



A report to discuss the impact of COVID-19 restrictions for individuals living with Autism and/or a learning disability, with a specific focus on access to services and the impact on mental health during this time.



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Introduction

The Autism Information and Advice Service, as part of Citizens Advice Mid Mercia, have conducted a survey specifically for individuals and/or carers of those living with Autism, as well as individuals and/or carers of those with a learning disability.

Derby and Derbyshire CCG, along with Derbyshire County Council are seeking to assess the impact of covid-19 restrictions, particularly in relation to how services have been affected or accessed, as well as the impact on mental health of those using the services. The survey aims to highlight the issues and identify any changes that should stay or remain by assessing what has worked well or not worked so well during this time.

This report will highlight issues and suggest changes that need to be made during the recovery stage of covid-19.

Method: Stage 1

In order to create and disseminate an appropriate survey we first sought feedback from some of our clients with lived Autism Spectrum Conditions (ASC) experience, and those with lived ASC and Learning Disability (LD) experience, as well as their families / carers and advocates.

We engaged our existing clients through telephone calls and emails, as well as approaching our partners in order for them to share the survey with their clients through various platforms and channels. Our partners have active social media platforms and a digital presence, which we utilised.

Furthermore, we approached professionals who have engaged with us previously, and asked them to share the survey with their clients in order to reach as wide an audience as possible within the time constraints.

We created two versions of the survey: an easy read version utilising imagery and one which uses accessible, worded questions instead. This allowed those answering the survey to choose the most appropriate version for themselves, based on their preference and level of cognitive and communicative abilities.

We knew from experience that many of our clients are likely to experience anxiety when answering questions 'on the spot'; therefore, we chose to engage with these clients first via telephone or email (dependant on their preference) to ask them if they would like to take part and to give them the opportunity to choose a time and delivery method of their choosing. This allowed our clients time to prepare and offer a contribution.

We provided guidance to our partners to provide the same approach in the form of written guidelines to follow when conducting and disseminating the survey. This ensured all participants were approached in a manner suitable for their needs.

As an introduction to the survey, we provided an overview of why this survey will help the ASC and LD communities, as well as what we're going to ask and how we're going to ask it. We ensured that any partners that we utilised adhered to this approach and utilised the client's preferred communication method.

Our approach was quantitative and qualitative, so as to ensure that we achieved the most comprehensive understanding of the experiences and viewpoints of the ASC and LD community. We recognise that ASC, or ASC and LD, are uniquely lived by every individual, so made it a priority to acknowledge that no one person experiences their ASC and LD in the same manner.

We recognised that a different approach will be required for those with ASC, versus those with ASC and LD, therefore we tailored our approach dependant on the client and their needs. The survey was created with the following in mind: length of survey to be comprehensive enough to capture the views of those completing the survey, without being too onerous and the language and imagery used to be accessible to individuals at all stages on the spectrum.

The survey was delivered via the following communication channels: email, our website via a downloadable form, telephone, post and social media across ours and partner pages.

All responses were anonymised but categorised as follows: I have Autism Spectrum Condition (ASC), I care for someone living with Autism Spectrum Condition (ASC), I have a learning disability or I care for someone with a learning disability. Please note, participants were able to select more than one option.

By using participants findings, this survey will cover the following:

- How people have been coping – emotions experienced and overall summary of emotional and mental well-being during the pandemic
- What support has been provided and from where
- What has worked for them and what they would like to continue
- What has not worked and what would they want to change in the recovery stage and beyond (for example, what services or support would they wish to see).

Method: Stage 2

The purpose of Stage 2 of the consultation was to gather qualitative data from participants, based on the themes highlighted in the initial survey responses and findings in Stage 1.

Reflecting on the results of the initial survey findings, we were able to identify key themes from participant responses that needed to be addressed and discussed further.

The key themes were:

- Mental Health
- Communication
- Education and Transition
- An open discussion to discuss what had gone well and what had not gone well with the services they usually accessed or tried to access during this period.

To gather participants, we used our existing clients that had consented to participating in Stage 1 of the consultation, as well as approaching professionals and key partner organisations to gain their perspective of the impact of the coronavirus on themselves as an organisation, as well as the client group they were working with.

Participants were given three options of how they could participate in Stage 2 of the consultation: participating in a focus group, a one to one telephone call with a member of staff or a questionnaire to be completed and emailed back to the service.

The most favoured method by participants was a one to one telephone call, whereby a member of staff from the Autism Information and Advice Service talked through the questionnaire and recorded participant responses on the form. A select few participants agreed to participate in a focus group, however, owing to different circumstances they could not or did not attend on the day. Professionals used the questionnaire method to provide a joint service response from an organisational and/or personal perspective.

Demographic information

The survey was promoted widely across Derby City and Derbyshire using a variety of platforms such as emailing partners and external organisations, social media, phone calls and the Autism Information and Advice Service website. The survey was completed by 87 participants.

Age

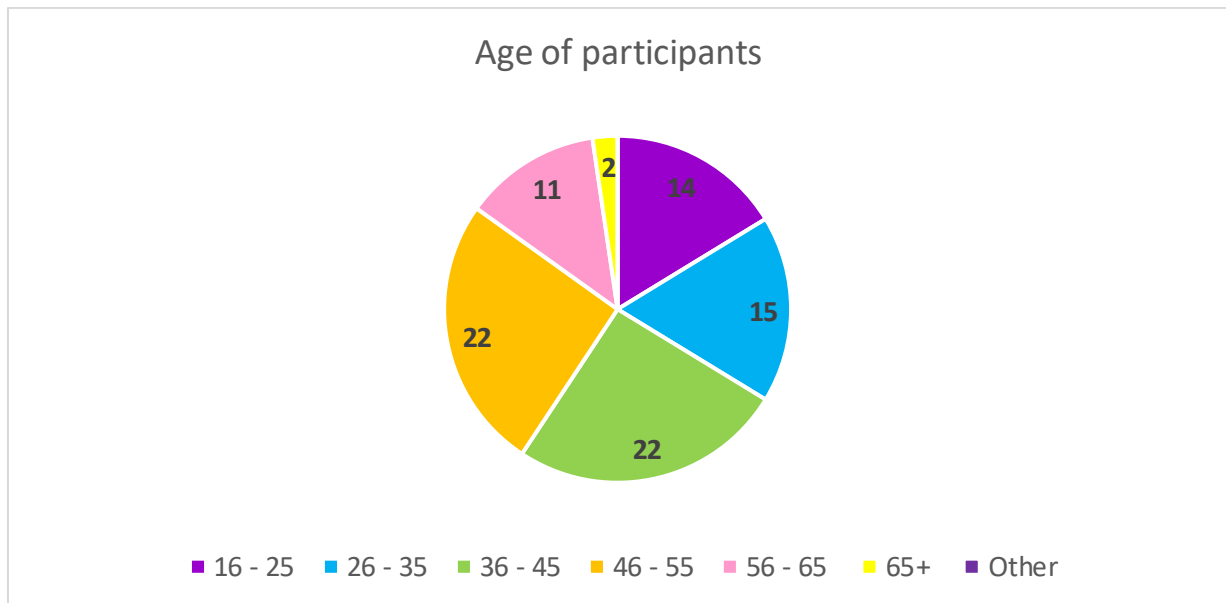


Table 1

The most common age of participants was evenly split between the two age categories 36-45 and 46-55, with the smallest number of participants being 65+. The survey generated an anomaly result as one participant answered “parent”.

Gender

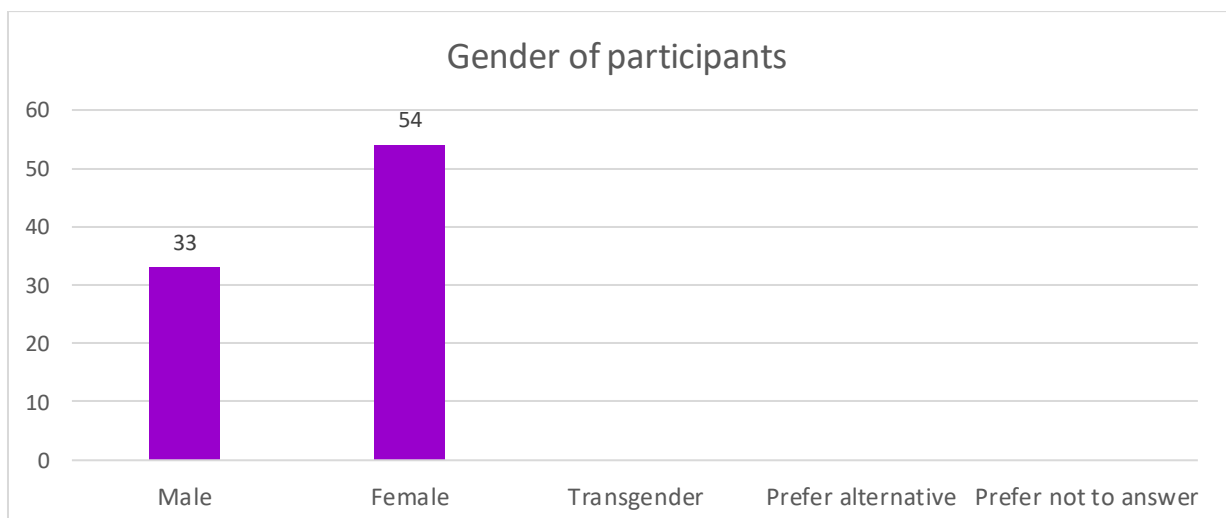


Table 2

Ethnicity

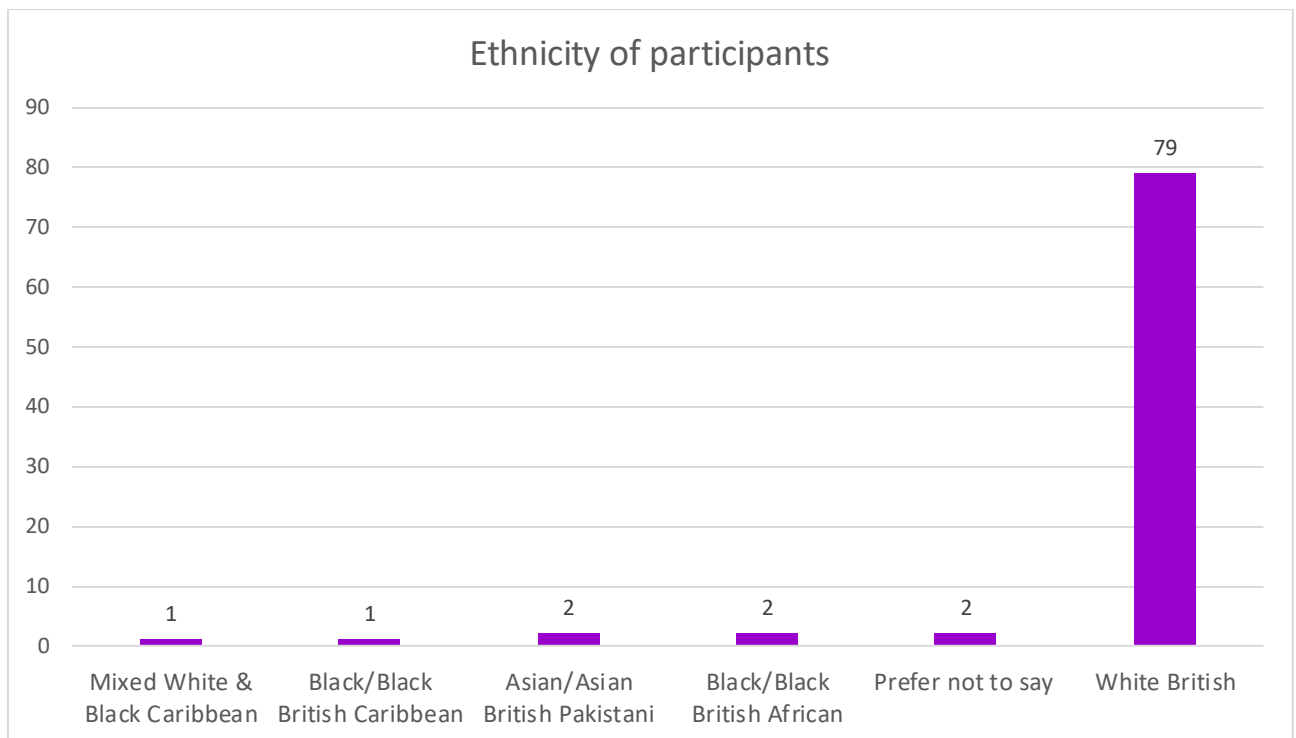


Table 3

90.8% of participants identified themselves as 'White British'. In order to try and accurately represent the Black, Asian and minority ethnic (BAME) groups across Derby City and Derbyshire, we contacted the following organisations:

- ° Shahra Care in Community;
- ° Pakistani Community Centre;
- ° West Indian Community Centre;
- ° Mandala Centre;
- ° Indian Community Centre;
- ° Peartree Medical Centre;
- ° Derby Family Medical Centre;
- ° Sri Arjan dev Sikh Gurdwara;
- ° Ramgarhia Gurdwara Derby;
- ° Siri Guru Singh Sabha Gurdwara;
- ° Hindu temple;
- ° Derby Bosnia - Herzegovina CC;
- ° Sinfin Carers Group

Participant Identity

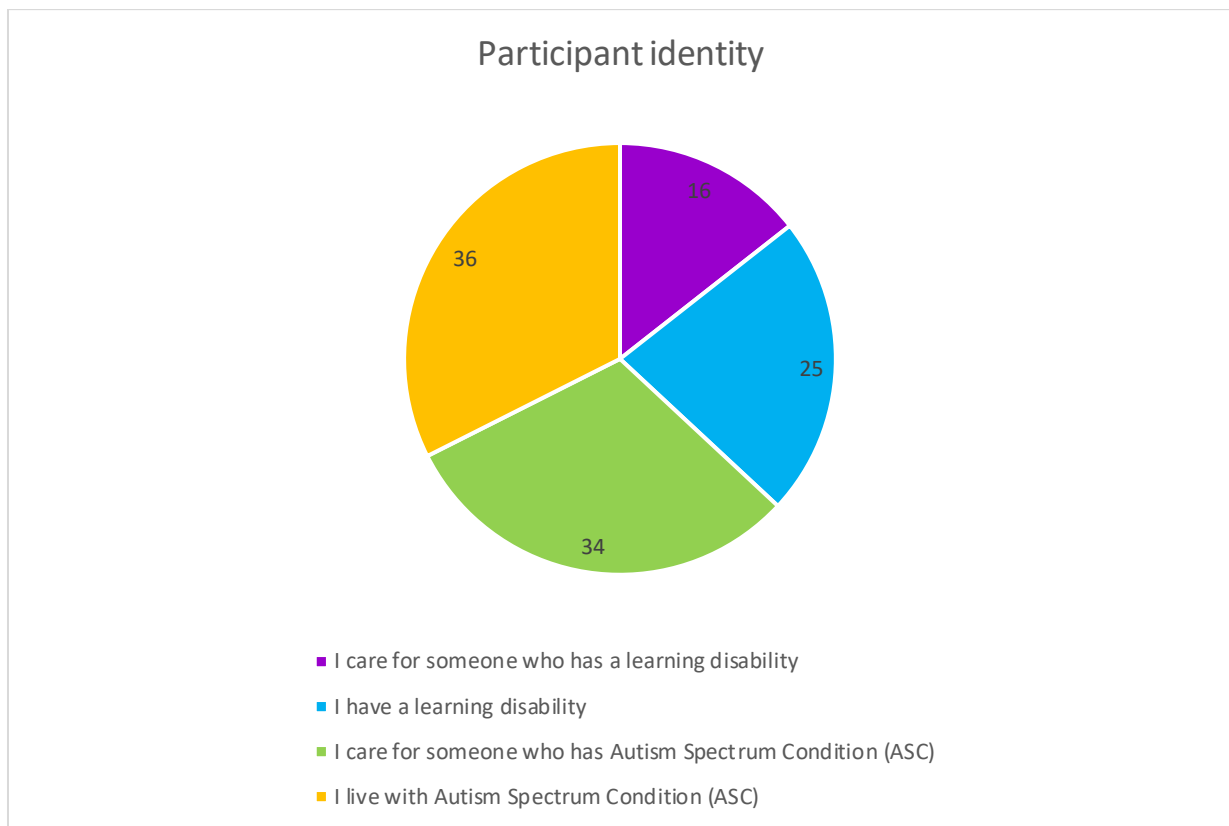


Table 4

The total number of participants that completed Stage 1 of the consultation was 87, however, some participants identified themselves in more than one category, for example, choosing 'I have a learning disability' and 'I live with Autism Spectrum Condition'.

How have people been coping – emotions experienced

A predominant theme running through the survey responses is that mental health has been affected by the coronavirus. The table below shows how participants rated their mental health prior and during Covid-19:

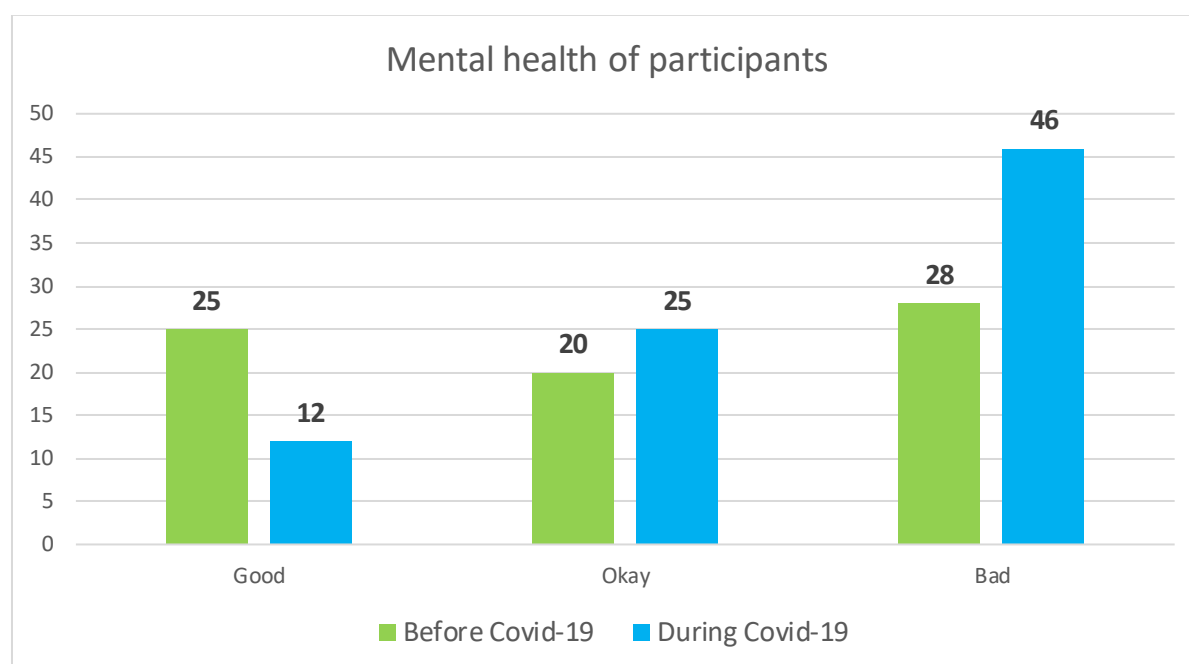


Table 5

There has been a significant decrease in the number of participants that rated their mental health as 'good' before covid-19 compared to during covid-19.

46 participants rated their mental health as 'bad' during covid-19 with only 12 participants rating their mental health as 'good'. However, there has been an increase of participants feeling 'okay' during lockdown.

In Stage 2 of the consultation, a participant identified as an individual living with autism and a parent/carer of someone with a learning disability commented *"I'd say that my anxiety and worrying about mental health was made worse during covid-19 but in lockdown I generally felt much better – especially autism wise"*, elaborating that *"going into and out of lockdown were the most stressful parts due to the change of what has been happening"*.

In Stage 2 of the consultation, participants were asked to explain what had affected their mental health during covid-19. A professional commented *"where services were not able to operate or needed to change in nature, this will have contributed directly to a decline in mental health"*. This was echoed by another participant who identified themselves as a professional, an individual living with autism and a parent/carer of someone living with autism: *"I think it is due to services not being able to operate but also the services are either not available or not offering the support people need"*. This was further supported by a professional/individual with a learning disability who said *"I would say there has been an increase in mental health due to lack of service provision"*.

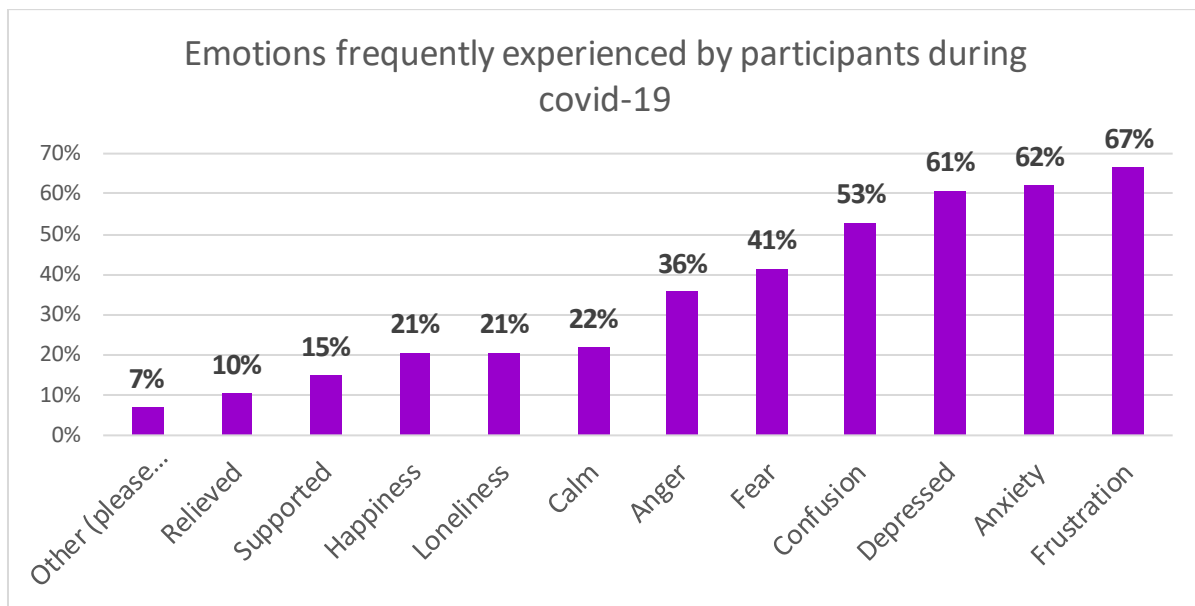


Table 6

This table highlights the most common emotions experienced by participants during covid-19.

In the 'other' section of the survey, a participant explained that they felt *"better because the world was calm and quiet"*, whilst another felt *"dissociative"*. Furthermore, a parent of an individual with a learning disability commented *"does not really understand about covid. I have tried to explain it to him and help him understand and keep him safe during this time with all the changes."*

Further to this, a participant identified as a carer of someone with living Autism and a carer of someone with a learning disability expressed *"I feel utterly exhausted. I am worried for my physical and mental health as I do not see my situation changing till almost October."*

A carer of a person with learning disabilities returning to work after being furloughed noted *"I found the return to caring 3 days per week became onerous by then as my whole life was rules; I have a relative whose mental health had declined so I had less support for my personal resources"*.

A further carer of children with special needs noted *"I am on my knees here and my life outside of my children is on pause. I am 100% focused on staying well enough to take care of my 3 children till they start back to school in the normal routine."* In stage 2 of the consultation, a participant identified as a professional, an individual living with autism and a parent of someone living with autism commented *"feelings of being trapped have caused stress and tension leading to more arguments and distress for all involved – many have felt they just cannot cope"*.

Further to this, one participant identified as living with autism commented *"it was pretty rubbish, distressing and frustrating, getting an un-shielding letter from the Government when they had not sent out a shielding letter in the first place, and my GP has no idea why I was sent this"*.

A professional highlighted that some mental health could have been caused by the *“anxiety of going back out into the world generally”* and *“issues around change of routine – into lockdown and now going back out into society again”*.

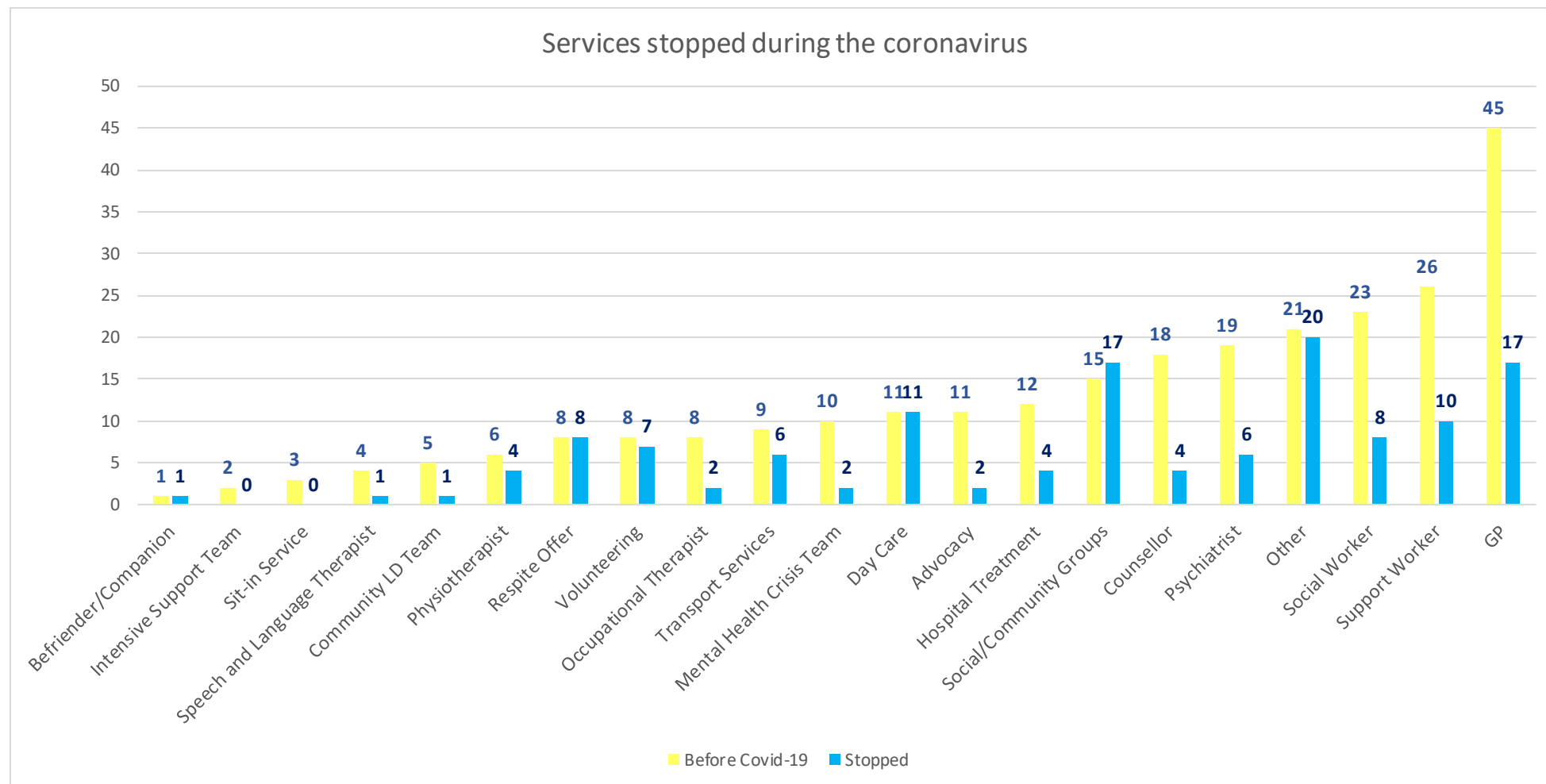
An individual living with autism suggested a decline in their mental health has *“made me more isolated during Covid-19, I did not like the change to my routine and everything else in the world changing around me”*.

A participant identified as an individual living with autism and a parent of someone living with autism commented *“we have become more isolated... we live in a town/village so everything to do with SEND isn't available in our area so that puts extra stress on me... when you are exhausted that is significant”*.

What support has been provided to participants before and during covid-19?

This table shows the services participants accessed prior to COVID-19 and the services participants reported had stopped during COVID-19:

Table 7



Prior to COVID-19

Table 7 depicts that the most accessed service by participants before COVID-19 was the GP, selected by 51.7% of participants. The other predominant services accessed by participants before covid-19 was a support worker, social worker, psychiatrist, counsellor and social/community groups.

In the 'other' section, participants identified:

- ° School (including special school),
- ° Child and Adolescent Mental Health Services (CAMHS),
- ° Private Clinical Psychologist,
- ° mental health carers art group
- ° the Acute Liaison Team

However, it must be noted that not all participants provided a narrative when they selected the 'other' option. In the comments section, three participants highlighted that they do not receive any support or have never received any support following their diagnosis of autism: *"I have not received any support for many years, I was diagnosed and literally told at age 18, sorry there is no funding to support you."*

During COVID-19

The table above displays a direct comparison between the services accessed by participants and the services identified by participants as having 'stopped' during covid-19. In Stage 2 of the consultation, a professional explained *"we are aware that a couple of organisations normally supporting autistic people as part of their offer closed their services completely over this time"*.

In the 'other' section, participants narrated that schools, special schools and alternative education provisions had stopped operating. Although 20 participants selected the 'other' option, not all provided an explanation regarding which service had stopped.

Further results to note are: out of 11 participants that accessed day care, all of them identified that the service had stopped; this is the same for respite offer. In total, 15 participants selected that they usually accessed social/community groups, however, 17 said that this service had stopped, suggesting a difference in perception.

According to participant selection, the services accessed the least by participants were:

- ° Befriender/Companion;
- ° Intensive Support Team;
- ° Sit-in Service;
- ° Speech and Language Therapist;
- ° Community Learning Disability Team
- ° Physiotherapist.

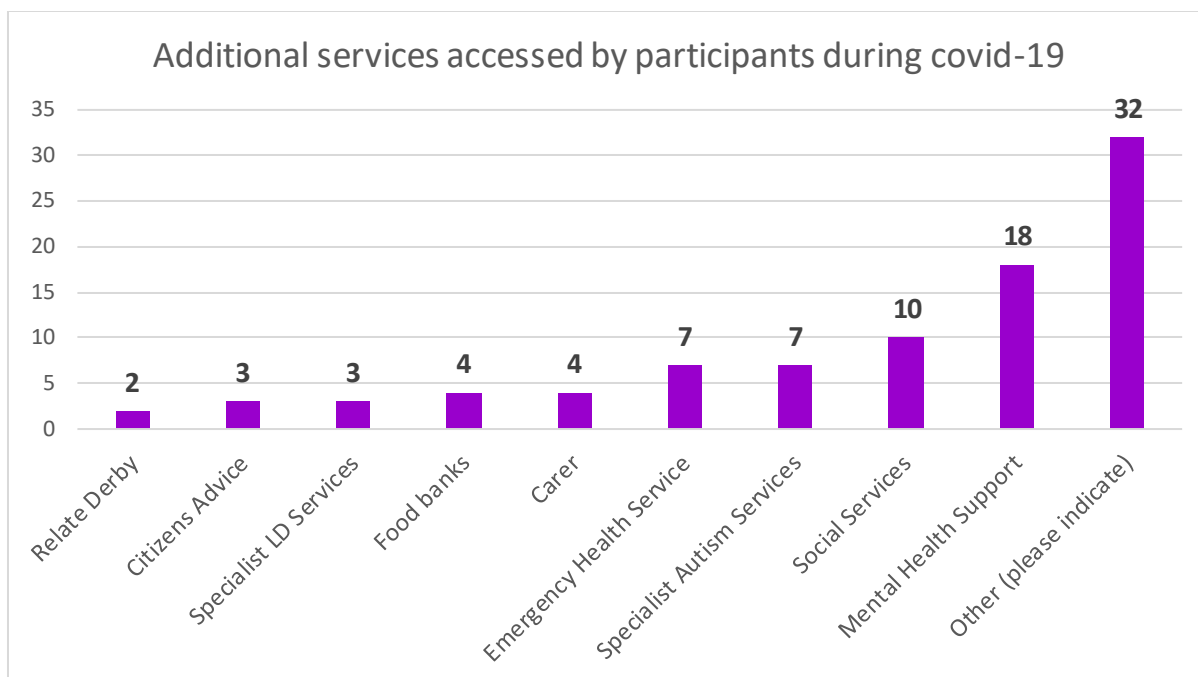


Table 8

Participants were asked to identify whether they had accessed any additional services during covid-19. Table 8 highlights the highest section as 'other' with the predominant answer being "none", "not been offered any support" or "there isn't really any support" as well as "family support".

Other services identified by participants were: Umbrella; Autism websites; Derbyshire Law Centre and Disability Law Service in London. It must be noted that not all participants elaborated on which 'other' services they had accessed.

The majority of participants that had accessed additional services, accessed mental health support, followed by social services and specialist Autism services.

In Stage 2 of the consultation, a participant who identified themselves as living with autism commented *"I was hoping to get some counselling and there is a bit of a prevention because of the covid-19 situation with accessing the services"*. This was echoed by individuals that identified themselves as living with Autism and having a learning disability as they explained *"I've been unable to access counselling services due to lockdown" ... "I was supposed to have appointments to see a psychiatrist but it got cancelled... messages weren't being picked up or passed on"*.

In addition to this, a professional in Stage 2 of the consultation highlighted *"when referring adults to the diagnostic unit on London Rd, Derby, there was no information that this service was closed/postponed... this service is currently over stretched anyway – this doesn't help people's mental health and anxieties"*.

What has worked well for participants and what would they like to continue with?

This table shows whether services changed their channel to phone, video or web-chat during covid-19.

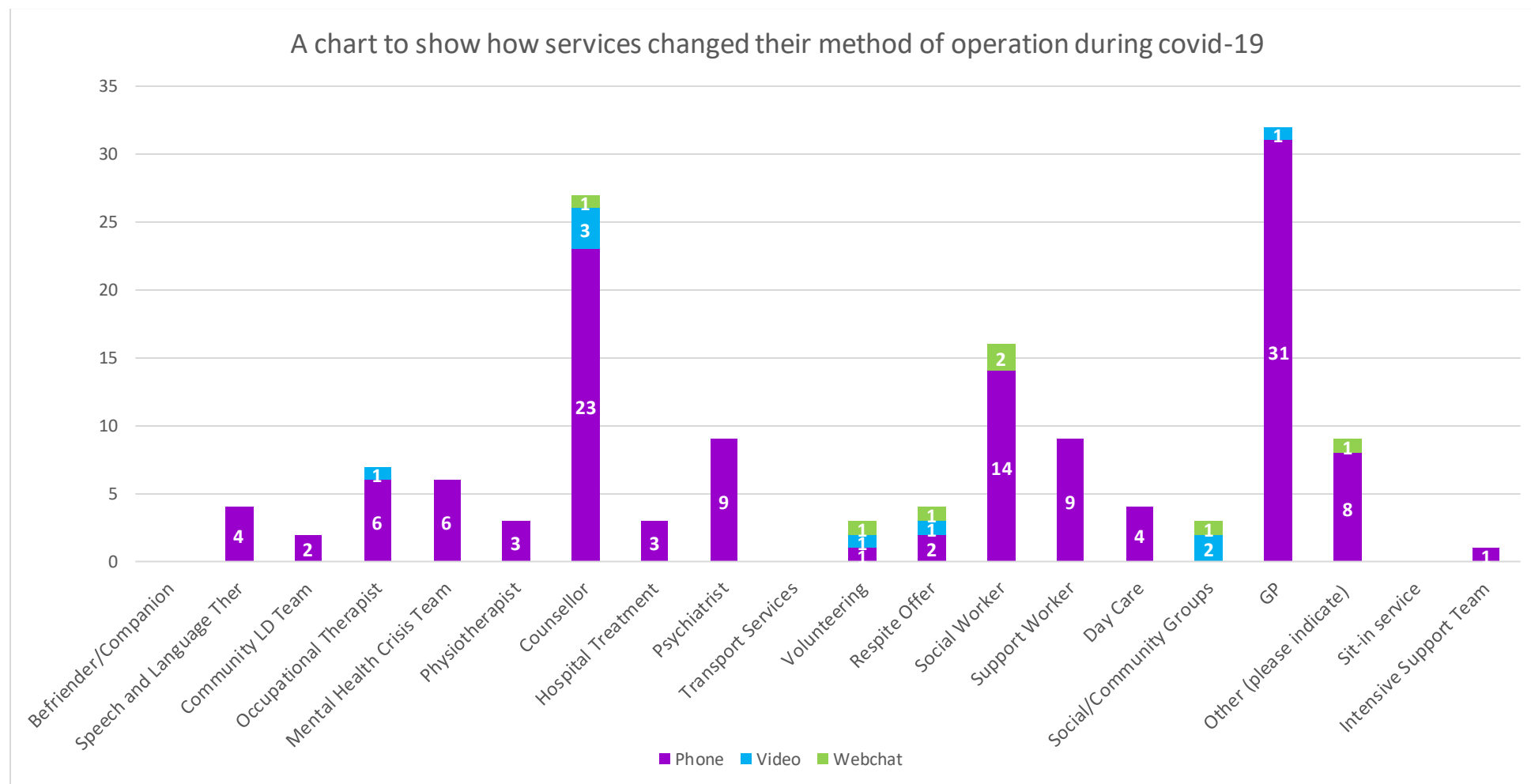


Table 9

This table depicts how participants rated the changes to service operation during covid-19 - this shows the percentage of people that responded about a service and whether they thought the change was good, okay or bad:



Table 10

Participants were asked whether the services they usually access had changed their operation method to phone, video call or web-chat or to indicate whether this service had stopped. The results have shown that some participants have not found the change in service operation to be good, whereas some have suggested they are happy with the change.

During stage 2 of the consultation, a participant identified as a professional, an individual living with Autism and a parent of an individual living with autism commented *“the change to telephone worked well for myself and most of the service users I worked with – some did not like telephone and preferred face to face communication”*. A different professional commented *“I find giving my clients a choice of the range of communication methods helps them to feel in control and helps to ease anxiety”*.

When asked about the effect on mental health, an individual living with autism commented *“I would say that it’s due to a change in how services are operating because I was still able to access some services but it was all via the phone. It was different not being able to put a face to the people that were supporting me”*. This was reiterated by another individual living with autism who noted *“a lot of autistic people will be drawn to routine and stability... a lot of services will have been put on hold or would have been adapted for the current times, but the problem is that these new methods can be uncomfortable towards autistic members”*.

A participant identified as living with autism and having a learning disability commented *“the change didn’t work for me... when I was having a meltdown they calmed me down over the phone but I don’t communicate well over the phone or email... it has caused me a lot of stress and anxiety.”*

Prevalent findings

Service	Good	Okay	Bad
Social/Community Groups	0%	13%	87%
Day Care	0%	11%	89%
Social Worker	0%	40%	60%
Volunteering	0%	9%	91%
Transport	0%	33%	67%
Psychiatrist	0%	41%	59%
Hospital Treatment	0%	33%	67%
Mental Health Crisis Team	0%	33%	67%
Community LD Team	0%	67%	33%
Speech and Language GP	0%	75%	25%
GP	17%	31%	53%
Support Worker	13%	44%	44%
Respite	15%	15%	69%
Occupational Therapist	25%	38%	38%
Counsellor	5%	52%	43%
Physiotherapist	17%	17%	67%

Table 11

This table shows the most prevalent findings from Table 10 on how participants rated the change to their service. The category with the highest percentage has been highlighted for each service accordingly.

The highest category overall was 'Volunteering', with 87% of participants rating it as 'bad', followed by Day Care and Social/Community groups.

It is worth noting that although the overriding response is 'bad', some participants found the changes to GP, Support Worker, Respite, Occupational Therapist, Counsellor and Physiotherapist as 'good'.

During Stage 2 of the consultation, an individual living with autism commented *"the change still worked to some degree... it's still hard when you can't put a face to the person you're talking to, they are just a person on the end of the phone"*.

A participant living with autism commented *"I found there was a delay in services getting in contact with me... other than that the services I used communicated with me when I required and also said I could contact them if I needed to speak to them"*.

Additional support

Participants were asked an open question to identify whether they had received any additional support from services during covid-19 that they would like to continue with.

Out of 87 participants, 63 provided a response to this question. Out of the 63 responses, 58.7% said that no additional support had been offered or received by participants.

Participants identified additional support from the following services:

- Autism service help lines and websites
- Church
- Social services for family support
- Child and Adolescent Mental Health Services
- Self-developed online support and community groups
- Carers in Derbyshire
- Counselling from Harmless (suicide and self-harm prevention charity) in Nottingham
- Talking Mental Health
- Counselling
- Specialist school offering online contact
- Derbyshire Information Advice and Support Service (DIASS)
- NHS-No Reply GP surgery text messages
- Citizens Advice
- Food parcels
- Autism Facebook group
- Mental Health Support
- Relate Derby
- Mental Health Team
- Carers Newsletter
- Psychiatrists

Participants made some comment on what has worked well for them during covid-19. In reference to the services listed above, participants highlighted that they would like to continue with the following support as they feel it has benefited them:

- Social Services;
- Carers in Derbyshire;
- Counselling from Harmless conducted via telephone and/or video;
- Talking Mental Health with an extension on counselling and
- Advice from Derbyshire Information Advice and Support Service (DIASS).

1 participant commented “not being at school all the time has been helpful”.

What has not worked – what would they want to change in the recovery stage and beyond?

The table below shows the services that participants rated as 'bad' in accordance with the change in operation:

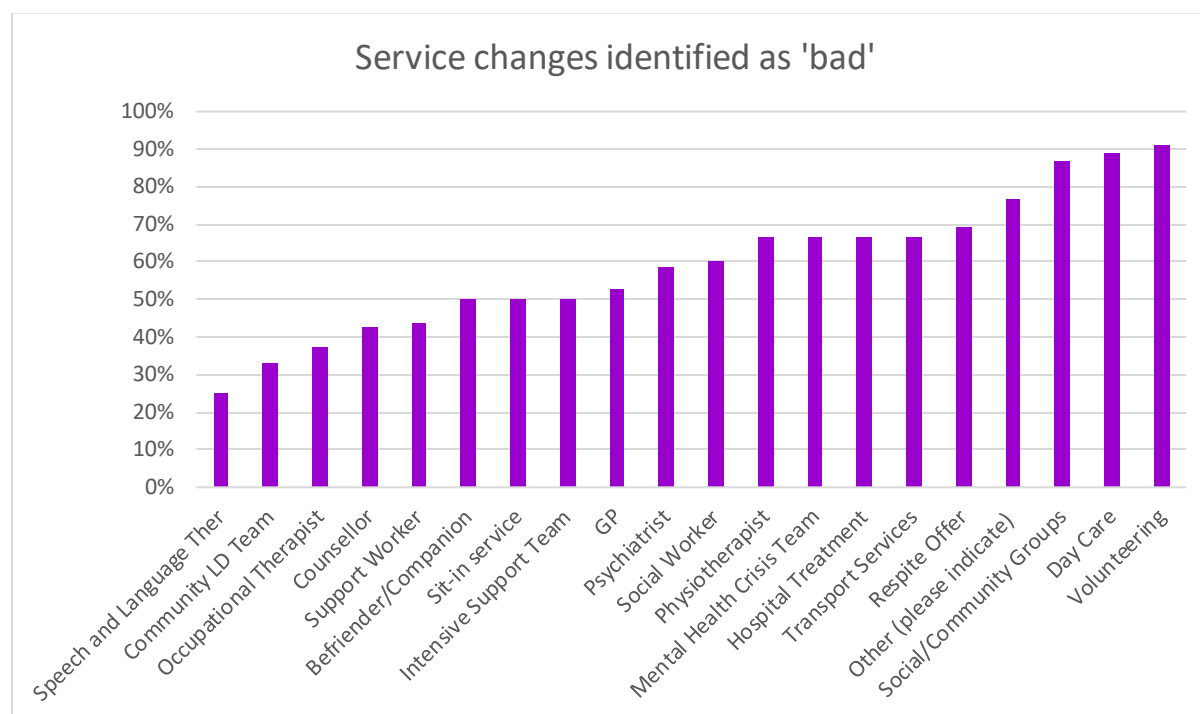


Table 12

The highest service change rated as bad by participants was volunteering followed by day care, which predominantly stopped during Covid-19.

During Stage 2 of the consultation, a participant identified as a parent of an individual living with autism as well as a professional commented *“schools are reopening in September and some have already done so... I fail to understand why extensive and intense planning in local authority day centres so that they too are now ready to reopen... In Derbyshire, there is still not clarity as to if or when the Day Centres are going to reopen in any meaningful way.”*

In the 'other' section, participants mostly selected that their support had changed to phone and described services such as school, liaison psychiatry, massage therapy, Advocacy and CAMHS. Please note that not all participants elaborated where they selected 'other'.

Communication:

A participant commented *“tried to do a self-referral for counselling with a local NHS therapy service but they only do video or telephone calls. But with my hidden disabilities, I cannot cope with telephone and video calls”*.

Another participant echoed this: *“I find accessing support over the phone or via video very difficult. As a result, I declined an appointment with my psychiatrist”*.

Another participant explained “support over the phone is helpful but sometimes harder to get my point across as opposed to in person”.

In Stage 2 of the consultation, a professional service highlighted *“a third of service users took up remote support with one or two stopping after a few sessions... this type of support has proved positive for all of those who chose to take this up and has contributed to an improvement in their mental health”*.

A participant living with autism identified “the switch to telephone and video consultations across the board is difficult for me. I have difficulty processing speech via telephone and it is much harder to pick up social cues and non-verbal expression. Often, I don’t know who’s turn it is to speak. It is also very poor for clinician/patient relationships which I find hard to build”.

Similarly, another participant commented “I first found talking to the counsellor and my GP over the phone really difficult. I find it hard to not actually see the person I’m talking to, but I kept trying and things did eventually get easier”.

In stage 2 of the consultation, a parent of an individual living with autism commented *“No one has been able to get any help so that had a big effect on everything; everyone I have spoken to...their mental health has been affected”*.

Education and transition:

In Stage 1 of the consultation, carers of participants with both Autism and learning disabilities referred to being sent inappropriate content from schools such as: *“School! Generic unsuitable work and no genuine welfare check”* and *“school appeal with Derbyshire Council and pulled residential placement away, this has not worked well”*.

A carer of someone with a learning disability said *“respite services stopped from March to the end of June except for generic emailed worksheets and craft activities that weren’t suitable for our boys”*.

During stage 2 of the consultation, a professional noted *“work for SEN children being offered out is extremely limited... I feel that parents of SEN children felt the emotional and regular support for parents, even those where school were contacting families, the contact often wasn’t regular enough”*.

This was echoed by another professional service who found *“the level of support for autistic children has been very low... We were getting more distressed calls than normal from the parents of children, as they were not getting support from their schools”*.

A parent of an individual living with autism noted *“school haven’t phoned or anything to ask how we are getting on – nothing... I emailed the school to tell them what we have in terms of resources and we were told to make the best of what we can. We received a school report but not any school work which really annoyed me as we are local to the school”*.

When discussing the changes to come out of covid-19, a professional suggested *“the use of video calls are a positive for those families who struggle with attending meetings in school, but now can be in attendance, by using the virtual media”*.

In stage 2 of the consultation, two participants, one being an individual living with autism and the other being an individual living with autism as well as a parent, referenced the benefit of free school meals *“when covid hit I became aware from other parents about vouchers for school dinners. I found out I did qualify for that which has been a life changer money wise”* whilst the other highlighted *“financial support with things like free school meals”* as something to continue with.

A participant identified as a professional, an individual living with autism and a parent of someone living with autism noted *“support from schools did stop... for the children their routines stopping has not helped”* whilst suggesting changes need to be made with *“emotional and practical support as children did not feel able or know how to ask for help with work sent and parents did not know how to support”*.

GP services:

Some participants referred to GP services and how they were operating.

One participant said that they had *“not received any support, nor been asked if support was required. GP would not see me.”*

Another participant living with Autism commented *“better care/service from doctor receptionist. More understanding that change can be hard for people with Autism, you are made to fight to be seen”*.

Further to this, a carer of someone living with Autism explained they had *“contacted doctors and not been helpful with supporting referral to Neurodevelopmental services”*.

A further carer of someone with learning disabilities commented *“needed help with getting my son a blood test after his annual health check over the phone. The GP was in my opinion unknowledgeable and didn’t provide any help or real understanding. Despite it being 2020, most things are still a struggle. I find that things are only found through looking and searching on the internet. Something we shouldn’t have to do, as well as being unpaid carers. There is usually nowhere to turn to for enough information”*.

In Stage 2 of the consultation, a professional service gathered from their service users that *“GP remote appointments, whilst not widely available, have given the opportunity to attend without fear of catching covid-19”*.

A professional highlighted *“I have experienced a wide range of responses from not getting past the receptionist– and being wrongly directed to A&E where the GP should have managed the issues... On a positive note I have heard of doctors referring straight to consultants”*.

When discussing the changes that could be made during the recovery stage of covid-19, an individual living with autism suggested *“ideally there would be video calls since doctors and such can get a better knowledge of a person’s condition, not just what they tell the professional”* whilst highlighting *“if the caller is not as knowledgeable in the field, this can lead to misdiagnosis or inappropriate advice given”*.

An individual living with autism noted *“the GP service and also the mental health service changed their appointments to telephone... I find talking to various different people challenging.”*

A participant identified as a parent of an individual living with autism and an individual living with autism highlighted *“I’ve been in touch with the doctors because my son was having meltdowns but I have heard nothing from them and that has been about two months now”*.

Social Care Settings/Providers:

A number of participants made references to the changes in social care providers and settings.

A carer of someone with learning disabilities explained *“there are a couple of clients who would normally access our respite service. They have not been able to utilise this service and it has been identified that there are challenges within the care setting”*.

Another participant highlighted *“social services have not worked well with me, failed to answer calls and send documents out”*.

Another participant did not like *“the way the support worker stopped, hard to just remove a service that you need and budget for”*.

A carer of someone living with Autism explained *“we had a key worker phone but she didn’t really have anything to offer – the only support we have received for our 9-year-old ASD twins is their school”*.

In stage 2 of the consultation, a participant identified as a parent of an individual living with autism and a professional highlighted *“communication to people and their carers should be and can be improved on... they want action which follows through from such communication”*.

A participant highlighted that they *“would prefer the support from family services to have been face to face or via zoom etc. rather than just phone/text. Also, support stopped suddenly once referred to Early Help – no contact from Early Help and no check in from social worker”*.

In Stage 2 of the consultation, a participant identified as an individual living with autism and a parent/carers of someone living with autism explained *“when you are under the amount of pressure that different people are in different situations, it would be nice if people spoke to you at least once a week to check in and say ‘how are you... You feel like you don’t exist in the system... during a global pandemic vulnerable people should be kept a close eye on especially on the mental health side of things”*.

A participant identified as an individual living with autism and a learning disability commented *“I wasn’t made aware that I could have applied for a social care assessment... I have been trying to cope with stress and anxiety... I’ve had to go all through lockdown with anxiety and I could have done with the medication through that. I feel like the system has been failing me”*.

An individual living with autism who is also a parent of an individual living with autism commented *“when you have got a disability social worker, that social worker should make it their business to know whether you are okay and that has not been the case”*.

Participant comment/recommendations

In Stage 2 of the consultation, we provided participants with an opportunity to highlight what had gone well for them as well as any changes they would make during the recovery stage of covid-19.

A participant identified as a professional, an individual living with autism and a parent/carer of autism commented *“I think overall there is not enough support for ASC – it would help to have a regular meeting place/support group”*. This was supported by another participant in the same category who suggested *“a younger person’s support network... our daughter, like many her age, is very social-media savvy...”*

A participant identified as a professional and parent/carer of an individual living with autism feels that *“what must happen is that family carers are consulted about the best ways forward should another lockdown occur in the near future and that not only are they “consulted” but they co-plan strategies for supporting people with learning disabilities and their families”*. Furthermore, the same participant from a professional perspective suggested *“the greatest change that needs to occur immediately is that day services and projects are made accessible again to people with learning disabilities... this may be on a rota basis or in a slightly different form”*.

A professional service recommended that *“from an autism perspective it is vital that communication methodologies are coproduced with service users (and delivery agencies) to ensure that they are optimum and fit for purposes”*.

A participant identified as a professional, individual living with autism and a parent of someone living with autism suggested *“a helpline that was open more – I think what people on the ASC spectrum need is a telephone help/chat line that can be accessed whenever they feel they need it – perhaps some online support groups for those that like and use technology”*.

In Stage 2 of the consultation, a professional recommended *“the use of text and social media... also the use of internet and email”* as well as *“the NHS platform called Patients Know Best”*.

A participant identified as a professional and an individual with a learning disability suggested *“there should be a pack sent out to households so everyone knows what’s out there and where to go. So, say GP surgeries order packs for their clients and there is a funding pot for this... or a text service or something that caters for all... posters in supermarkets/hospitals as an example”*.

Summary of recommendations

1. The use of text/social media/web-chat/online support groups as a communication method, for those that would prefer this method.
2. Consistent and cohesive communication from services e.g. universal operation methods for GP surgeries.
3. Weekly check-ins from services such as: schools, support workers, social workers and mental health workers.
4. Keeping some support as virtual, when and where preferable for the client.
5. Resuming face to face meetings where possible with safety measures and protocols in place.
6. Involving parents/carers/services in the development of new strategies and planning of services.
7. Re-instating of day services and respite in a covid-19 safe environment, even if this has to be on a more limited basis such as a rota.
8. The development and implementation of a learning disability hub, similar to that of Autism Information and Advice, for both Derbyshire County and Derby City.
9. Broadening the support and services available to individuals living with autism to Derby City, as well as Derbyshire County.

Conclusion

Overall, there was a healthy response and engagement in the survey in both Stage 1 and Stage 2 of the consultation where participants have discussed what life has been like for them during 'lockdown'. The survey responses were varied and did include some positive feedback from parents, carers, individuals living with autism and individuals with a learning disability.

From the survey responses, the most prominent themes that the CCG and Derbyshire County Council may wish to progress are:

- Supporting the mental health of all, with a strong emphasis on the vulnerable community such as individuals living with autism, individuals with a learning disability and parents and/or carers.
- Involving clients in critical decisions and processes in regards to changes to health and social care settings/services.
- Broadening the options for help and support available to those with a learning disability/living with autism, for both Derbyshire County and Derby City residents.
- Information packs for each local authority district regarding specific LD and autism services.

The last two bullet points can be addressed by using and involving a 'hub', such as the Autism Information and Advice Service. During the lockdown period, it has been evident from participant responses that there has been a lack of information from health and social care services and settings across Derby City and Derbyshire County; this needs to be urgently addressed should a second lockdown occur.

It would be useful to have an information pack for each of the eight local authorities (as well as Derby City), detailing the services and support groups that are available in each area, specifically for individuals living with autism and/or a learning disability, including carers and families. With additional funding, this is something that the Autism Information and Advice Service would be confident in producing, to ensure those living with autism and/or a learning disability remain supported during this crucial time.

Accessibility is a large component of individuals not being able to access relevant information, therefore, the information packs would be available as downloadable resources from the service's website - which is accessed by individuals and professionals across the county - and circulated to our large number of partners and each local authority. The information packs could also be utilised by GPs/social prescribers in each local authority, as well as being made available as a paper version to post out to clients and patients. It is essential that all services take responsibility for providing an update of any changes that have or are going to occur; this could be done by using a centralised service, such as the Autism Information and Advice Service, to provide regular updates with relevant information, which is then shared timely and appropriately.

A joined-up approach to collaborate autism and learning disability services across both Derbyshire County and Derby City would greatly benefit both communities, whilst filling the gap in services where there is an overlap in issues concerning both learning disabilities and autism. Feedback from clients overall has suggested that the provisions for both communities does not stretch far enough, and it is often a struggle to access information and to navigate between different services.

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