	6.7
Sexuality	1	6.7
Social care support available	1	6.7

No. of respondents – 15
Respondents could give more than one answer

- Information around mental health (66.7%) and healthy relationships (46.7%) were most commonly mentioned.
- Parents/carers would also like to see information about effective parenting and this should also consider having “non neurodiverse siblings too.”

Is there any other support for parents and carers you would like the Hub to provide?

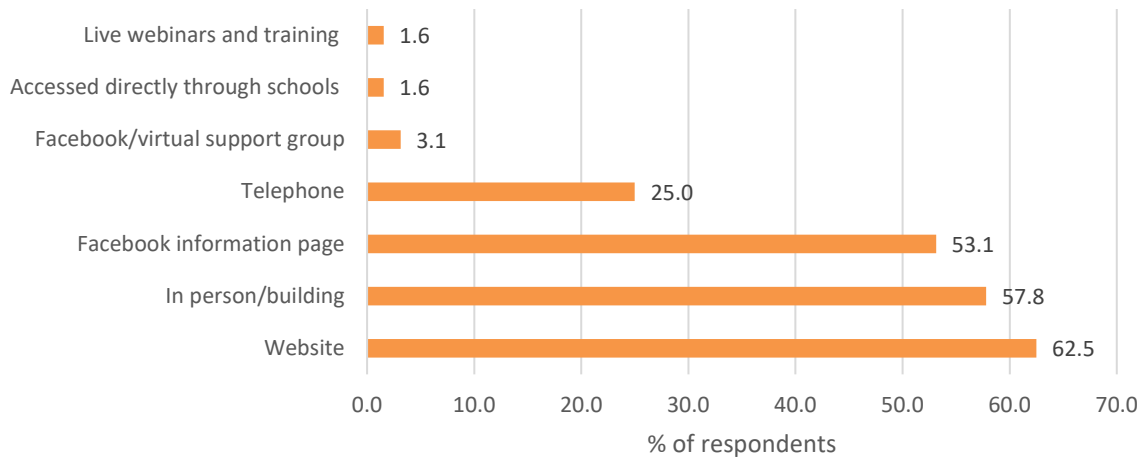
Support	No. of respondents	Percentage of respondents (%)
Talking therapies	3	25.0
Access to an Occupational Therapist	1	8.3
Accessible swimming pool facilities	1	8.3
Activities for children	1	8.3
Additional evening support groups	1	8.3
Creche/childcare available at Hub	1	8.3
CYPS on site at drop-ins	1	8.3
Have more than one Hub site	1	8.3
HINT Team on site at drop-ins	1	8.3
One-to-one support	1	8.3
Peer support for parents/carers	1	8.3
Peer support for teenagers	1	8.3
Weekly hub drop-ins	1	8.3

No. of respondents – 10
Respondents could give more than one answer

- Suggestions around additional support included access to Talking Therapies, regular presence of specific support services at drop-ins, additional Hub sites and drop-ins and access to peer support.

All respondents, regardless of whether they had used the Hub or not, were asked about the future set-up of the Hub. Currently the Hub is accessed by visiting The Elgin Centre in Deckham or using the private Facebook group.

What set up would you prefer the Hub to be in the future?



No. of respondents – 65
 Respondents could give more than one answer

- Having an online presence in the form of a website and Facebook page/group was supported by 62.5% of parents/carers.
- Over half (57.8%) would like to be able to physically access a space to use resources and receive advice and support.
- There was less support for access via telephone (25.0%).

Views of autistic adults

- In focus group settings, autistic adults shared their views on local information provision around autism and their awareness and use of Gateshead Autism Information Hub as well as suggestions for improvements to the service.
 - 10 people who attended Atypical Support, Inspired Support or Skills 4 Work shared their views.

Key themes

Local support and information needs

- Participants named a range of places they could get information and support but emphasised that this is needed most when people are newly diagnosed.
- When considering the positive aspects of local support and information, most cited Inspired Support and Skills 4 Work. The positive attributes of this support are two-fold - practical and social. Service users learn new skills and gain work experience to help them in seeking jobs and also practical life skills such as using public transport. The social aspect includes having a routine, developing friendships, having peer support and overcoming personal barriers. Both organisations provide a person-centred approach which is very much valued.
- Several people highlighted gaps in local provision for autistic adults; they feel that resources and therefore services are focussed on children and young people and their families at the expense of adults. People living close to the border with Durham feel that their location limits them in where they can get support and feel frustrated that they are unable to access services in Durham. Service-specific issues related to services not being focussed on autism and their individual needs and goals not being identified or met were raised.
- When considering improvements to local information and support, participants requested more information focussed specifically on autistic adults. However they cautioned that this information should be in a range of formats and include visual aids and be concise with the opportunity to learn/read more elsewhere. They wanted to know what is available to them at the outset and the structure of local autism services. They felt that support around diagnosis could be improved in terms of waiting times, GPs signposting to resources whilst waiting to be assessed, restrictive evidence needed to support a diagnosis and once diagnosed, information around what behaviours are linked to their diagnosis.

Specification for the Hub

- Although open to all, the Hub currently has a focus on supporting parents/carers of children and young people. Only two people had heard of the Hub, they described their only visit as overwhelming due to its busyness and noisiness and the sheer volume of information on display. They felt that the service was not for them as they were asked if they were a parent or carer and then not offered any other support.
- Future use of the Hub for this group would require changes to the space to ensure it did not overwhelm them and keys with information colour-coded and corresponding visuals would help. Information resources should be in a range of formats including paper-based, online and face-to-face presentations and concise with bullet points and illustrations. Information about employment should also be available.
- In terms of the support available within the Hub there were requests for access to computers, support to use them and peer supporters. Monthly drop-ins with experts were welcomed but

they would need to be advertised well in advance and would need accompanying information for them to take away and digest, and to not be too long. A Facebook group was also suggested.

- It was felt that the Hub should not be restrictive in its format although some cautioned that a telephone would not work for them. They also suggested regular online support sessions and podcast. Before visiting a physical location for the first time participants would like details of its exact location, how to get there and what it looks like and once inside would like support from a buddy.
 - Participants suggested a range of ways the Hub could be advertised in future.
-

Summary of findings

Accessing support and information

To understand where autistic adults currently go for information and support about autism they were asked about any local and national resources that they access.

Local support and information

Participants mentioned the services listed below but several made the point that they no longer seek information about their Autism as they have been diagnosed for a long period of time and only required information when they were newly diagnosed.

Service	No. of participants
Skills 4 Work	5
Gateshead Council website	3
Inspired Support	3
Local health services	3
Atypical support	2
Autism North East	2
Autism in Mind	1
Friends and family	1
Making Every Contact Count Champions	1
North East Autism Society	1

National support and information

Only three participants mentioned accessing national resources and all had used the National Autistic Society.

What is good about local information and support?

Participants were asked what they thought was good about local information and support.

Those who attend Inspired Support discussed the positive aspects of the service:

- It is person-centred – asking service users what they are interested in, what they want to achieve and giving them choice.

- They use the interests of service users to teach them employment skills.
- It provides opportunities for service users to learn new skills, creating a sense of achievement and satisfaction.
- Its focussed scope - supporting people with learning difficulties and autism - means that it is not overstretched.
- It provides an opportunity to develop friendships and helps service users with their social skills.
- It offers a space to relax where they are understood.
- The peer support service provides excellent support. For example, when someone is stressed, they can empathise with that person and provide the support they need. The service has also given them the opportunity to learn and share different coping strategies.

Participants who attend Skills 4 Work discussed the positive aspects of that service:

- It gives them routine and “gets them out of the house.”
- Offers them the opportunity to make new friends.
- Enables them to get work experience and learn new skills.
- Supports them to overcome personal barriers.
- Helps them to develop life skills such as using public transport.
- The people are nice and help with whatever they need.

One participant also mentioned a positive experience they had when accessing Universal Credit which had signposted them to support services including Skills 4 Work.

What is not so good about autism services/information sources you have used?

Participants were also asked what they thought was not so good about local information and support.

- Lack of services and support
 - A lack of services and support for adults was the issue for two participants.

“Everything just seems to be about kids. I get that's probably their biggest funding and they have to but it's really not fair. It's quite off-putting when you're like trying to find out stuff about autism and you just keep getting, here's what your parent should be doing for your children and you're kind of like, this isn't helpful, that won't work for me.”
 - One participant who lives very close to the border with Durham described how they accessed a particular service because it was the only one available to them in their location. Furthermore, when recently receiving support from a social prescriber they were told that there was only one service available to them in their area, “she said there was nothing else that she could offer me. There was absolutely nothing else and that was the end of the conversation.” They did mention a service in Durham city but they were not eligible because they live on the edge of Gateshead.
 - Upon very recent diagnosis, another participant was informed of support they could access which was two-fold, the National Autistic Society and Atypical Support.
- Service specific issues
 - Two people discussed their experiences of specific services but did not identify them. One participant had accessed a service which they felt had just done “the bare minimum” in

terms of supporting them, they felt that the service had not tried to understand them and left them feeling patronised.

- Another participant felt a service they attended had too wide a scope in terms of the type of people it was trying to support and as a consequence was not focussed on the individual. They were not set individual goals and were only offered group activities with service users aged between 11 and 30. They felt they did not benefit from the sessions as they were not doing something that interested them and did not learn anything: “[I was] trapped in an endless cycle of not getting anywhere.”

How can we make local information and support about autism better?

In terms of sources of information a number of points were made:

- One group felt that whilst there is a lot of information out there about autism, much of it is written for parents/carers or professionals and not actually aimed at autistic people themselves.
- They felt that information websites are not very useful as they do not take in information through reading it and need visual aids.
- As people take in information in different ways it was suggested that resources need to be available in a range of formats.
- There was also a view that information needs to be condensed into the most important points. Supporting information should be available but not all in the same place as this would be overwhelming and it was felt that they would not be able to remember it all.

When considering support specifically:

Diagnosis

- It was suggested that support around diagnosis could be improved. One individual felt that they had to justify to their GP why they felt they were autistic and that the GP tried to suggest they were not autistic - “everyone is on the spectrum” “trauma can make you experience some of these symptoms.” They felt that support and information was only available to those who appeared not to be coping and that information was only available to them after diagnosis.
- It would be helpful after diagnosis to be able to understand what behaviours are linked to personality and what are neurodivergent.
- It was felt that waiting times for a diagnosis needed to be reduced.
- It was also felt that the process needs to change so that people moving locations during their diagnosis should not have to start the process again.
- The emphasis on school records as evidence for childhood symptoms meant for one participant that they have been unable to get a diagnosis so they now feel that they are in limbo with nowhere to go and no support, which they described as “mentally and socially draining.”

Types of support

- In terms of the support available, two people felt that they did not know what to do to get support. They are unaware of how autism services work – what they are and who works in them.
- They felt that health professionals do not provide information about what is available and instead they have to ask for specific support which is difficult when they do not know what is out there. They suggested advocates would help in this process.
- Participants also felt that services need to ensure they are providing support that is fulfilling and worthwhile for the individual and is meeting their personal needs.
- It was felt that group support was more beneficial than individual support.

Gateshead Autism Information Hub

As part of the review of Autism support, we also wanted to gauge awareness, use or potential future use of the Gateshead Autism Information Hub. Although open to all and not explicitly stated, the Hub currently has a focus on supporting parents/carers of children and young people who have had an autism diagnosis or are waiting for a diagnosis.

Have you heard of Gateshead Autism Information Hub?

Only two focus group participants had heard of the Hub and had visited together. They had visited once to attend the drop-in following a 40-minute drive and had planned to go again but despite checking opening times online, when they got there it was closed for the summer holidays which left them feeling frustrated.

They found the Hub overwhelming because of the amount of information that was available, how busy it was and therefore how loud it was. People also assumed they were parents/carers of children with autism and not autistic adults.

“There's [sic] folders upon folders upon folders, it's overwhelming. And both me and my partner are educated to quite a high level. So, it's not, like, you know, we're bad around paperwork and stuff. But when you first see it, it's overwhelming.”

“There was that narrow gap [between the] table and then it was like having to corral yourself through that to get to this quiet area [using air quotations on "quiet area"]. I sat down to try and get myself under control, and this lady, she didn't mean anything, but she came over and started chatting to me. I couldn't hear her because it was loud so that was quite stressful for me. I don't like being approached and talked to head on and she wasn't... she was a parent of an autistic child. So, I was kind of like I'm not. A, I don't want kids and B, cannot relate to what you're saying... there can be a bit of a clash sometimes because they just assume you're parents as well. And then they tend to be like... she looked really surprised, she was kind of like, oh, well, I don't know how to talk to you now.”

What services/information could the Hub provide for autistic adults?

Participants were asked to consider if they used the Hub in the future, what services and support they would like to see provided. One cautioned that it was important to try and get it right first time as a bad first experience of using the service might put some people off accessing it again.

“Once you've had one bad experience, they tend to just never want to come back. Just retreat and move on, I'm guilty of it myself, if I have a bad experience somewhere, I just will try and avoid that place. I won't go back to Greggs because they stopped doing the vegetable bake. I'm like, well, nothing there I want anymore, I just don't go there anymore, that's sort of like how autistic brains tend to work.”

Design of the space

- Participants felt that having a room full of information leaflets, booklets and other resources would be overwhelming for them.
- They suggested that having a key with pictures and colour coding explaining the types of information and the topics they cover would be helpful.

Information

- There was a consensus of opinion that information should be available in a range of formats and not just written word – with some saying it would be too much information that they would not be able to read.
- Bullet points were mentioned as a way to break up information and pictures or photographs were also very useful to illustrate and enable a greater understanding. For example, if the information was describing a service they could use, they could provide a photograph of the front of the building or door they had to go through.
- In addition to paper information, participants would like the information to be available online so they could refer to it when necessary.
- One group felt that they would prefer to talk to a person to get the information they need rather than reading leaflets and other written resources. However, they would also like the main points of the conversation noted down into bullet points so they could take it away and look at it later.
- It would be useful to include information about employment. It was felt that there is an assumption amongst support services including the Hub that people with autism do not work and therefore information was lacking around employment/support to get jobs etc.

Support

- Participants felt there should be computers available for them to get online and requested support to use the internet to help find certain websites and information so they can use it regularly.
- Some also felt that peer supporters should be available at the Hub.
- They felt that having monthly expert drop-ins at the Hub to give talks and share information would be useful, however:
 - They would need the key points of the talk to be written down for them in an easy-to-understand format, so they could take it away and look at it again.
 - They cautioned that too much information or too long a session could be overwhelming for them.
 - The sessions would need to be advertised well in advance.
 - People should be given the choice of whether they want to attend or not.
 - There should be a commitment from the expert to attend as participants had experienced sessions being cancelled at short notice which made them feel let down.
- Some participants felt that a Facebook group would be a useful resource but should be open access and not private.

Format of the Hub

Participants were finally asked if they were to use the Hub in the future, how they would like to use it; they were given four suggestions:

- Visiting the Hub in person
- Visiting a Facebook page
- A website
- A telephone line

One group felt that it would be good to have the Hub in all the formats suggested as having it in as many formats as possible would make it more accessible. “The Hub should be there for as many people as possible in many different ways.” They also suggested:

- Having a regular Autism Hub podcast.
- Having Zoom/online sessions to run alongside face-to-face.
- However, others felt that a telephone service would not suit them as they liked to see who they were talking to.
- One group said that visiting the Hub in person would be their preferred choice as they liked the face-to-face interaction but cautioned that opening times and the location would need to be consistent.
- Before visiting the Hub for the first time, participants would like to know its location and what the building looks like so they could plan their journey and some suggested that having a transport buddy would be helpful.

“The information needs to be [specific] because autistic people plan things out. I am not somebody who'll just turn up and wing it.”

- Others felt that whatever the format of the Hub, there should be a buddying service to guide people when they use it for the first time.

How should the Hub be advertised?

One participant who had heard of and visited the Hub described how they had learned about it through word of mouth in 2018, three years after their diagnosis. They felt that there should be better advertising and that online information about it should be kept up to date.

A number of participants suggested ways in which the Hub should be advertised in future:

- Social media e.g. Facebook and Instagram
- WhatsApp
- Word of mouth
- Speaking to community groups
- Physical format e.g. posters and leaflets

Views of Autism Information Hub volunteers

- Via questionnaire, volunteers who currently operate the Gateshead Autism Information Hub shared their experiences of providing the resource and offered suggestions for improvements to the service.
 - Three people shared their views; one volunteer has actually run the Hub on behalf of Gateshead Council since its inception in 2016 and two support the main volunteer.

Key themes

The scope of the Hub

- Volunteers see the Hub as a service which provides information, advice, support and signposting for anyone with a connection to autism, e.g. parents/carers, autistic individuals, professionals, practitioners, or anyone with an interest in autism although most service users are parents/carers of autistic children. People find out about the Hub from a variety of different sources including Facebook, Gateshead Council website and signposting from professionals.
- It has good links with professionals who sometimes visit ahead of signposting their clients/service users. Some professionals attend the monthly drop-in events to support individual queries.
- Volunteers feel the service works well and in particular:
 - The monthly drop-ins offer an informal space to share experiences with others, a huge range of information and support from professionals which are very well received and sometimes overbooked.
 - The support groups where friendships are made and people support one another.
 - The Elgin Centre location and access to the Centre's sensory room.

Suggested improvements to the Hub

- It was felt that more face-to-face sessions are needed to meet the needs of the people of Gateshead and this will require more staff/volunteers. Greater attendance from professionals at drop-in sessions to support individual queries and more time dedicated to each person was also suggested and this should also cover mental health advice/prevention for people with autism.
- The Hub would benefit from a permanent and larger space.
- There should be an agreement in place with relevant services to routinely send information to include in the resource files and information about mental health and local social activities should be included.

Volunteer support

- Volunteers value their role and get a lot out of it including sharing the knowledge they have gained and supporting others. Two volunteers will continue to work at the Hub in the future but one is standing down due to the role becoming pressured with increasing numbers of service users and service users attending with more complex needs. They feel that a larger pool of volunteers and having a clear process for applying to be a volunteer would help them in future.

Summary of findings

Purpose of the Hub

To gauge volunteers' understanding of the role of the Hub, they were initially asked what it was set up to do and all were clear of its purpose. They described it as providing information, advice, support and signposting for anyone with a connection to autism, e.g. parents/carers, autistic individuals, professionals, practitioners, or anyone with an interest in autism.

Attendees

A variety of people access the Hub including:

- Mostly parents and carers of autistic children and young people, which includes grandparents, kinship carers and other relatives.
- The support group element is only for parents and carers of autistic children and young people (no professionals or children are allowed to attend).
- Workers (Council, NHS, independent, charities) who want to see what the service is offering before advising people they work with to access it.

Awareness of the Hub

People find out about the Hub from a variety of different sources:

- Facebook search for autism support locally.
- Facebook groups where the service has been advertised (information about meetings at the Elgin Centre are routinely shared with a list of other autism/SEND (Children with special educational needs and disabilities) Facebook groups locally, to mutually promote each other's services).
- Gateshead Council website.
- Signposted by NHS or Council services, e.g. Health Visitors, Social Workers, Children and Young People's Service, schools, Bowel and Bladder nurse, etc.
- Word of mouth (recommendations).

Interaction with other services

A range of professionals and services attend the Hub to provide information and advice to service users on a one-to-one basis (during the pandemic, this took place online in the format of an information/training session).

- Contact Sleep Counsellor
- Disability North
- Feel Good CIC
- Gateshead Council SEND
- Gateshead Council Transitions Team
- Gateshead Council Early Years
- Gateshead Parent Carer Forum
- NHS Bowel and Bladder nurses
- NHS Children's Occupational Therapists
- NHS Children's Speech and Language Therapists
- NHS Paediatrician

- SENDiass (Special educational needs and disability information advice and support service).

Other organisations also send information to promote their services which is included in the resources available to browse.

Positive aspects of the Hub

Volunteers identified aspects of the Hub that they felt work well:

- The drop-in offers:
 - A welcoming, informal and accessible space for people to use.
 - Refreshments and having a volunteer dedicated to this activity allows other volunteers to provide support and advice to service users.
 - A place where people with similar issues and concerns can come together and share their experiences and advice. They feel listened to and not alone. "The social aspect is vital."
 - A huge range of available information.
 - The opportunity to speak to professionals on a one-to-one basis to gain advice and information.
- The support groups offer:
 - A chance to link up with other parents/carers in similar circumstances. Friendships are made and people get the opportunity to talk freely about things they may not be able to talk about elsewhere, which helps with their own self-care as well as their capacity to support their children.
- The Elgin Centre location
 - The Play Development Team are very supportive of the Hub.
 - The administration team are reliable, prompt and efficient.
 - Hub visitors have access to the sensory room.

Suggestions for improvements

Volunteers also shared areas where they felt improvements could be made to the Hub. They noted that they rarely received criticism from service users but identified several areas where changes could be made:

- Offering
 - It was felt that the current provision was insufficient to support the needs of the people of Gateshead and that there was a need for more staff working within the Hub.
- Sessions with professionals visiting the Hub
 - Drop-ins often include a visit from a professional who can talk to individuals about their area of expertise and offer advice and information. Both volunteers and service users would like to see sessions from professionals at every drop-in event.
 - Both volunteers and service users would like to see longer professional sessions to enable service users to have more time with them (currently they have about 10 minutes with the professional).

- The Elgin Centre location
 - The Hub would benefit from a permanent space - the rooms used for the Hub need to be set up and then emptied after use; set up takes about 90 minutes (for the drop-in events) and packing up takes a further hour. This is obviously very consuming but also involves some physical activity.
 - The size of the space should be increased as information resources are constantly expanding and the current space does not allow for additional display space.

- Information provision
 - Searching out information and resources to include in the Hub drop-in events is time-consuming and, in many cases, comes too late (which matters if for example it is a training course that users have to sign-up for to get a place). It was felt that it would be helpful to have an agreement in place with relevant services (Gateshead Council, NHS, independent charities and other agencies) to routinely send through information to include in the files at the drop-in events.
 - Service users have asked for more information on what social activities are available for them to access in Gateshead.
 - It was also felt that there should be more resources and support from specialists around mental health advice/prevention for people with autism.

- Drop-in sessions
 - At present there is often a bottleneck with new users coming into the Elgin Centre and being shown round the resources and given information about the support on offer. It was therefore felt that there is a need for more 'meet-and-greet' volunteers to welcome visitors and show them around.

Support for volunteers

Volunteers suggested the following would help support volunteers working at the Hub in the future:

- It was felt that having a process in place for prospective volunteers to come directly to the manager of the Hub, and resource set aside for the manager to review any applications would speed the process up considerably.
- If there were a larger pool of volunteers to staff the drop-in sessions or give others a break that would also be helpful.

Views of professionals

- During interviews, 13 professionals who work with autistic children, young people and their families and autistic adults shared their views and experiences of Gateshead Autism Information Hub and other information provision and support around autism in Gateshead.
 - Three people in the Early Help Service (Children’s Centres) Team
 - One person in the HINT (High Incidence Needs) Team
 - Three people in the Early Help Service (Early Help Team)
 - Two Directors of Atypical support
 - One Director of Skills 4 Work
 - One Community Paediatrician (Gateshead Health NHS Foundation Trust)
 - One Speech and Language Therapist (Gateshead Health NHS Foundation Trust)
 - One Senior Portage (Early Years Assessment and Intervention Team, Gateshead Council)

Key themes

Positive aspects of local autism support

- A number of services were recognised as offering good support around autism within the locality. Gateshead Autism Information Hub was seen as a vital resource and other services mentioned included Gateshead Local Offer, Gateshead SEND (Special Educational Needs and Disabilities) and Barnardo’s Gateshead SENDiass (Special Educational Needs Disabilities Information and Advice Support Service). Pre-school diagnostic assessments were also highlighted as a good example of multi-disciplinary working.

There are not enough autism support services to meet needs

- However, it was felt by all groups that there are gaps in provision and, as such, people are not getting the required support that they need. Gaps highlighted include support for autistic adults, support for parents and carers post-diagnosis (particularly around managing behaviours), support for autistic children and families who do not have a social worker and support for young autistic people (especially during transition). There is a need for additional allied health professionals such as Occupational Therapists and Speech and Language Therapists.
- In addition to plugging these gaps, a range of other suggestions were made including moving diagnoses into the community and involvement from autistic people in the design of services.

The Autism Hub is a valuable resource

- All professionals view the Hub as a very valuable resource for parents/carers across Gateshead and the peer support aspect in particular is felt to be a vital component of the local autism offer. They signpost to it, accompany people to it, provide professional advice and support at drop-in sessions, and use it to ask advice.

Gaps in provision

- However, gaps in provision have been highlighted including a lack of support for autistic adults and a number of barriers to access have been identified. They include being unable to travel to the Hub due to financial and time restrictions, lack of childcare, drop-in sessions only available during the day, anxiety and mental health and cultural differences.
- However, professionals mentioned a number of ways in which these barriers can be addressed and also put forward suggestions for additional information and support.

There is support for the new Autism Hub draft model

- Professionals on the whole are in support of the Autism Hub draft model, with drop-in sessions across Gateshead, parent/carer workshops and peer support sessions being seen as the most valuable extensions.
-

Summary of findings

Working relationship with autistic people

To provide context to the views and experiences of the professionals, they were initially asked how they or their team supported autistic people.

Team/Position	Work relating to autism
HINT (High Incidence Needs Team)	<ul style="list-style-type: none">• Support schools to make adaptations to their settings through identifying elements that need to be changed to meet the needs of autistic young people.
Early Help Team	<ul style="list-style-type: none">• Work with, and support families and children around social and emotional skills, wellbeing, income and advice. This is a preventative service.
Children's Centres	<ul style="list-style-type: none">• Organise holiday programmes and activities for children with disabilities and within these programmes, work with autistic children and their families.
VCSE (Voluntary, Community and Social Enterprise) professionals	<ul style="list-style-type: none">• Directors of organisations that support autistic adults.
Diagnostic professionals	<ul style="list-style-type: none">• Work within Paediatrics, Speech and Language Therapy and Portage teams and support families pre-diagnosis, during the diagnosis and post-diagnosis.

What do you think of the autism services available currently in Gateshead?

Early Help Team

- The team feels that there are not enough autism support services in Gateshead to ensure that families have the support they need.
 - It was noted that prior to COVID-19 there were more services available, and it is doubtful as to whether the services have re-started after the pandemic.
 - It was felt some families who would benefit from certain local authority and health services are unable to access them due to the child not fitting the support criteria.

“And I've literally just got the case, I've been out, I did an initial home visit, met the little boy...And mam was saying that there's no respite, they don't have a social worker involved. FACETS (Families and Children Empowered Through Specialist Support), which would be obviously respite, not overnight care but through the day, would be ideal for this little boy during summer holidays. But he hasn't got a Child in Need Assessment. So, we can't access it... It is because the other thing is like Active Kids, which is inclusive, would be no good to him because it's too large a group, he wouldn't be able to cope. But he can't go into FACETS because he hasn't got an assessment. So, I can see how frustrating it is for parents.”

- It is recognised that Gateshead Autism Information Hub is an essential service as it is one of the only autism support services universally available in Gateshead. However there has been feedback from some families that the format of the Hub is not helpful for them.

Children's Centres

- The Team feel that there are not enough autism support services within Gateshead to match need, and that the only thing they can signpost to is the Hub.
 - This is partly due to the fact COVID-19 led to several services shutting down which have not been able to re-open.
- They also feel that some autism services which are running would benefit from more promotion. Schools were suggested as a good place for this to be actioned.
- It was also highlighted that families find it frustrating that they cannot access some specialist services which would benefit them, due to not having a social worker to organise this on their behalf.
- There is also felt to be a gap in service provision for younger autistic people in Gateshead.

VCSE Professionals

- VCSE professionals working with autistic adults highlighted that there is little to no support services for autistic adults in Gateshead, with the majority of services being aimed at children, parents and carers.

“I know there's social groups around the North East that are really good and I will recommend people to them, I just know they are quite far to travel, Washington or north Newcastle or Durham.”

- They also felt that the Hub was aimed at parents and carers and not structured to be friendly to autistic people, citing the amount and format of information resources. They suggested that information sheets should be no longer than one page to prevent individuals from becoming overwhelmed and include pictures/visual prompts.

Diagnostic Professionals

- It was felt there is not enough support for families post-diagnosis.
 - One professional recommends services that are in Newcastle and Northumberland because they have no knowledge of any groups that are within Gateshead.
- Professionals find they are plugging the gap and supporting families post-diagnosis even though this sits outside of their job role.

“But what we find we are doing that really isn't our role is the post diagnostic support for a family. And that can be quite time-consuming and involved because obviously, it's a time of crisis for a family and we feel like we're drawn into that...you cannot not, because we are the regular people they see that have been involved with during the assessment, we're there at Child Development Team. And you have to provide that support afterwards. Otherwise, it's not good.”

What is good about autism services in Gateshead?

HINT Team

- The Autism Hub is recognised as a very valuable resource and is crucial for families to get information and support.

Early Help Team

- The Autism Hub is identified as a vital resource within Gateshead, particularly the peer support element.
 - However, it was noted that it is only a voluntary resource in both aspects of personal experience and professional capacity.

“One of the things and I'm sure they do have it monthly or something like that, is a support group for parents to come together. Parents, carers, to come together because they empower each other and share experiences. They can laugh, cry, do whatever they want to do and they can understand each other because nobody else is in their shoes really.”

- Other services the team highlighted were Growing Healthy Gateshead 0-19 service, Gateshead Local Offer, Gateshead SEND (Special Educational Needs and Disabilities) and Barnardo's Gateshead SENDiass (Special Educational Needs Disabilities Information and Advice Support Service).
 - It was noted the one of the reasons the Barnardo's Gateshead SENDiass service works so well is because it is independent of the local authority.

Children's Centres

- Gateshead Local Offer and leisure centre swimming pools running SEND sessions were highlighted as positive examples of support by the Team.

Diagnostic Professionals

- Pre-school diagnostic assessments work well within Gateshead services.
 - Good links with the education team, preschool education team and speech and language therapists mean that assessments are streamlined, and they are able to get good pre-referral information. In turn, this then means shorter waiting lists and the process is not as long and drawn out which works well for families.

What is missing from autism services in Gateshead?

Early Help Team

- The Early Help team identified several areas where more resource is needed:
 - Support for children and adults who have just been diagnosed.
 - Support for young people through transitions such as leaving school/college.
 - Support for parents/carers especially around managing behaviour and everyday support for families.
 - They highlighted that when families get a diagnosis, the only thing they get after is a package of information and made the point that there is a strong link between not having the right support in place and impact on mental health.

“There's one of the little ones I work with, he's only three. And he's just received a diagnosis of autism. And I was at the diagnosis, supporting mam. And there was a lot of professionals

there, and they were all lovely with the little boy lovely with mam. But she got that diagnosis, and she left and that's it. She'll get a package which she has received, a package of information, but that is it. And this you're talking about a mam who is single mam, four children, one now with a diagnosis of autism. And she's got health problems. She doesn't have family support...And that's it, like you know, go on, crack on. And it's not good enough, is it?"

- There is also a need for more peer support which they see as one of the most valuable types of support.

Children's Centres

- Workers feel that there needs to be a more extensive range of services for families and for individuals with autism.
 - All families and individuals are different and a service that is suitable for one family, may not be suitable for another one.

VCSE Professionals

- It was felt that there is a major gap in support service provision for autistic adults.
 - Many of the adults the VCSE professionals work with were diagnosed after the age of 24 and struggled to find support services that they could access.
- Another area where there is a gap in provision is when young people finish school/college there is little support available and if they do not know about services they can access, young people often "disappear into the ether."

"If you're in the know, you know everything and if you're not in the know you don't know about anything."

Diagnostic Professionals

- Diagnostic professionals feel that there is a funding gap with NHS services as there are not enough allied health professionals to meet the needs of children within autism services.
 - There is a lot of dissent from parents/carers who are not able to access services their child needs because of this.
 - Many parents are turning to independent speech and language therapists because NHS waiting lists are so long, which has resulted in waiting lists within this sector too.
- It was also suggested that there needs to be an Occupational Therapist NHS commissioned service to help meet the needs of sensory therapy.

"But if you go for a sensory assessment, that is all you get is an assessment, you won't get therapy because it can't be done. So, from an NHS perspective, we need to look at this again. And we need the commissioners to see and I understand there is a lot of other demands on commissioners, doctors, nurses, etc...But we kind of are and always have been the forgotten services."

In an ideal world, what would you like to see change in autism services in Gateshead?

Early Help Team

- The Team suggested heavy investment into neurodiversity from the government as something they would like to see.

- It was also suggested that diagnoses could be provided at the Autism Hub rather than the Queen Elizabeth Hospital as it can be quite difficult for parents and the Elgin Centre is a family friendly environment.

VCSE Professionals

- It was felt that autistic individuals should be involved in autism service design from the beginning.
- It was suggested that having a separate adult focused autism hub and a child focused autism hub would be ideal and the VCSE sector would be happy to help support this.
- Another suggestion was that autistic adults could come in and speak to parents/carers about their childhood to raise awareness of behaviours and how they can manage them.

Diagnostic Professionals

- It was felt that a post-diagnostic support pathway would be immensely beneficial for families.
 - Suggestions of what this could look like include:
 - Counselling support services for families post-diagnosis.
 - A drop-in group run by the Hub to bring newly diagnosed families together.
 - There used to be an occupational therapist clinic where they would bring newly diagnosed families together, but it no longer takes place due to lack of capacity.

Gateshead Autism Information Hub

All interviewees had heard of and used the Hub in some capacity. They were asked about this use, how it supports their work and how it supports the people they work with.

How do you use the Hub?

Team/Position	Use/interaction with Hub	Frequency of use
HINT (High Incidence Needs Team)	<ul style="list-style-type: none"> • Attended drop-ins in the past to answer questions around education and provide signposting support 	<ul style="list-style-type: none"> • Previous regular attendance (not commissioned to do so) but due to high number of referrals and lack of capacity they are no longer able to attend
Early Help Team	<ul style="list-style-type: none"> • Signpost people to the Hub • Attending the drop-in sessions with families they are working with • Contact the main volunteer for advice and support 	<ul style="list-style-type: none"> • One Team member would attend drop-ins every 2 months with families they were working with. This stopped during COVID-19 and has not yet restarted • Another Team member lets families they are working with know they would accompany them in attending the Hub, but no one has taken up their offer as of yet • All signpost to the Hub regularly
Children's Centres	<ul style="list-style-type: none"> • Work in partnership with the main volunteer around information and advice 	<ul style="list-style-type: none"> • Signpost to the Hub regularly • Physically attend the Hub occasionally

	<ul style="list-style-type: none"> Engage with parents/carers at drop-in events to let them know what services they can offer Signposting families they are working with to the Hub 	
VCSE (Voluntary, Community and Social Enterprise) professionals	<ul style="list-style-type: none"> Signpost people to the Hub 	
Diagnostic professionals	<ul style="list-style-type: none"> Signpost people to the Hub regularly Engage with parents/carers at drop-in events to offer advice 	<ul style="list-style-type: none"> Signpost to the Hub regularly Include information about the Hub in the post-diagnostic information pack which is sent to families Previously attended drop-in to offer advice

How does the Autism Hub support your work?

HINT Team

- The Hub allows the HINT team to have somewhere they can signpost to within Gateshead to get more information and advice around autism.

Early Help Team

- For the Early Help Team the Hub provides a place for professionals to go to learn new skills, strategies and gather information.
- It is a resource that all families in Gateshead can access so they are able to signpost all families that they work with.

Children's Centres

- The Hub supports professional development through working in partnership with the main volunteer to share knowledge and expertise.
- The co-location of the Autism Hub and the Children's Centres Team at the Elgin Centre means they have a closer working relationship.
 - The Children's Centres Team also supports the Hub in many different ways, such as directing people where to find it within the building, and providing information if the Hub is not on, such as when the next drop-in session is and how they can find information until the next one.

VCSE Professionals

- The VCSE workers see the Hub as a valuable information point.

Diagnostic Professionals

- One interviewee stated the Hub did not support their work at this moment in time. However, if they knew more about what the Hub could potentially offer, then there would be a possibility of it supporting their work.

- Others highlighted that signposting to the Hub was important as they are able to offer the resource when there is not much else to offer.
- Another interviewee felt that the Hub drop-in sessions allow professionals a better environment to emotionally support families in a way that a clinical setting can prevent.

“On that particular visit, there was a mum who came along, who had been through the diagnosis relatively recently, to my session. And she really, really struggled. She was really emotional because her older child also has diagnosis and other needs. And her younger child had just been given a diagnosis, but he was more severely impacted by his autism. And she was struggling...And she just sort of sat and cried. And it was just to sit and offload. And actually from my perspective, it was easier that she was crying in that situation than what it would have been if she'd come to a [clinical] appointment with me and cried. Because I could offer a cup of tea, I could offer a biscuit, they were there. I could offer other people as a signposting because they were there, rather than being in a clinic appointment and maybe not even having a tissue to offer.”

What benefit does the Autism Hub have for the people you support?

HINT Team

- The Team identified three valuable aspects of the resource:
 - The opportunity to meet other parents/carers with the same experiences and receive informal peer support – this was identified as the biggest benefit.
 - The wealth of information and knowledge available from the main volunteer.
 - The opportunity for parents/carers to have one-to-one support from professionals.

Early Help Team

- The Team felt that the Hub offers families the opportunity to learn about new information and strategies to help them support their child at home.
- However one interviewee had received feedback from some families that it was not useful for them because the format of information was not what they were hoping for and some found the drop-in sessions to be “cliquey”.

Children’s Centres

- Workers see the Hub as somewhere parents and carers can get information in a welcoming space; they feel it provides comfort that they are not alone, especially immediately after diagnosis.

It is not just a resource of information, but also a place where parents/carers can meet other people in similar situations, enabling them to experience peer support and feel less isolated.

VCSE Professionals

- The Hub does not benefit the autistic adults the interviewees support as it is aimed more towards the parents/carers of autistic children and those who have just been diagnosed.

Diagnostic Professionals

- One of the main benefits cited was that the main volunteer who runs the Hub is extremely hospitable. They felt that families need this type of interaction to show them that the diagnosis is not all negative.

- It is also beneficial in that it acts as a ‘bridge’ that links families who are post-diagnosis with a wide range of people who all have a connection to autism.
- However, one interviewee had not received much feedback from families about the Hub but those who had fed back did not find it helpful due to opening times and the Hub’s location not being accessible for them.

Suggestions for improvements to the Hub

Team/Position	Suggestion
HINT (High Incidence Needs Team)	<ul style="list-style-type: none"> • Commissioned occupational therapist and Early Help presence at the drop-in sessions • Parenting courses • Drop-in sessions available throughout Gateshead, with a central base. • Open more regularly than once a month • Additional staff to run the resource (not rely on one main volunteer)
Early Help Team	<ul style="list-style-type: none"> • A whole family approach should be used to aid family understanding of autism - especially important to help neurotypical children understand why their neurodivergent sibling is treated differently • Provide childcare whilst drop-in sessions are taking place - it would also allow the children to meet other children who are like them and a buddy system could be implemented • Drop-in sessions available in other areas of Gateshead e.g. Blaydon and Birtley • Hub workers to provide schools with training around how to support children and families with autism
Children’s Centres	<ul style="list-style-type: none"> • More regular sessions • Sessions in different areas of Gateshead • Retain physical element of the Hub • Provide childcare whilst drop-in sessions are taking place • The Local Offer Team could support the Hub with its social media and communications
VCSE (Voluntary, Community and Social Enterprise) professionals	<ul style="list-style-type: none"> • Having different online formats to allow for greater access to Hub information, e.g. a website • Available in other areas of Gateshead e.g. Birtley to link up with other SEND services • Develop a user voice group
Diagnostic professionals	<ul style="list-style-type: none"> • Host regular educational webinars on different topics e.g. sleeping, toileting, behavioural issues and eating difficulties • Professionals from education to attend drop-in sessions • Develop a post-diagnosis support group (mirroring the pre-diagnostic pathway support group for families where the child has social communication difficulties) • Champion parent/carer mental health • Provide childcare whilst drop-in sessions are taking place or organise events where children can come along e.g. away days

What do you think of the draft autism hub model?

As part of the review of autism services, interviewees were shown a potential future autism hub model and asked to give their views on it.

Autism Hubs Draft Proposal

DROP IN SESSIONS ACROSS GATESHEAD	ONLINE PRESENCE	COURSES	SIGNPOSTING	PEER SUPPORT SESSIONS
<ul style="list-style-type: none"> Providing information Speak to professionals Meet other parents 	<ul style="list-style-type: none"> Maintenance of Facebook page as an online information resource 	<ul style="list-style-type: none"> Parent/carer workshops to understand autism Internal staff training to build capacity 	<ul style="list-style-type: none"> Access to information and signposting to other relevant services in Gateshead 	<ul style="list-style-type: none"> Coordinate peer support parent sessions for those wanting to meet others, build connections and friendships

HINT Team

- The HINT Team felt that the Hub already provides most of the services on the Autism Draft Model, but the parent/carer workshops would be an addition.
- They are unsure on what “internal staff training to build capacity” means, so further clarification on an updated version of the model would be welcomed.

Early Help Team

- There is support for the geographic expansion of the hubs and professionals attending drop-in sessions. It was suggested that this should include social workers, staff from the Toby Henderson Trust and North East Autism Society.
- Staff training around autism would be beneficial and it is something the Team have asked for.
- They support the signposting element of the model and suggested children’s mental health and emotional wellbeing teams and sensory support services should be the focus.
- The Team see peer support as the most important element of the model, but this should be available for young people and teenagers as well as parents/carers.

Children’s Centres

- The model was welcomed and it was suggested that the geographical extension of the Hub could be linked with future Family Hubs.
- Workers felt that the online presence strand of the model could be more extensive.

VCSE Professionals

- VCSE professionals highlighted the lack of support for autistic adults, noting that just about all the support is for parents/carers.
- It was noted that many more people are getting diagnosed with autism later in life and there is nothing in the Hub model to support these individuals.

Diagnostic Professionals

- It was suggested that some of the parent/carer workshops should be carried out online in a webinar format to make it more accessible.
- For those that are carried out face-to-face it is advised that the sessions are practical and individualised.
- There is potential for collaborative working between the Hub, Speech and Language Therapy, Portage and Occupational Therapy as they already have training courses and workshops for families ready.
 - Two of the Speech and Language Therapists in the Gateshead Child Development Clinic are National Autistic Society Early Bird trained.
 - It was felt that it was important to use NHS staff in Gateshead for the parent/carer courses and workshops, who know the system and what is on offer, and not an outside company.
- One professional suggested that within the signposting aspect of the model, there needs to be information about Autism services that are outside the area of Gateshead because of the lack of support within the locality e.g. Autism Northumberland, Tim Lamb Centre, True Colours Theatre Group, Shiremoor Adventure Playground.
- It was felt that importance should be placed upon the peer support sessions.

Groups who struggle to access the Hub

People living in Outer West Gateshead were the only reported group who had struggled to access the Hub. However interviewees suggested groups who they felt may struggle - people with social/threshold anxiety or mental health issues and people from different cultural backgrounds who may find it difficult to ask for support.

Barriers to accessing the Hub and suggestions to improve accessibility

Interviewees were asked to share things that they felt might be a barrier to people using the Hub and put forward any solutions to overcome them and improve accessibility.

Barrier	Description	Solutions proposed
Travel to Hub site/location of Hub	<ul style="list-style-type: none"> • Due to Gateshead being a large locality, those without a car struggle to get to different places • It is especially difficult for families who live in the Outer West (it takes 2 buses and 1.5hrs to get to the Elgin Centre). People living in the Inner West, Birtley and Barley Mow would also struggle. Some locations mean having to travel into Newcastle and back out to reach the Centre • Time and financial costs mean that it is prohibitive 	<ul style="list-style-type: none"> • Have outreach sessions at a range of locations across Gateshead • Have several Hub sites across Gateshead • Ensure new locations have good public transport links
Co-location	<ul style="list-style-type: none"> • The fact that the Hub is in the same building as a nursery can be a barrier to 	

	some people entering the building on their own	
Location within building	<ul style="list-style-type: none"> The location of the Hub within the Elgin Centre is a barrier as it is “hidden away upstairs” 	
Lack of childcare	<ul style="list-style-type: none"> Not having any childcare and child support is also a major barrier to accessing the Hub as it prevents parents and carers from coming along to the Hub on their own 	<ul style="list-style-type: none"> Have a sensory room that is maintained by staff Make the space more child-friendly
Limited format	<ul style="list-style-type: none"> In person and paper-based resources limit people being able to access resources and support 	<ul style="list-style-type: none"> Hold online sessions as well as ones in person
The timing of the sessions	<ul style="list-style-type: none"> The timing of the sessions prevents working adults from being able to attend the drop-in sessions 	<ul style="list-style-type: none"> Have drop-in sessions and information and support sessions during the evening
Group setting	<ul style="list-style-type: none"> Some parents/carers feel uncomfortable discussing their issues in a group setting 	<ul style="list-style-type: none"> Have smaller group or one-to-one sessions
Limited sessions	<ul style="list-style-type: none"> The amount of drop-ins available is also a barrier, as if an individual is busy on the day of the drop-in session, they may have to wait another month to be able to go and get the information they need 	<ul style="list-style-type: none"> Drop-in sessions need to be more frequent. Sessions need to be at regular intervals to enable people to plan their visit in advance
Social/threshold anxiety	<ul style="list-style-type: none"> Anxieties around meeting new people can also prevent parents and carers from accessing the Hub 	<ul style="list-style-type: none"> Hold some of the sessions online Staff could arrange ‘meet and greets’ outside the building so people do not have to enter the building alone Have clear signage for the Hub so people know they are in the right place Send out pictures of the outside and inside of the Hub building so people know what to expect
Closed Facebook group	<ul style="list-style-type: none"> Makes it difficult for people to join and get information 	<ul style="list-style-type: none"> Make the group public

Do you find that information sharing is an issue when working with partner organisations?

Interviewees could not identify any issues around information sharing when working with partners.

Conclusions

As summarised above, engagement with stakeholder groups generated a large amount of information about autism services in Gateshead and Gateshead's Autism Information Hub. From this data we are able to address the research questions posed:

- What is working within autism services?
- Are there any areas where improvements could be made?
- What impact does the Hub have?
- What gaps exist within the Hub provision?
- What barriers prevent people from using the Hub?
- How does/can the Hub support autistic adults?

What is working within autism services?

Some awareness of local resources

Parents/carers identified a wide range of places they would initially go for professional support around autism with GPs, the Hub and schools most frequently mentioned. Autistic adults also named eight local resources or organisations they were aware of that offered information and support including Skills 4 Work, the Gateshead Council website and Inspired Support.

High quality local resources

One quarter of parents/carers reported satisfaction with local information and support and for most, this was down to the quality of the support they received from the Hub (discussed in more detail below) due to the wealth of knowledge workers have and the timeliness of this support.

Autistic adults attending Inspired Support and Skills 4 Work enthused about the quality of the support they receive on both a practical level – learning new skills, gaining work experience and life skills – and socially, citing having a routine, developing friendships and having peer support. Both organisations provide a person-centred approach which is very much valued.

Professionals also highlighted the Hub as a good source of autism support as well as Gateshead Local Offer, Gateshead SEND, Barnardo's Gateshead SENDiass. Pre-school diagnostic assessments were also highlighted as a good example of multi-disciplinary working.

Are there any areas where improvements could be made?

There are a number of areas where improvements could be made to local autism services.

Awareness of local resources

For one fifth of parents/carers who were dissatisfied or neither satisfied nor dissatisfied with the amount of local information and support available to them this was because they were not aware of any local information or support. Furthermore, autistic adults requested targeted information around what resources are available to them and the structure of local autism services to be provided upon diagnosis.

Amount of local information and support

Professionals feel that there are not enough services to meet local need and highlighted gaps around support for autistic adults, support for parents and carers post-diagnosis, support for autistic children and families who do not have a social worker and support for young autistic people.

This was evidenced in the parent/carer survey where half were dissatisfied or very dissatisfied with the amount of local information and support available to them; they felt it is limited and this is particularly evident immediately after diagnosis. This was echoed by autistic adults who reported a lack of services and support for their cohort. They requested information focussed specifically on autistic adults and put forward ideas around how to make it accessible for them such as providing a range of formats, visual aids, conciseness.

Diagnosis

Autistic adults felt that support around diagnosis could be improved in terms of waiting times, GPs signposting to resources whilst waiting to be assessed, restrictive evidence needed to support a diagnosis and once diagnosed, information around what behaviours are linked to their diagnosis.

Support for young people leaving school

Professionals felt that there is a gap around support for young people during transition and when asked, seven in ten young people who shared their views on leaving school felt that they would need support to help them achieve their future goals. In particular they would like support around accessing and attending further education and learning new skills. The group identified attributes they would like in a future support worker with someone who they felt safe with, someone who showed them respect and kindness, someone who was fun, and someone they could think of as a friend, mentioned most frequently.

Quality of local information and support

For several autistic adults, the support they had received in the past did not meet their expectations. Citing two different services, there was an issue with them not focussing on individual needs and therefore the support they provided was not useful to them and they gained very little from it.

Accessibility of local information and support

For a minority of parents/carers, their dissatisfaction with the amount of local information and support to accessibility related to a limited range of locations, operating hours and long waiting times. Location was an issue for several autistic adults too who live close to the border with Durham and although more accessible to them than Gateshead resources, they are unable to access them.

Themes around awareness and accessibility are also evident when considering the Hub offering and are discussed in more detail below.

What impact does the Autism Hub have?

It is a valued local resource. After GPs, the Hub (alongside schools) is the first port of call for parents/carers when seeking professional support around autism. Furthermore, the Hub was identified

as the most commonly used source of local information about autism and fundamentally, satisfaction with local information and support around autism is linked to positive experiences of the Hub. For most, the Hub has been used on more than one occasion with some reporting over 10 visits to the Elgin Centre. Parents/carers are more likely to access the physical building but the online Facebook resource is also well used. They use the resource to primarily access information about autism, receive support from peers and receive advice, either from Hub workers or professionals who attend the monthly drop-in sessions. They value the “great advice,” “informative articles” “amazing support from peers and professionals” “friendship and understanding.”

Volunteers working in the Hub report that the service works well and in particular the monthly drop-ins which offer an informal space to share experiences with others, the huge range of information, and support from professionals which is very well received and sometimes overbooked. The support groups offer a space for people to support one another and strong friendships are developed. The Elgin Centre’s location with access to the Centre’s sensory room is felt to be a positive.

Professionals emphasised the value they placed on the Hub. The main volunteer worker is a fountain of knowledge for them and the people they support, it is the first place they signpost people to and it is a place for professionals to learn new skills, strategies and gather information. Some attend the Hub to reach out to parents/carers who need one-to-one advice and support and feedback from users is that this is very much appreciated. They feel that the peer support aspect in particular is a vital component of the local autism offer, it provides comfort to people particularly immediately after diagnosis.

What gaps exist within the Hub provision?

Access to the resource

The Hub has no permanent physical space with things being set-up and then taken down after every session – this is time consuming and requires significant physical activity on the part of the volunteers. Furthermore, it was felt that the space is too small and not future-proofed. Professionals felt that users would benefit from being able to access the Hub from several locations across Gateshead.

Hub volunteers and professionals feel that operating times are too limited (three sessions covering 5 and a half hours) and do not meet local demand. Moreover, volunteers felt that they were limited in the amount of support they could provide service users and consequently more staff are needed to ensure that Hub users are fully supported.

Additional information and support

Hub volunteers acknowledged that up-to-date information was not always possible due to the timely process of having to contact organisations and request it.

Parents/carers suggested a range of information topics they would like to see covered by the Hub and in particular mental health, healthy relationships and effective parenting/behaviour management strategies. Hub volunteers echoed the demands of parents/carers for information about mental health and also felt there was a need for information about local social activities, groups and events. Professionals felt there was a need for educational webinars on different topics e.g. sleeping, toileting, behavioural issues and eating difficulties.

Professionals feel a whole family approach should be used within the Hub to aid understanding of autism. They also suggested the establishment of a post-diagnosis support group and requested peer support for young people/teenagers. Parents/carers also suggested support from Talking Therapies, provision for young adults and support for children during school holidays in the first instance.

Attendance at Hub drop-in sessions by professional support services is a key element of the offering and one-to-one sessions are often oversubscribed. Currently this is ad-hoc but Hub volunteers and service users would like every drop-in session to include visits from relevant organisations. Moreover, they feel that service users would benefit from longer one-to-one sessions.

Professionals echoed these views and suggested having an occupational therapist and Early Help presence at each drop-in session. They cautioned however that this would require formal commissioning of services. Having access to education professionals, social workers and staff from the Toby Henderson Trust and North East Autism Society was also suggested.

Additional formats

There is support for the continued access to a physical resource offering face-to-face advice and support however parents/carers and professionals would also like to see greater online presence with the development of a website, the continuation of the Facebook information page and for a minority the establishment of a virtual support group. This would allow for greater access.

Draft Hub model

The draft Hub model looks to address some of these gaps and professionals were generally supportive of the proposals. They did however suggest that the online presence could be more extensive and that signposting services need to provide information on support outside of Gateshead due to a lack of support within the locality, they also suggested that peer support should be prioritised. For autistic adults, there is still no support.

What barriers prevent people from using the Autism Hub?

Lack of awareness

Amongst parents/carers there is a lack of awareness of this resource with more than two-in-five parents/carers unaware of its existence.

Accessibility

Over half of parents/carers who have heard of the Hub have not used it and this is primarily down to the accessibility of the resource. The session times do not fit with working schedules and bedtime routines, the Elgin Centre is too far for some to travel to and there are no childcare/creche facilities available to facilitate a visit. Professionals echoed these barriers and also highlighted the location of the room within the Elgin Centre, co-location with a nursery, social/threshold anxiety, the group environment and the fact that the Facebook group is private.

How does/can the Hub support autistic adults?

For autistic adults, the Hub has very little impact on their lives as resources and support is currently focused on children and young people and their parents/carers.

Barriers to use

Very few autistic adults taking part in this research were aware of its existence and those who had visited the Elgin Centre experienced accessibility issues. They found the busyness, noisiness and the sheer volume of information on display, within the Hub building overwhelming. It was felt that the resource is not for them with one participant describing a visit where they were approached by a peer and asked if they were a parent or carer and when it established that they did not fit this cohort, they were not offered any other support.

Suggestions for improvements

If the Hub is to become a useful local resource for autistic adults there is a need to increase awareness of it. It would also require changes to the physical space to ensure it does not overwhelm; upon entering the space a key with information colour-coded and corresponding visuals should be prominent, any information resources should be in a range of formats including paper-based, online and face-to-face presentations and concise with bullet points and illustrations. Before visiting the physical location for the first time participants would like details of its exact location, how to get there and what it looks like and once inside offered support from a buddy. To aid this development a user voice group could be established.

In terms of additional information and support, there was a specific request for resources around employment, access to computers and support to use them and the availability of peer supporters. Any drop-ins with experts would need to be advertised well in advance and would need accompanying information for them to take away and digest and not be too long. A Facebook group was also suggested.

Considering the future format of the Hub a face-to-face and online resource would be accessible (some would struggle to use a telephone) and regular online support sessions and podcasts would be helpful.

Recommendations

In response to the findings outlined above, some recommendations have been made.

Raising awareness of local information and resources

- There is a need to raise awareness of the local information and support available to autistic adults and parents/carers of autistic children and young people.
 - It is recommended that a comprehensive communications plan is created to ensure that service user groups are aware of the range of services available and for each, the scope of the information and support provided, any criteria for accessing this and locations and opening times etc. This information should be available in a variety of formats including paper and digital, Easy Read versions should also be available and should consider the formatting suggestions put forward by autistic adults. Provision in other languages should also be developed.

Improving accessibility of the current provision

- All groups reported examples of people having to go outside of Gateshead to access relevant support or struggling to find resources close to home.
 - It is recommended in the first instance that a mapping exercise of current resources is conducted to identify what is available within Gateshead to understand where there may be gaps in terms of geographical areas. If gaps are identified, consider whether some services could be relocated. Alongside this, ensure that potential users have clear information about how to get to current locations including public transport links and again, consider suggestions from autistic adults about the format of this information.
 - Consider whether an agreement could be negotiated between neighbouring authorities to enable people to use facilities outside of their local authority.
- Operating hours of services were also seen as barriers to use by a minority.
 - It is recommended that services are reviewed with the possibility of offering after work opening times one day per week.

Increasing provision

- Autistic adults, parents/carers and professionals feel that there is simply not enough local information and support available. Autistic adults want information and support that is specifically for them and parents/carers feel that resources are limited.
 - Whilst appreciating the pressures on budgets, it is recommended that Gateshead Council facilitates a meeting of local providers to discuss their current offering and what more could be done to increase provision particularly around support for autistic adults. Any new provision must be person-centred, helping people develop skills and reach individual goals.
- Professionals would like to see more peer support, and more allied health professionals brought in to meet demand.
 - Explore whether more peer support could be offered as part of the Hub.

- Examine budgets to see if there is capacity for additional allied health professionals such as occupational therapists and speech and language therapists.

Additional support around diagnosis and post-diagnosis

- Both autistic adults, parents/carers and professionals identified a gap in dissemination of local information and support at time of diagnosis. Autistic adults requested information around what behaviours are linked to their diagnosis.
 - Explore what services and support is available immediately after diagnosis for both children, families and adults and consider the development of a post-diagnostic support pathway. This should include accessible information as agreed by key stakeholders, being mindful not to overwhelm.
- For autistic adults, long waiting times for diagnosis and no signposting support from GPs whilst waiting to be assessed were issues.
 - Consider a standardised offering for people (adults and parents/carers of children and young people) waiting for assessment and diagnosis provided by GPs upon presentation.
- Professionals suggested having diagnoses in the community in a more family friendly environment would be beneficial.
 - Explore whether it would be possible and whether this could be part of the Hub.

Resources to support young people

- Professionals feel there is a gap in provision for young people generally and also during transitions.
 - Review provisions for young autistic people and identify resources to plug any gaps.

Improvements to the Hub

Awareness raising

- As with other autism services there is a lack of awareness of the Hub.
 - Consider the development of a comprehensive communications plan taking into account the accessibility requirements discussed above.

Accessibility

- Some parents/carers who have heard of the Hub have not used it and this is primarily down to accessibility with session times being restrictive for those who work and at the same time as children's bedtimes, the Elgin Centre being too far for some to travel to and no childcare/creche facilities available. Professionals echoed these barriers and also highlighted the location of the room within the Elgin Centre, co-location with a nursery, social/threshold anxiety, the group environment and the fact that the Facebook group is private. Autistic adults find the space overwhelming due to noise, footfall and the amount and type of information on display.
 - It is recommended that use of the Elgin Centre is reviewed.
 - Session times should be reviewed to ensure that they are accessible for all and more offers of online access available. Access to the Facebook group should also be reviewed.
 - Consider developing a user voice group.
 - Consider having physical Hubs in several places across Gateshead.
 - Consider the provision of on-site creche/childcare facilities/sensory room maintained by staff.

- Consider having a key with information colour-coded and corresponding visuals to help navigation of the space.
- Consider having information resources in a range of formats including paper-based, online and face-to-face presentations and concise with bullet points and illustrations.
- Consider the development of resources for people to use ahead of their first visit outlining the exact location, how to get there, what it looks like and once inside, offer support from a buddy.

Operations

- A permanent physical space for the Hub is needed to reduce burden on volunteers whilst the current location lacks space to expand. Autistic adults need a space which is not crammed with resources and would also like access to computers to help them access online resources.
 - It is recommended that the Hub receives a permanent home, whether this be in one location or several, the space that is used should be exclusive.
 - It is recommended that any future spaces are large enough to display the considerable amounts of paper resources in an accessible way, with room to expand as necessary and space for computers.
- Volunteers and professionals report that the five and half hours of support provided by the Hub per month does not meet local demand.
 - Consider having the Hub building open more regularly and consider additional online support.
- Volunteers feel unable to meet demand from users.
 - Consider increasing the number of workers at the Hub.

Provision

- Focussing on children and their parents/carers means that the Hub is not accessible to all.
 - Consider widening the scope of the Hub so that it is supportive of anyone with autism (and their parents/carers/families) regardless of their age or consider a separate autistic adult Hub resource.
- Gathering up-to-date information about local services and support is very time consuming for volunteers.
 - Consider developing an agreement with relevant services to routinely send information to the Hub to include in resource files.
- A range of additional topics were suggested for inclusion in the Hub and professionals felt a whole family approach should be adopted.
 - Review these suggestions and consider whether they could be added to the resource and in particular information around mental health, healthy relationships, effective parenting/behaviour management strategies and employment. Also consider including relevant local social activities, groups and events.
- A range of additional support was suggested for inclusion in the Hub from parents/carers, autistic adults requested access to peer supporters and professionals felt that peer support sessions were the most important element.
 - Review these suggestions and consider whether they could be added to the resource and in particular access to Talking Therapies via the Hub, peer supporters for autistic adults, some sort of provision for young adults and support for children during school holidays.
- Access to professionals during drop-ins is important to parents/carers but currently this is on an ad-hoc basis. The provision is often over-subscribed and users are restricted to a short amount of one-to-one time. Professionals would like to see a regular presence from occupational therapists, the Early Help team and education professionals.

- It is recommended that every drop-in session should offer support from a professional which may need to be commissioned and that one-to-one time is increased to allow all queries to be covered.
- There is support for the continued access to a physical resource offering face-to-face advice and support however parents/carers and professionals would also like to see a greater online presence. Autistic adults would like regular online support sessions and podcasts.
 - Consider the development of a website, virtual support groups, podcasts and educational webinars.

Appendices

Appendix 1: Profile of parents/carers

Please note that not all respondents chose to complete these questions

