

## Autistic experience of COVID-19 legislation and guidelines Survey May-June 2020



### Introduction

The aim of this survey was to create a 'snapshot' of autistic experiences in Scotland of the COVID-19 emergency legislation and guidelines, and of how autistic people have experienced the ways in which these have been communicated, implemented and policed during the lockdown situation.

The core questions in this survey were around communication and messaging regarding the law and guidelines, and direct experiences of being approached by police. Other additional questions have been asked to create some context for these experiences, for autistic people and families living in Scotland in 2020. Question 18, for example, asks for respondents to say whether or not they feel the human rights and needs of autistic people are recognised and understood within Scottish society generally ie pre-COVID19 as well as during the lockdown?

It is of course, important to recognise the limitations of this kind of survey, where respondents will be those most motivated to take part and who want to have their voices heard. On the other hand, these are lived experience reports and while one person's experience might not be exactly another's, it is understood in the context of qualitative research that if one person has an experience, it will almost certainly reflect the similar experiences of many. Qualitative research doesn't ask questions of 'how many?', it asks questions of 'who?', 'what?', 'how' and 'why?', helps us to identify needs, concerns, barriers, gaps in provision, and supports the creation of answers and solutions.

Common themes here include lack of clarity of messaging around the legislation and guidelines, with high anxiety around all the uncertainties; very high anxiety around the prospect of being approached by police and how the individual's (or their child's) autism may not be understood, accommodated or may even possibly cause serious issues. Other peoples' behaviour is another high concern and lack of clarity about how to respond when non-compliance is observed (or perceived). Anxieties and frustration around a general lack of understanding of autism and the needs of autistic people, within the police force, but also within society as a whole, have been expressed. These themes are all reflective of the ongoing feedback received from the wider autism community through eg the SWAN networks, our weekly Mental Health and Wellbeing webinars, the Scottish Government Improving Understanding of Autism Campaign Advisory Groups and the wider social media networks.

Most worryingly, perhaps, are the reports of too many in the autistic community being unable to access their right to exercise outdoors for mental health and physical wellbeing, through confusion around what is permissible and what isn't, through intimidation and judgement of others, and fears and anxieties around others' non-compliant behaviours. There are extremely highly elevated levels of anxiety for autistic people, who are prone to being anxious and of experiencing high levels of stress and exhaustion at the best of times, which this clearly isn't.

The section of the public, which will undoubtedly include some autistic people, that has been calling for more strict policing, may well be, as discussed at the IAG meetings, only considering the policing of others' behaviour and not their own, with lack of tolerance at play. A small number of reports from this survey complain of what was termed by one as 'heavy-handedness' by police while many more express dismay and anxiety at what is seen as lack of compliance and a call for more robust policing, so it does seem as if perhaps, as the saying goes, it's not possible to please all of the people... It may be, however, that many of those latter are making a plea for reassurance as much as anything else. In local areas, we have witnessed many incidences of non-compliance, some from people from out-with the area, some from within. A greater police visibility in local towns



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and villages might have been helpful - and still might be - to reduce high levels of non-compliance and to give assurance to the highly anxious, both autistic and non-autistic.

Only a few instances of police engagement were reported through this survey (6) but it does appear that there have been some occasions when police responses could have been more thoughtful and appropriate. However, as one respondent pointed out, any lack of awareness of autism, and its impact on individuals and families, in some of our police force, should be seen - not excused but contextualised - within a wider society where autistic people are often misunderstood, marginalised and discriminated against.

On the plus side, an example of good practice was given where police engaged positively with a young autistic man and his friend, and that's always helpful to hear too.

COVID19 has, as has been widely observed, served to highlight some of the inequalities and inequities embedded in our society. Many of these are stark: poverty is probably the greatest inequity we have, including poverty of housing, employment, ie unemployment and where people are working, employment conditions, opportunities, choices. Disabled people, including autistic people, are often those who are poor, unemployed, lacking in opportunities and with limited choices. Even those who are well resourced experience discrimination and judgement in our daily lives. Emerging are some of the more subtle ways in which some portions of our population - including autistic people - may be discriminated against or marginalised within this kind of crisis. Some common assumptions, for example, about capacity and ability which all autistic people, from those who have high support needs to those of us who 'don't look disabled', often experience on a daily basis, have been reported as exacerbating our challenges in this 'new normal'. Combined with the fears about what post-COVID might look like for our community, and each of us as individuals, that are common to autistic and non-autistic people alike at this time, is our heightened personal awareness of the ways in which our autism impacts and often disables or marginalises us.

Expressed by the respondents to this survey has been anxiety, fear, thoughtfulness, insight, humour too. This is not a homogenous population but one of complexity, variable circumstances, different personalities. Not all autistic people consider themselves as disabled, for example, but more to the point perhaps, many are reluctant, frightened even, to disclose their status in any setting, for a quite well-founded fear of prejudice, discrimination or targeting. There is pride too, and a reluctance to ask for special consideration.

One respondent wrote 'Don't make people hate us by going on about our special rights'. That must surely represent a sad indictment on our society, that internalisation of a common narrative of autism, one of deficit and burden, and for an autistic woman to believe that asserting her human rights would be to seek special privileges and would cause people to hate her.

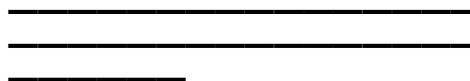
Disabled people, including autistic people, often have less autonomy and greater degrees of dependency than others (along with other groups, such as single parents for example, or those in domestic abuse situations): dependency on carers, on family, dependency on expensive technology, yes, but also dependency on other people's awareness, discrimination, compassion, kindness. These are not always readily available, but when they are, they make all the difference in the world to those receiving them.

The survey is structured as 'sets' of main questions with supplementaries to elicit some of the more qualitative, experiential aspect of autistic peoples' perspectives from lockdown. Some of the responses have been laid out here as quantitative percentages and pie charts with key themes summarised and described through verbatim reporting. Numbers of respondents to each question is given.



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### The survey summary

- Yes
- No
- Somewhat/in parts

**Q1 Do you feel you understand the COVID-19 emergency legislation and the accompanying guidelines? eg do you understand the**

**difference between them?**

respondent nos 71

38%	(27)	<b>Yes</b>
15.5	(11)	<b>No</b>
46.5	(33)	<b>Somewhat/in parts</b>

**Q2 Please describe in no more than 150 words what you feel would have helped you to have a better understanding of the COVID-19 emergency legislation and the guidelines? 57**

There were a number of issues raised here, but not surprisingly many of them revolved around clarity of message. Some respondents felt they did understand the difference, some didn't and the majority felt they could have done with better, clearer guidance of what the differences were/are. What's especially concerning here are the reports of autistic people not taking opportunities to go outside, to exercise and for mental health and wellbeing because they were too overwhelmed by what appeared to be confusing messages.

"They keep changing too often. I find it confusing to know if they are for England or Scotland where I live. As I don't know what's for me I just stay at home and in my back garden".

"Initially stay at home was clear. But then it became a bit more confusing. Even now my son is frightened to go out incase the police ask him where he is going"

"Regarding walks. I had conflicting advice from professionals about whether I can drive 10 miles to one of my 'safe' walks. I haven't been for a walk yet. They dont know what to say and dont want to get in trouble".

This question asked respondents to make suggestions as to what would have helped. Different media for presentation of information was a common suggestion, including the use of visuals, pictures, diagrams, lists. The suggestion below regarding TV has been mentioned on other forums too. We've discussed on the IAG and elsewhere social inequalities that are being highlighted



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during this COVID-19 crisis including unequal access to the internet; the use of TV to disseminate messaging is an obvious route but appears to not have had the level of impact that might have been hoped for.

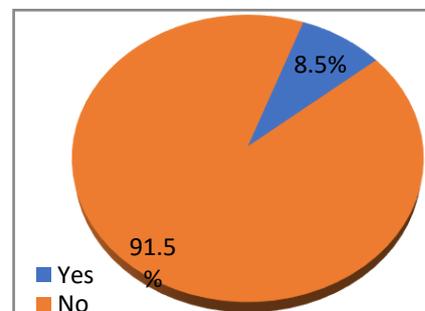
“I like no ambiguity, columns, colours, pictures and one website that I know gives this information. I have found the Scottish Government website difficult. Difficult to find information in one place, the writing has too much of the same text size and format. Basically, need graphs and colours”

“ Short. Words. With. Diagrams”.

“One of those lists with 2 colums - one legislation and the other advice”

“If my school had explained it more”.

“More government announcements and information boards on TV. A dedicated TV channel would be good.



Dismay over the lack of consistency with how respondents perceived their own understanding of the guidelines versus other peoples' has been a consistently common theme throughout.

“Clear guidelines that everyone was doing as some people are not following the rules”

**Q3 - 10 Have you, or any of your family, e.g. a teenage child, had any direct experience/s of the policing in Scotland of the emergency COVID-19 legislation? By direct experience we mean that you or your child has been approached/stopped by the police.** **71**

**8.5% (6) Yes**  
**91.5% (65) No**

Out of 71 respondents, 6 reported they - or a child - have had direct experience of police intervention.

It's worth reporting on all six of these verbatim.

“9 year old autistic cycling on rural road”

“Went to the park, it was not in walking distance, it was a short 2 minute drive but we needed grass and water, we needed space and to run. We were told that we needed to remove ourselves and go home and shouldn't be away from our direct home area, even if we were autistic. It resulted in me shaking and crying, and going home”.

“My son was stopped and questioned about why he was out as it was later in the evening. He was asked to hurry along and get home again as quick as possible. It was more to do with the time he was out and the fact he was with a friend who he shares a house with.”

“Solicitor dealing with Police “



“I am a woman with Asperger's Syndrome, and I have an autistic son. On 13/05/20 I received a call from the police regarding my parking at a site by Glentress Forest. Because the road leading to the car park had been closed off I had decided to park by a gate where the previous day I had seen a car parked. This gate gives access to a private site which I assumed was closed due to the Covid restrictions just as the road was. Seeing as there had been a car there the day before I thought it was ok to park there to go for a walk with my son. I took a short walk and a few minutes later I got a call from the police saying that I had been reported because of my parking.”

“I was sitting on a bench in the local park taking a break in the middle of a walk, and was told by a police officer that I was not allowed to sit down, and had to get up and leave.”

The latter exchange took place in Queen's Park, Glasgow, the solicitor described his interventions as taking place in a station and in public, the 9 year old boy was cycling on a Highland rural road (Caithness), Glentress is in the Borders and the park was in Paisley.

Respondents were evenly divided between whether they understood why they or their child was approached by the police, or didn't or only partially or were unsure **6**

33.3%	(2)	Yes
33.3%	(2)	No
16.7%	(1)	Somewhat
16.7%	(1)	Not sure

How respondents translated the incidents they reported was variable as were the events. Only 1 felt their child had been treated fairly and reasonably, the other 5 were either personally distressed or in the case of the solicitor, unhappy with the police behaviour.

### **People did feel they were being discriminated against.**

The parent of the 9 year old describes their reaction as:

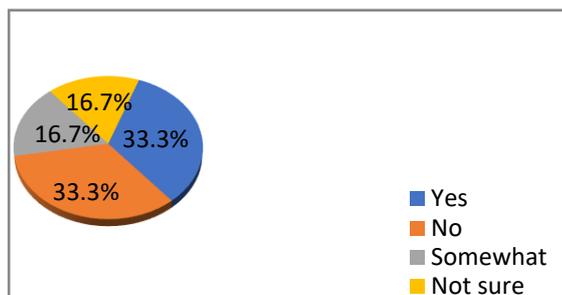
“I think he was stopped (he was alone, unaccompanied) in order to exert control and power. He was asked, 'is this the 1st time you've been out today?'. At least, that is what he told me when he returned home”

The parent of the older boy was more sanguine about the incident:

“I think they possibly thought it was two friends meeting up outside of their respective homes. It was 11pm at night so later for people being out and about, they were going to the local shop before it shut”. and “He was warned not to go out and about late at night again, he was happy with that and wasn't overly upset by the experience”.

Those stopped in parks were bemused and upset and felt they'd been discriminated against:





“We were together in the park playing? We kept our distance from others”. “We were the centre of attention, everyone was looking at us, I was a mess of emotions and it wasn't nice”.

“I have no idea if this was a law or not, if so very ableist as exercise is allowed but only if you don't need breaks?”

The incident in the Borders left the family upset and anxious:

“The officer reassured me from the start that as a local, I was entitled to go for a walk, but not to park there. The officer acknowledged the lack of parks in the area and I believed I explained it would have been impossible for me to reach the place without driving. I am an anxious insecure driver as it is and this did not help my driving at all. Also it made my son, who is very much aware of rules, even more wary of going out for exercise”.

The solicitor's comments:

“Inconsistent approach , no fault of police who are policing unclear guidelines”

“Habeus Corpus. All Human Beings are essential. Government has no right to force police to to enforce this dystopian legislation. Walking down the street with your child should not be a Crime known to the land of Scotland”.

From these incidents, only 1 of the respondents believed they had been treated fairly, 2 felt they definitely hadn't and the other 3 were not sure.

#### Q11 - 12 Did you feel you or your child were being discriminated against?

6

50.0%	(3)	Yes
16.7%	(1)	No
33.3%	(2)	Not sure

Comments:

“I'm autistic, I was supposed to be able to go places that calmed us, within social distancing”

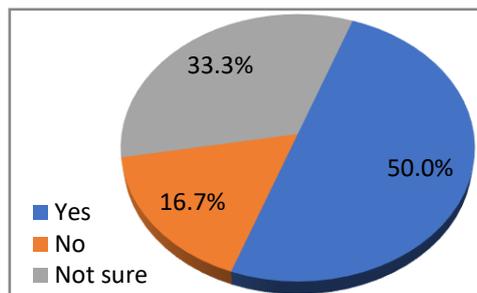
“On this occasion I do not feel it was actually the police who we felt discriminated by, but the actual individual who reported us. Because autism is not acknowledged or understood by the locals, and because my son moves between my place and my ex partner's, I know the neighbours have commented on it in relation to the Covid-19 situation. That said, excluding weekly shopping, neither my ex-partner nor I or my son, have been in contact with anyone other than each other throughout the lockdown. I am foreign born and that does not sit well with the local community, and having no connection with the local residents and being a single mum of an autistic child makes me feel very vulnerable and isolated. I fear that the neighbours will use any excuse to target me and my son as I know they have done previously with other people who did not “belong”



“All human beings are essential . The Scottish Government has no moral right to enact legislation that interferes with the Liberty of its citizens they are acting ultra vires”

**Q13 - 14 Did you feel your personal circumstances were considered and taken into account, for example that you might have a 'hidden' disability or health condition, or that your child might be autistic? 6**

16.7% (1) Yes  
66.7% (4) No  
16.7% (1) Not sure



“My boy was frightened. I'm surprised he managed to talk and managed to get home after. He hasn't really gone cycling since. There is no way the police could possibly have known he was disabled. He certainly would not have said, 'hey, I'm autistic'. It makes no sense to stop and question a young child cycling on a rural road where there are no people, few houses, little traffic”

“I mentioned to the officer that my son has a disability but I cannot remember whether I specified that he is autistic. In my experience mentioning that I have Aspergers tends to have a negative effect, and rather than understanding that leads to more discrimination”

On the positive side, 1 respondent explained:

“The police my son described were patient, understanding and gave him the chance to finish what he was doing none of it was confrontational”

**Q16 Please describe in no more than 150 words what would have helped to assure you the police were able to consider your personal circumstances or if you felt your circumstances were being considered, then please describe in what way did the police act that demonstrated this? 6**

“don't know”

“N/a impossible for police to enforce rules for fascist dystopian and authoritarian regulations in a style of policing which is in any way acceptable”

“They would have stopped being loud, and let us be”

“Acknowledgement of the disability would have been helpful. Once again, I do not feel that the officer was being unfair at all on this occasion. On the contrary, I believe that he was very friendly in his handling of the call. This said, I am not certain that he was aware and able to understand my points in relation to autism”

“They showed me that they were not willing to consider my personal circumstances, or the disabled experiences more widely”

“My son didn't feel the need to disclose his diagnosis as he felt he was being treated fairly. They hadn't really considered the time apart from the shop maybe shutting so when the police spoke to him and were calm in explaining he was able to take that on board”



**Q17 What are your main questions or concerns regarding the policing of the COVID-19 emergency legislation and implementation of the guidelines going forward over the next few months?**

Responses to this question fell mostly into 5 broad categories, which are outlined below, each with a number of sub-categories

**1 COVID - 19 legislation and guidelines: messaging to the public**

**This key category of respondent concerns fell broadly into the following areas:**

- **need for clarification around the law and the guidelines, especially translation of the latter**
- **need for clarification on being able to travel to exercise and for mental health**
- **need for clarification and awareness raising for the wider public regarding specific guidelines for autistic and other disabled people**
- **concerns around discrimination**

selected verbatim reports:

“I worry that current guidance expresses a strong preference for autistic people having a care plan to allow deviation from exercise guidance. Many of us have no healthcare support at all”

“Why have disabled people not on super vulnerable list not been able to get deliveries from supermarkets”

“How can my volunteers and lay helpers who take me out for 'fresh air walks' can obtain a card that says they are outside of their home/driving their car away from their home address take an autistic person for a walk? They are not related to me or employed by an autism organisation.”

"Apart from the media how am I supposed to know what I can and can't do?"

[my concern] “Being allowed out with a carer”

“i wasn't even sure how safe it was to go to hospital appointments and locations keep changing”

**2 Policing**

**Anxiety at the prospect of being approached by police and and questions around:**

- **how can they ensure they are easily identified as autistic without having to give a lot of explanation?**
- **what would the police say to them ?**
  
- **would they or their child be able to speak under that level of stress?**
- **are all police officers well trained in understanding autism?**
- **experience of what is described as ‘heavy handed’**
- **experience of feeling potentially discriminated against**

selected verbatim reports:

“I am anxious about being questioned by the police if on my own and also not being believed that I am autistic”

“Do the police have guidelines if someone tells them they are autistic?”



"I was anxious on behalf of my son that he would be stopped as he wouldn't have been able to respond. Eventually we got a sunflower lanyard for him to wear. To help alert people to his communication difficulties"

"I'm worried about not being able to get words out to explain myself if I'm stopped for some reason"

"I'm very worried I accidentally break the rules because that would be incredibly stressful."

"If they do need to approach me give me physical space, be patient & give me extra time to think (I'm 'processing', this takes time & energy!)"

"Usual concern that neither me or daughter "look" autistic, so police will not give us time to answer their questions, understand why we are flustered, or believe us"

"I'm visibly trans and was with my support worker who is also trans, was it transphobia? idk"

### 3 Lack of understanding of autism generally and lack of accommodations

- **lack of facilities, lack of accommodations eg car-parking or toilets to enable disabled people accessing the more remote areas they were thought they had been told they could**
- **lack of awareness of autism in the general population**

selected verbatim reports:

"Why has access for autistic people not been communicated better - I am constantly asked why I'm going out by others"

"I worry that marginalised groups are judged more harshly within society when deviating from guidelines or even when sticking to them"

"Why have disabled people not on super vulnerable list not been able to get deliveries from supermarkets"

"I am allowed to go places but can't get them as car parks are shut - why have no arrangements been put in place"

"How to contact them with urgent concerns if I can't use the phone."

### 4 Anxieties around other peoples' behaviours

- **observed non-compliance and the potential impact on the safety of the respondent or/and their families**
- **how to respond to perceived non-compliance in others**

selected verbatim reports:

"I'm scared to go out. People don't follow the rules, I'm trying my best but it's really hard"



“Being verbally attacked by members of the public. Eg one woman lectured me because she thought I was not leaving enough room (on an empty street) for other vehicles to park.”

“Enforce correct use of PPE when the public use them - especially gloves”

“Why are we being told not to meet up yet people are doing it all the time”

“If neighbours breaking it what do you do?”

### **5 Concerns around specific circumstances eg care support, travel etc**

These are primarily for individuals with care support needs

selected verbatim reports:

“I worry that current guidance expresses a strong preference for autistic people having a care plan to allow deviation from exercise guidance. Many of us have no healthcare support at all”

“How can my volunteers and lay helpers who take me out for 'fresh air walks' can obtain a card that says they are outside of their home/driving their car away from their home address take an autistic person for a walk? They are not related to me or employed by an autism organisation.”

“Being allowed out with a carer”

“My son doesn't understand “social distancing”, explain it to him”

As an aside, there were one or two responses to this question that were difficult to translate or categorise. Autistic people are thought to have limited senses of humour; experience of working with autistic people shows this is most certainly not the case, we laugh a great deal when in each other's company. However, sometimes it can be hard to gauge, and certainly in the context of a written survey response, to know what is intended. One respondent wrote “I keep touching my face as a stim. I should get extra hand gel”.

### **Supplementary question “do you have any ideas or suggestions for the police in terms of addressing your question or concern?”**

Respondents offered the following suggestions and requests. Most of these are pleas for higher levels of autism training and of baseline knowledge, and routes to accommodations for autistic people and their families.

“Be aware the impact of overload or meltdown lasts way beyond the period of obvious distress. Give clearer insight into when or why they stop someone who is obeying the rules”.

“Be slow, gentle and kind in your communication if you can. Please learn about sensory overload and recognise that autism can have an internal dimension that you dont see and that this is a scary new world we are trying to navigate and although we look strong, we need your help and support with feeling safe”.

“Could you have a local autism officer who could be an email contact of something. An outreach officer maybe. Some way of flagging vulnerability as done with domestic abuse”



“Car stickers or something that could quickly identify the person in the car has a hidden disability and may need to drive to a quieter location or may get very anxious or distressed if stopped by the police.

“Make it easier to report people who verbally attack you for no good reason so autistic people can feel safer about going out. Having a police liaison person for autistic people to email/text their concerns to who could pass information on to the police if appropriate or else advise them on what their right are and what they should do. I am often not sure how the police will respond to things, in the past they have made me feel stupid for things, even for example when I handed in £20 I found in the street which was the honest thing to do, they made me feel stupid for not keeping it. So now I feel like I shouldn't report minor things eg when someone scraped my car when it was parked legally in the street I didn't report it, I am still not sure whether I should have or not. Or when the woman in the street verbally attacked me for no reason I didn't report it, I don't know if the police would have done anything. I feel like I am just supposed to put up with things unless I am physically assaulted.”

“I want to highlight the fact that perhaps local police liaison should have a bigger role in making sure that autistic people such as myself and my son are not targeted unfairly by busy bodies who do not know or understand the nature of autism, and use it as an excuse to slander us, and possibly get us in trouble with a -potentially- less understanding officer”

“I would like the police to be more visible and apply the guidelines and laws, so that we can all be safer.”

“defund the police, they do more harm than good”

And finally, for this question, on an upbeat:

“No. They're doing ok from my perspective”

**Q18 Do you believe that the human rights and needs of autistic people are recognised and understood within Scottish society generally ie pre-COVID19?**

The answer to this question could possibly be summarised by the respondent who wrote “Lol no”.

Almost unanimously, respondents felt that even with some gathering improvement in awareness of autism, understanding and acceptance both have a long way to go. Stereotyping, in terms of autism and, intersectionally, of autism and gender, stigma, prejudice, discrimination, lack of awareness of relevant equalities legislation and lack of accommodations were all described as aspects of the autistic lived experience. There is recognition that things are slowly improving perhaps in society as a whole, but a general sense that we have a lot more to do, to create an understanding, genuinely inclusive society for all.

“No way to answer that in 150 words! Across the board I feel unseen, unsupported, misunderstood, dismissed, and discounted. Even by places and people who are supposed to be autism friendly. I'm under no illusion "society" would find it better if I just didn't exist”

“We always get some ignorant adults staring rudely at what may be seen as odd behaviour. ie. pacing in a queue, holding ears at a show/football match, flapping hands/arms when excited, my 33 year old son regularly kisses me when outside in the street (for reassurance) adults regularly stare rudely!”



"There needs to be much more understanding and much less judgement. Autistic boys become autistic men, but as autism is 'newer' in girls, it hasn't filtered through to awareness of autistic women yet. I think the scottish government is on the right path but it takes time"

"Overall I feel that my rights are met, however not in all areas. Employment and rights to reasonable adjustments are not always met. I work in care for autistic children, and have experienced directly and indirectly through stories by parents of basic human rights being unavailable, such as access to services and education."

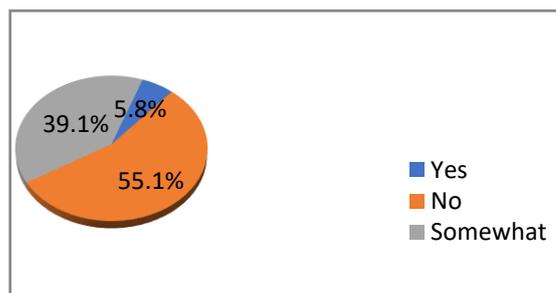
"We are consistently treated as non-entities - the fundamental assumption is that we have no capability or agency. This is entirely subconscious, but it's also constant. We are told that we are broken, and then treated that way. When it comes for consultation, autists are consulted last (if ever), and then mostly only a checklisting exercise. We are dehumanised constantly, by all agencies and most of our advocates. So no. Our 'human right's are not respected."

"People don't often recognise or understand invisible disability. They pick and choose which parts they believe and form inaccurate assumptions about what you can and can't do"

"I feel autistic people are treated as 'lesser'. I feel people don't care about our challenges in society ranging from healthcare needs, shopping needs, when someone approaches us and sensory needs."

"People expect us to function as they do and it affects our human rights and ability to live in society. I don't feel good enough or cared about. I'm too 'high functioning' (label I hate) for people to see I need help and I appear too unaffected to be treated with support. I feel utterly left out, uncared for and feel like I'm treated as not having a disability. It affects my life everyday, and my interactions. Appearing so 'well adjusted' is a great barrier to receiving any support or care, and I'm sick of it. It affects my mental health everyday and I do believe my human rights aren't met as a result of how I am"

"Whenever I disclose my autism the response has been negative. I don't think people have any real idea what it is, or the array of ways it can manifest, and just take it to mean "socially inept idiot". Or "socially inept lovable genius" if I give my formal diagnosis of Asperger's, which is maybe close to accurate description of me, but in no way touches on the things that are actually disabling in my life!"



#### Q19 And within the current COVID-19 context? 69

5.8%	(4)	Yes
55.1%	(38)	No
39.1	(27)	Somewhat



The responses to this were perhaps surprisingly variable but again reflect feedback coming in from the autism networks which is that most autistic people are aware of themselves as belonging to a wider community; they are aware that the entire population is experiencing a form of collective trauma, not just the autistic one, and that also much depends on people's own lived contexts - how well resourced they may be, what levels of support needs they may have, family contexts eg, being at home with children, having elderly parents to care for, partners with or losing jobs, themselves having or losing employment and so on.

However, there is a picture emerging that the lack of awareness and understanding of autism that was prevalent pre-COVID is manifesting in the current situation in specific ways. The lack of awareness and accommodations many experienced in relation to aspects of life such as shopping, clarity of guidelines regarding exercise and care support, and so on, as described in the earlier questions, are highlighted here.

"When dealing with such an immediate and dangerous issue it is unrealistic to consider all minority groups individually. Police need training in autism but now is probably not the best time? The rules are clear stay at home"

"Our needs are different- I need my support in supermarkets but only one person is allowed in"

"Don't make people hate us by going on about our special rights"

"I am sick of the positivity messages on the tv and online to help people cope. If i am not coping it is because it is really bad for me not to have routine! Every single normal day is an exercise in 'pushing and being positive'. There is no recognition of how bad it can be if you feel you are suffocating. Not everyone can reach out for help. If i had had coping strategies for coping with the lockdown as an autistic person it would have been wonderful but i feel 'dumped'."

"My level of stress, as an autistic, is pretty extreme nowadays ... I am in a high level of fear at all times now."

"no ones rights matter currently"

"I don't think people in general have any understanding of either the positives (like how lovely it's been having control over my home environment and the way I spend my time within it, or even how much less stressful being out is when people aren't coming distressingly close to me) or the negatives (like being trapped in my home while my neighbours renovate their entire flat, or the uncertainty of everything, or - worst of all - feeling so completely cut off from peace and nature, which is vital to my mental wellbeing). The medical profession certainly don't understand how inaccessible they've made healthcare"

"In addition to the above, I have been prevented from going in shops (single people only) when I need assistance. I can't handle the atmosphere, the lack of rules. I have gone hungry and a result and felt so alone."

"I feel so scared of the rules, and other people's prying eyes. I don't suffer domestic abuse (I used to), now it's just emotional/verbal abuse. Due to this, I felt I had no where to escape due to the exceptional circumstances only outlining safety. Additionally, I could not see my partner (who is my emotional support person)"

"The rules don't take into account people's disabilities"



**Q20 In no more than 250 words, what do you think needs to be done to improve recognition of the rights and needs of autistic people within Scottish Society?** **54**

Overall, the answers to this question were positive, and overwhelmingly the majority response was to seek training and education, the raising of levels of understanding across society in all areas. This wasn't always just regarding autism, but disability generally and also a call for greater understanding and acceptance of 'difference' and awareness of the benefits and values brought to society where there is such. Public awareness campaigns were asked for and a number of respondents talked about the need for the lived experience narrative to be given greater space and credence; for autistic adults who are able, to be more visible, and for autistic people to 'speak up for themselves more'.

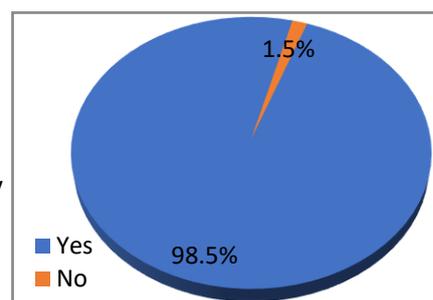
More consistent and easily accessed diagnostic services, better adult autism services, overall, one stop shops, for example were cited as was understanding that some autistic people may not look disabled and may have great capabilities and talents but also need support and accommodations. More awareness of autism in females was also mentioned. One respondent suggested that 'people shouldn't be afraid to ask questions... should ask autistic adults what their needs are instead of either assuming or dismissing'.

Many conversations over the last few weeks have shown that autistic people are aware this COVID crisis has demonstrated that some of the accepted social 'norms' and presumptions around employment practices, for example, quite patently don't work for all, and that new ways of doing things, some of which actually benefit autistic people, such as working from home, should be not just possible but actively encouraged going forwards.

"1. Acknowledge that for many of us, our autism isn't immediately obvious to others.  
2. Medically, we MUST be taken seriously. We do matter.  
3. We can contribute to society but our ways can be different and in some ways limited when measured against the general population. In other words, I feel there must be differentiation and adaptations to accommodate us, and value whatever our contribution is, if that makes sense".

"I don't know. I get the impression most people would rather I either kill myself or go through conversion therapy to be more like them. Perhaps if they understood the positives of autism more they'd stop begrudging the ridiculously minor accommodations needed for what they see as negatives? I wish they cared more... or at all, really. I like being around people, but it's so reliably traumatic I've given up trying."

"We need people to care, fund and implement change in society. Ranging from healthcare inequalities, shopping hours (should still be a thing during COVID - I don't look vulnerable, so I'd be challenged entering shops), gov needs to care, society needs to care and CHANGE. We need to stop living this high pressured life."



"More visibility to public eg on tv. Autistic people visible in high profile roles. When autism discussed whether on tv, or in decision making capacity, always, always consult autistic people. Schools decide on best support for autistic kids without seeking advice of autistic adults who have been through educational process. Society needs reminded that autistic kids grow into autistic adults - workplaces have to be a lot more accessible, do all jobs really have

to be filled by team workers and people oriented persons? Some jobs can be done alone, or from home?"

### Some demographics

#### Q21 Are you or your child autistic, either formally diagnosed or self-identified?

67

98.5% (66) Yes  
1.5% (1) No

#### Q22 Please include the following information about yourself (you are able/willing to share with us).

This was broken down into:

**Age** 96.7% **58**

This ranged from 14 to 65 years with the majority (37) sitting within the ages of 30 - 50 and another 9 between the ages of 51 - 60

**Ethnicity** 95.0% **57**

All of these described themselves as being Scottish, British, white or caucasian (or 'British beige aka white' in one case)

**Gender** 100.00%

**60**

5 described themselves as male, 1 as NB, 1 as AFAB and one as trans masculine. The other 52 described themselves as female, Fem or F; this is not surprising as the survey was distributed initially through the SWAN networks.

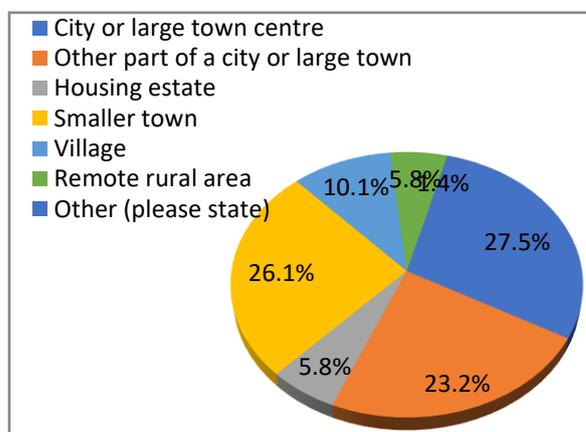
**Disability** 86.7%

**52**

A couple of respondents would not describe themselves as disabled - "?" and "I am not disabled, I am autistic", but the majority described themselves as having one or more disabilities, including autism, ADHD with co-occurring health conditions for 8 respondents that included epilepsy, anxiety, Major Depressive Disorder, severe Joint Hypermobility, Chronic Fatigue

**Other health conditions** 66.7% **40**

These included: meunieres, EDS hypermobility, OCD, depression, anxiety, childhood trauma, pain, ME, Fibromyalgia, RA, thyroid, IBS, arthritis, panic attacks, auto-immune disorders.



**Geographical****64**

Respondents came from across Scotland, in a fairly even distribution: Aberdeenshire, Aberdeen city, Moray, Falkirk, Forth Valley, Lothian, Perth and Kinross, Dundee, Tayside/Angus, Fife, Midlothian, East Lothian, West Lothian, Edinburgh, Stirling, Glasgow, East Dunbartonshire, Renfrewshire, East Renfrewshire, East Ayrshire, south Ayrshire, Dumfries and Galloway, Argyll and Bute, Scottish Borders.

**Type of geographical setting****69**

city or large town centre	19	27.5%
other part of city or large town	16	23.2%
housing estate	4	5.8%
smaller town	18	26.1%
village	7	10.1%
remote rural area	4	5.8%
other: housing association created neighbourhood	1	1.4%



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