

Community Autism Support and Advice Service for Adults – Public Engagement Report

1. Introduction

1.1 Background

The existing contract for the Community Autism Support and Advice (CASA) Service, currently known as CASA comes to an end in March 2024.

The Service was first commissioned as a result of the previous Autism Strategy (2018-2021), which had the provision of post-diagnostic support identified as the highest strategic priority for Gloucestershire. This continues to be consistent with the local strategic direction and in line with Gloucestershire's All Age Autism Strategy (2022 – 2026).

The Service aims to provide information, advice, and guidance to support autistic people have meaningful, high quality and unrestrictive lives. It is a countywide Service and supports pre and post diagnostic assessment, offering a wide range of interventions and support.

The service is provided to:

- Adults 18 years and over.
- Young persons aged 17 years who are in transition from children and young people's services.
- Individuals with a diagnosis of autism (with absence of a learning disability)

The individual must be either:

- Living in Gloucestershire, and/or
- Registered to a Gloucestershire GP, and/or
- Funded by Gloucestershire County Council and/or NHS Gloucestershire

Current contracting arrangements have been reviewed to deliver a more robust, inclusive, and consistent approach across Gloucestershire, ensuring the voices of autistic individuals receiving support are heard. An evaluation of the current Service has been undertaken to inform proposals for a new commissioned Service.

To inform the recommissioning and long-term investment, a public engagement exercise has been conducted. This report brings together the findings of the public engagement and proposed recommendations. This document will be included with the Cabinet Paper to seek permission to commission a new Community Autism Service for Adults in Gloucestershire.

1.2 Pre-engagement work

Commissioners evaluated the current service provision and utilised other research and engagements to inform the direction of a new service model.

1.3 Public Engagement

A public engagement was conducted to gather the views of the support required from a post-diagnostic autism support service. A survey was published on the Council's engagement platform and was open for 6-weeks from 28th April to 11th June 2023. Hard copies of the survey were available on request. The survey was promoted across a range of platforms.

A total of 81 people submitted a response to the online survey. There were no requests for the paper version.

1.4 Response to engagement

This feedback will be brought together to develop the service model and procurement approach of the Community Autism Support and Advice Service in Gloucestershire. Identified actions relating to feedback provided by demographic groups is included within the Equality Impact Assessment that accompanies these proposals.

2. Pre-engagement consultation and research

2.1 Service evaluation

The evaluation and engagement consisted of multiple avenues to obtain as accurate a position of the service and the proposed amendments that would be needed to future proof it in its development. These consisted of the following methodology:

An evaluation of the current service which included:

- A client Survey which was available online and in a hard copy
- An online Staff Survey
- Visit to CASA drop ins across the county to inform how the service is run in localities and ensure factors around geographical locations are considered going forward.
- Utilising contract monitoring data from the current provider.

The evaluation of the current service was undertaken which sought to understand how the areas of current delivery were working and what changes might need to be made as part of the recommissioning process. Individuals who engaged in this process were able to give their feedback on how a future service could be developed. This facilitated an opportunity to highlight any potential service changes, the future service delivery model and draw attention to any anticipated problems.

Key findings:

There needs to be an equitable approach across Gloucestershire. 1-1 support is beneficial to those who have received it and need to be person-centred, non-judgmental and supportive. Signposting continues to be a valuable resource which supports most people. A service which is flexible to the needs of the people accessing it is key. Peer support is an important element in connecting with others

and creating meaningful connections and supportive networks. Partnership working with support services is key. Drop Ins are useful informal spaces where people can connect with others, as well as find out more about autism.

2.2 Additional research and learning

Research and learning from other key areas:

- Healthwatch's Adults with Autism Report
- Engagement work via the Autism Partnership Board

Key findings:

- Accessible information in all formats is key for those who need to access the service.
- There should be access to an information passport which the individual owns that they can use to highlight their wants and needs.
- Autistic individuals need support pre, during and post diagnosis which needs to be open-ended.
- Support received should be from one consistent staff member and should be structured around the individual's needs.
- Provision for carers and the autistic individual's wider circle of support for information, advice and guidance is key.
- A Service that can support professionals with reasonable adjustments is important.

3. Public Engagement (28th April 2023 – 11th June 2023)

The survey was developed using the Council's Engagement HQ Platform (<https://haveyoursaygloucestershire.uk.engagementhq.com/>). The survey used both open and closed questions to gather thoughts towards the proposals for the new service. This was available online and in hard copy (in English) upon request. No questions in the survey were mandatory (either online or offline copies), therefore not all questions were responded to.

The survey was publicised using a variety of methods:

- Publication across all GCC social media pages and website and internally through TalkSmart.
- Promotion to key stakeholders including but not limited to; key commissioning colleagues across GCC and the ICB (including public health), social work teams, Gloucestershire Carers Hub, and Integrated Locality Partnerships.
- Promotion to all commissioning teams within GCC.
- Autism Partnership Board.
- Lived experience Group.
- Learning Disability and Autism Clinical Programme Groups and their wider stakeholder group.
- GHC's expert by experience team.
- ICB staff newsletter.
- Healthwatch bulletin.
- VCS Alliance newsletter.
- GCC Health & Social Care Providers bulletin.
- Know Your Patch Networks.

- GP Bulletin.

3.1 Survey Responses

A total of 81 people submitted responses to the online survey. Please note that the highlights mentioned below are a mixture of summarised themes as well as actual examples received as part of the engagement survey.

Q1. “Which of the following best describes you?”

Someone who would use a service for autism support	16
A professional	35
A carer, friend, relative or colleague of someone with autism who may benefit from using a service which provides them with support and advice around autism	27

- Three ‘Other’ responses were received, who all expressed they were a combination of all three options.

Q2. “Which district do you live in?”

Cheltenham	19
Cotswold	6
Forest of Dean	10
Gloucester	19
Stroud	23
Tewkesbury	3

Q3. “Are you familiar with any of the following services available in Gloucestershire? If yes, which services are you familiar with?”

CASA (Community Autism, Support and Advice)	38
Gloucestershire’s NHS Autism Diagnostic Service	48
Gloucestershire’s Carers Hub	53
Gloucestershire’s Parent Carer Forum	29
CALMHS (Community Advice, Links and Mental Health Support)	31
Social Communication and Autism Assessment Service (SCAAS)	19
Gloucestershire’s Self Harm Helpline	25
National Autistic Society	55
Community Wellbeing Service	26

Other Services people were aware of include:

- Online Facebook support groups.
- Stroud's Neurodiverse Universe,
- Stroud District ADHD support group,
- Other NHS services e.g., Recovery Team, MHICT, CLDT
- Autistic girls' network, PDA society
- All sorts

Q.4 “Have you used any of these services before? If yes, which services have you used?”

CASA (Community Autism, Support and Advice)	24
Gloucestershire's NHS Autism Diagnostic Service	27
Gloucestershire's Carers Hub	24
Gloucestershire's Parent Carer Forum	16
CALMHS (Community Advice, Links and Mental Health Support)	11
Social Communication and Autism Assessment Service (SCAAS)	8
Gloucestershire's Self Harm Helpline	4
National Autistic Society	25
Community Wellbeing Service	11

Other Services people have used included:

- NHS psychological services
- the Owl Centre
- Peer-led drop in set up by a Social Prescriber
- Autistic girls' network,
- PDA society

Q5. Please select the option that best describes your view on the following statement: “It is important that autistic people can access support and activities which are available in their local community.”

Strongly agree	70
Agree	8
I don't mind either way	1
Disagree	0
Strongly disagree	2

Most respondents agreed with the outlined statement with 86% of respondents Strongly Agreeing and 10% of respondents Agreeing.

Key themes from those who Strongly Agreed include:

- Very hard to find opportunities for social interaction, particularly in the more remote areas such as Stroud and North Cotswolds.

- No awareness of the available services thus needs more promotion.
- Engaging in community-based activities provides opportunities for autistic people to interact with their peers, build relationships and develop social skills fostering a social connection.
- More outdoor and sporting activities needed.
- There are not enough support networks locally.
- Assessment and diagnosis of autism is far too long, and no support for people who are waiting for their assessment. Families are struggling to understand their child/sibling/partner, which causes a significant amount of unwanted stress and anxiety for all parties involve.
- Searching online can be very difficult for neurodiverse families.
- Support needed with getting a job where I can be authentic, so I don't burn out and get unwell.
- Out of normal office hours would be appreciated for those of us who work.
- It is important to have different levels of support dependent on need.
- Local needs to mean local especially if public transport links aren't optimal.
- It is not only important it should be their right equal to everyone else.
- As long as autistic people aren't forced into inappropriate settings to ensure provision is local.

One person who did not mind either way said:

- "I don't view my local community as my community. I like online and don't always like to be involved in things that are so local to me".

Q6. Please select the option that best describes your view on the following statement: *"It is important autistic people have the option to access 1-1 support from a consistent service member."*

Strongly agree	57
Agree	19
I don't mind either way	2
Disagree	0
Strongly disagree	1

Most respondents were in agreement with the outlined statement with 70% Strongly Agreeing and 23% of respondents Agreeing.

Key themes from those who Strongly Agreed are:

- This is crucial for autistic people.
- There must be trust with the Service member.
- Change can really affect people, so consistency is the key.
- Autistic people and their carers might benefit from being directed to spaces that are outdoors without being in big busy hubs.
- This is important so people do not need to repeat themselves and they also build up a relationship.
- It is important that anyone who needs support of that level has access.
- It would be helpful if 1-1 support could be available whilst seeking diagnosis.
- There needs to be long-term 1 to 1 support if needed.
- Autism is individual, the impact it has on the individual is unique and therefore must be supported in a way that each person can engage with and benefit from
- It is important that those who are supporting autistic people have the necessary skills and training to do this.
- Structure, familiarity, and routine can be very important for an autistic person, often making the difference in being able to do something very simple.

- It gets challenging and a bit exhausting explaining my condition to lots of different people - both for myself and for everyone else.
- Particularly important when education ends.

Those who Agreed said:

- This depends. Consistency if good, and can be essential, but when what is delivered is poor quality or unreliable, then making that consistent is terrible.
- My son needs known person so struggles to access holiday clubs and social activities due to lack of continuity of staff.
- This will be more important for some people than for others.
- This may or may not be important for the person, consistent processes may be the key rather than the person.

One person was unsure about available services to access without family assistance.

Q7. Please select the option that best describes your view on the following statement: *“It is important the circle of support for autistic people have the option to access information, advice and guidance on topics around autism from a service.”*

Strongly agree	65
Agree	13
I don't mind either way	2
Disagree	0
Strongly disagree	1

Respondents were in agreement with the outlined statement with 80% of respondents Strongly Agreeing and 16% of respondents Agreeing.

Key themes from those who Strongly Agreed are:

- There seems to be high dependency on technology to deliver services presently. Sometimes this can be overwhelming for parents of autistic children and autistic adults.
- For many people, they do not know how to help the autistic person and are concerned they may get it wrong, so the support should be there for them too.
- This work needs to be done respectfully - nothing about us without us.
- There is a lot of information out there so a signposting service would be helpful,
- It depends on the level of need and disability.
- The more access to information, advice & guidance, the merrier!
- As a mother of an autistic individual, it's important for everyone to be on board with support to encourage and to be able to support communication if needed.
- Some families struggle to accept the full implications of an autism diagnosis (others find the diagnosis a relief as it explains some behaviour)
- Shared understanding can provide a unique level of understanding and empathy because of the first hand experiences of the challenges and strengths related to autism.
- When I got diagnosed with autism, my entire family had to evaluate both themselves and I since there were implications that expanded past just myself. I ended up needing support in explaining to my loved ones what was happening to ME. It would be incredibly helpful to have support in sharing awareness of my condition, and potentially even creating a 'user manual' for myself so that my family, friends, colleagues, etc have some insights how to get the best version of me. And giving me expertise as well in how to advocate for my own needs and normalise boundaries.

Those who Agreed said:

- This can be delivered by a range of services working together rather than a service as this might not reflect the reality of what is happening.

Those who did not mind either way said:

- It's important that age / education specific information is available, but it doesn't matter where it comes from so long as it is accessible.
- Many autistic adults don't have a circle of support. These are more important than an advice service. If the right people are in the circle of support, there should be the ability to find out what is needed.

Q8. Please select the option that best describes your view on the following statement: *“It is important that people who self-identify as autistic or are waiting an assessment have access to support.”*

Respondents were in agreement with the outlined statement with 64% of respondents Strongly Agreeing and 27% of respondents Agreeing. 6% of respondents didn't mind either way and 2% Strongly Disagreed.

Strongly agree	52
Agree	22
I don't mind either way	5
Disagree	0
Strongly disagree	2

Key themes from those who Strongly Agreed are:

- Self-labelled conditions should not have the same access to drugs or support services.
- Diagnosis waiting times are very long, access to assessment is variable, and autistic people's difficulties are often dismissed, poorly understood and they have difficulty explaining their challenges to others.
- The sooner people get support the quicker they will be able to adjust.
- Currently there is nothing, and this needs to change.
- It is vital that support is offered to prevent significant negative impacts of waiting for a formal diagnosis.
- The year that I was waiting for my assessment was extremely lonely and confusing.
- People with Asperger's may not like to be labelled as Autistic.
- Any time of uncertainty can be difficult, particularly for an autistic person. Having support during this time can allow a person to express their concerns, questions and feelings and receive understanding from empathetic support. Preparing someone for a possible diagnosis can help them to become advocates for themselves. They can begin the process of learning about available services, rights and how to navigate the support systems available to them.
- Autistic people are vulnerable and can be marginalised by their own family, particularly previous generations who are suspicious of mental health needs or see conditions like autism as personal failings that you should strive to overcome. Empowering individuals to take ownership over their autism is important since there are so many dangerous assumptions made about it, and plenty of people we trust who dismiss our concerns and symptoms. It leaves you with a lot of self-doubt and poor self-esteem.

Those who Agreed said:

- This is a difficult one, if someone self identifies, some would not meet the threshold for diagnosis in a professional setting. However, people should have access to support regardless of their motivation for accessing help.
- It is hard being diagnosed and getting support, and there is a negative narrative for undiagnosed self-identifying autistics.
- Care givers and supporters need to be signposted to the correct place and at the earliest involvement in their family’s care pathway.
- There needs to be some clearer understanding around 'self-identifying as autistic' as the motivation for this is not always clear given that autism isn't a choice. Perhaps there are other trauma-based issues needing support.

Those who did not mind either way said:

- There needs to be a sign posting service which can offer low level support if needed but focuses on those with the most need.

Those who Strongly Disagreed said:

- I would strongly disagree with the concept that autism is a condition you can "self-identify" with. It would lead to the question whether you can "self-identify" with any disability/medical condition you wish to?
- I would think either it is a service any person can access (thus no need to "self-identify") or it is a service for people with a specific diagnosis. One option may be to have an aspect of a service (e.g., online resources with information) that are accessible to anyone.
- Many people will have some features of autism within their personality and there are other conditions that have overlap with symptoms. Therefore, there will be many people who may self-identify with aspects of this. There could be a risk of diluting a service such that there is limited resource for people with greater needs due to it being open to all. (Assuming resources have some limitation).

Q9. Please select the option that best describes your view on the following statement: “It is important that a Community Autism Service supports local communities and services to enhance their offer to support autistic people through reasonable adjustments.”

Strongly agree	58
Agree	20
I don't mind either way	2
Disagree	0
Strongly disagree	1

Respondents were mostly in agreement with the outlined statement with 72% of respondents strongly agreeing and 25% of respondents agreeing.

Key themes from those who Strongly Agreed are:

- Specialist support and knowledge is crucial for people to access vital services.
- Ensure provisions are clearly communicated across the community and information is easy to find online.
- I want to have as much choice as possible in life and a Service would be in a good position to build capacity in the community, if the work was co-produced and led with autistic people.
- A support service would be vital to support the process of reasonable adjustments and help keep people in employment, contributing to society, thriving, and feeling well.
- The issue here is what is considered 'reasonable' which is rather subjective. However, reasonably should be appropriate to autistic individual's needs. Strategies that help one person are often not appropriate to another, there is no one size fits all.

- Depends how far reasonable adjustments go, some not accessible.
- Autistic people must have support so they are able to lead a full life in which reasonable adjustments can be made to help them in whatever aspect of life they currently need help with

Those who Agreed said:

- It would be highly beneficial for services, like Occupational Health to be aware of signposting and services they can recommend for employees and line managers. Furthermore, training and advice regarding types of reasonable adjustments would be well received.
- This will depend on the capacity of the service to do so. Advocacy on a case-by-case basis may be more valuable initially.
- Early involvement must be of benefit to the person who needs support. It usually takes too long for the person to be acknowledged as requiring support and are signposted incorrectly.

Those who did not mind either way said:

- Too many advisory/signpost services that aren't working with autistic/ND people.

Q10. Please select the option that best describes your view on the following statement: *“It is important that the service supports family, friends, or a person’s wider circle of support with information and guidance on autism, and how it may impact an autistic person’s life.”*

Strongly agree	52
Agree	23
I don't mind either way	4
Disagree	0
Strongly disagree	1

Respondents were mostly in agreement with the outlined statement with 64% of respondents Strongly Agreeing and 28% of respondents Agreeing. 5% of respondents neither agreed nor disagreed.

Key themes from those who Strongly Agreed are:

- We have had no support as parents not found anything appropriate other than peer support networks and a short course with PDA society.
- If you support the family of an autistic person, in turn you can support them.
- It will be important to consider the individual's mental capacity and choices around what information is shared with family/friends and who takes the lead on this.
- The information needs to have input from autistic people. So much of the information handed out is written about autistic people by NT people with little understanding of lived experience of autistic people.
- As noted, before, such information & guidance needs to be coming from the social model of disability, rather than the deficit-led medical model which vilifies being neurodivergent as a curse & burden on family & friends.
- Having extended family who either disbelieve or don't understand the diagnosis is very problematic for older, late diagnosed autistics. It would be incredibly helpful to have a professional to let the wider family know that their 'difficult ' or 'unusual' family member wasn't being wilfully obstinate or antisocial etc.
- There is a wealth of information on the Internet for this or set up peer led groups.
- Support for family etc shouldn't come at the cost of support of the autistic person.
- Knowledge is key and will give strength to the family and the wider circle of influence.
- It should be available for those who want it, and it should be easily accessible.

- Often relatives or carers have little understanding of autism, and this can be a real source of tension, psychoeducation is essential.
- Often autistic people find it difficult to articulate what they want to say so it is important that their wider circle of support is included in plans, especially if those plans include the support from their support community. Also, the support community need to be well informed about what is available for the autistic person so they can be effective in the support they are delivering. Some friends/family can be over helpful and need guidance on how they can empower their autistic family member/friend.
- Parents are ignored and made to feel worthless.
- It affects the whole family's lives not just the autistic person.
- Autism is a very complex condition and family, friends, and circles of support need help in understanding the condition and what they can do to make life easier for the autistic adult.

Those who did not mind either way said:

- Sometimes it is nice to keep this separate.

Q11. Please select the option that best describes your view on the following statement: “Peer support should be an integral part of the support offered as part of the service.”

Strongly agree	50
Agree	19
I don't mind either way	9
Disagree	2
Strongly disagree	1

Respondents were mostly in agreement with the outlined statement with 62% of respondents Strongly Agreeing and 23% of respondents Agreeing. 11% of respondents did not mind either way and 2% Disagreed.

Key comments include:

- It can be helpful, but some peers can be quite fixed that their solutions.
- Autistic people struggle to maintain supportive relationships and are overly reliant on family members.
- This is always of benefit to any cohort or service.
- Some people will feel more comfortable with peer support and should have access to this option.
- Nothing about us without us. More time must be given to employing Autistic people to do these roles as they know what being autistic is about.
- This should be embedded right from the start and for autistic people, they would find this very beneficial.
- Peer support is so important to prevent individuals from feeling isolated and having to navigate a complex, traumatising time on their own.
- Needs to be catered to each individual and at that individual's pace.
- I have found peer support invaluable as I navigate the system and find out more about autism (and ADHD)
- Professionals who can make appropriate peer support matches would be best, so an already vulnerable adult isn't inadvertently made more vulnerable.

Those who did not mind either way said:

- Need to be mindful that people are matched with others correctly, and that peers do not set off certain behaviours through stress etc.

- Suggest that this would be logistically difficult but yes if possible.
- This may or may not be useful to the individual.

Those who Disagree said:

- While it may be helpful at times, I'm not convinced this is always needed or appropriate.
- It does not have to be an integral part of the service. Peer support needs to be optional; some people would not want this and may not wish to have their information/diagnosis/difficulties shared with peers.

Q12. “Why might you contact an autism support service?”

Support with understanding autism and its impact on life and daily routine	34
Information and advice on support somebody with autism	43
Support to learn skills and mechanisms to manage life and daily routine.	35
Concern someone I/we care about	25
Seek support for the person I am working with.	26
Feeling lonely/isolated	25
Volunteering opportunities	12
Seeking guidance on what other support services may be available.	43
Support to access activities/groups in local community	34

Other reasons people provided were:

- Support to access suitable employment opportunities
- Support for practical things like benefits, breakdown admin tasks that I find difficult. I am wary of learning 'new skills to manage life' as I feel this offer can feel like teaching masking. I would also want advocacy and access to coaching.
- For validation. For feeling like you belong perhaps for the first time in your life. For finding your people and talking about how your autism impacts you. For not being the only weird one at last. Someone on hand that 'gets it'. To share information about what works and how to navigate systems.
- Support with getting support, such as PIP applications.
- Advice on dealing specifically with sensory sensitivities.
- Referrals to CLDT for autistic people without a learning disability or people with a learning disability who could access this autism service.
- Much more work is needed in providing services by fully trained staff. Without full autism training no staff can meet the needs of autistic people or make appropriate reasonable adjustments to help them.

Q13. What issues or experiences of cultural or health inequality relating to you or the community you represent that you would like us to consider?

Comments included:

- Isolation and healthcare go hand in hand and not always supported.
- Trauma informed care, Gender fluidity, alienation, the need for benefits agency to be understanding. The need for employers to show absolute flexibility to creating no-stress environments.
- Need suitable access to autism friendly mental health services that are therapy based and adapted to the needs of autistic adults. Person-centred, trauma informed, and autism formed

therapies are needed. We should not be overmedicating our autistic adults. Therapies based around interest, or an activity would be more appropriate.

- More suitable accessible signposted outdoor spaces
- The employment aspect is critical, better access for young people who transition between services so that they have existing relationships with key community services.
- My biggest problem after being diagnosed was accessing information and help.
- Improving diagnosis wait times.
- Information should be provided in all formats (different languages, easy read, verbal etc..).
- Training on autism should be more widely available to all communities and promoted well within them.
- Most services forget our rural communities and are based in Gloucester, this means those who find travel difficult are marginalised.
- My family is mixed heritage and I feel that my autistic sons have both been perceived as 'aggressive and disruptive and naughty' at their schools over the years. These behaviours are as a result of their autism, but they sent me on parenting courses and preferred to view my sons through the lens of 'aggressive young black males' than think outside of that box and wonder whether they may be neuro divergent. Being female also has also meant that my daughter and I have not had our Autism picked up, despite ticking so many boxes and being in the GP repeatedly for years with issues relating to our autism. We were overlooked consistently and when I finally found our answers, we have had those refuted. It's almost killed us. Quite literally.
- Lack of joined-up services. Esp. where multiple conditions/comorbidities exist.
- I feel there is still a real lack of understanding of what autism is, and how it can affect people. Autism is still widely seen through the lens of a deficit model, and these attitudes can have a detrimental effect on day to day living. I do not feel that I need support to live and function in the same way as other people. I feel that I need other people to understand that I do not function in the same way as them, nor do I wish to.
- Being a cis woman and being given the age-old "you don't seem autistic!" spiel... better understanding around how femme-presenting people (mostly those socialised as female) can present differently, breaking these outmoded stereotypes.
- Continued use of offensive language by people who should know better.
- I'd appreciate some weekend or evening peer support sessions.
- I waited almost 3 years for ASD diagnosis so was self-identified for that time. I didn't feel confident enough to ask for help without proof of diagnosis.
- Lack of formal diagnosis of mental health conditions in Autistic people, particularly 16-25 age group.
- More guidance / support for those wishing to integrate with neurotypical social groups / activities.
- Would like to see the term 'working diagnosis' with adjustments made accordingly and routinely.
- Support for siblings of autistic people. We are often forgotten about and act as a form of indirect carers when we don't want that stress or burden. Also, the issue of autistic adults living with their elderly parents - these are often forgotten about too and cannot access carers allowance if they have certain savings.
- Access to services for autistic girls without learning difficulties is really limited in the community now.
- The education system is not a good fit for autistic people. There needs to be solid education options for bright autistic people who are capable of good grades. Mainstream needs specialist units, just trying to help teenagers survive mainstream without proper support is not enough.
- There is just such limited opportunity for people to mix, learn new skills, make friends etc. supported.
- The voice of those autistic people and their families who have moderate and severe learning disabilities. Often the most able speak for the less able, despite lack of experience.

Q14. Any other thoughts or comments that you would like to share about a community-based autism service?

Comments included:

- Flexibility of contact, timeliness of acknowledgment and clear plan of engagement is essential for this service.
- The community based autism service needs to have multi-skilled people that cover the range of needs that autistic people have e.g., occupational therapist, social worker, Registered Nurse, physiotherapist.
- CASA is an invaluable resource. Something for under 18s (secondary school age) would be amazing, and for primary school age, perhaps some parent/carer support?
- This requires further investment and better access.
- Better liaison and partnerships would be good through shared forums.
- Provide services outside of working hours to ensure those who are still working can access them.
- Intersectionality is so important and recognising that not everyone wants to be together and make friends. Practical support is helpful. An autism service that can advocate and campaign to address system barriers rather than always focusing on support would be helpful.
- Make it realistic, set clear expectations, ensure it has a focus on those with the greatest needs.
- I don't understand why there isn't a more holistic approach to neurodiversity given the massive overlap of symptoms and of people with dual diagnosis.
- It's very important and very needed! I am very grateful & fortunate to have found CASA, and to be part of it. It is essential for my life. I had nothing but neurotypicals & neurotypical society to deal with, before. It's amazing to find somewhere I belong for a change, where I'm accepted & understood! It's allowing me to feel like my actual 'real' life is starting now!
- It needs input from autistic people. We need to be talked to, not talked about.
- Autism awareness training for GPs is key, especially concerning the differences of presentation in girls & masking adults.
- Respite services are essential.
- Meeting spaces must be accessible and tailored for the people using them (ability to adjust sound, lighting, temperature etc).
- It would help me in my work if I had access to very simple information for the individual waiting assessment, their family members about how autism can affect them. Information for autistic people going through menopause - what to expect and how it may affect their ability to mask and interact with others.
- Fostering inclusive communities can only be achieved via a community based service.
- It would be great to have this available from age 12.

4. Conclusions and recommendations

This report will be included as an appendix to the Cabinet paper seeking permission to recommission the Community Autism, Support and Advice Service in line with the proposals for the service.

If permission is granted, we will be seeking to implement the findings from this engagement alongside our previously conducted research, engagement, and service evaluation.