

# How a Community Organisation Adapted During the COVID-19 Crisis

September 2020

By working with our colleagues in the Community and Voluntary sector, we have a series of reports on our website that capture the experiences and issues from the point of view of services and groups that support local people in the community.

This is an independent case study showing an example of one community organisation's story of adapting and what the future holds.

## About the organisation



Asperger's Voice self-advocacy group is run by and for adults with Asperger Syndrome in West Sussex.

## What were the immediate challenges?

Asperger's Voice self-advocacy group would normally meet face to face, monthly in Burgess Hill with approximately 3-8 members. They were due to hold their annual Autism conference '**Understanding Autism**' on the 1<sup>st</sup> of May which had to be postponed due to the pandemic and unsure when it will be run again; not being able to hold this event has deprived 50-60 people of the chance to meet in a safe space and support each other.



*It has been really difficult coping with no venues open and if we did reschedule a new date for the event, we would need a new venue so that we can incorporate social distancing in the layout for the room - we would need a quiet place and a main area. Social distancing for us is difficult and transport would be another issue.*



They have contacted all members on their mailing list by email or telephone. However, many find talking on the phone very difficult. *“Going to virtual meetings is the best of a worse situation - it is either do nothing or keep going.”* It has been difficult for some with emails as they need face to face interaction with our condition. One of the biggest challenges has been lack of information - *“it took the Government 7 weeks to produce an easy read version of the COVID guidance”*.

They developed a document to help members, which contains information, contacts of organisations who can support, tool kits produced by various groups and where to go for COVID-19 information.

Another immediate challenge when Lockdown was announced, was the access to Supermarkets and the lack of specific foods available. Some members have Personal Assistants (PA) and Carers but some were turned away from the supermarket because they only allowed one person in at a time. Others were reliant on friends to go shopping for them and there was a major issue with not being able to get the right foods that they required due to specific dietary requirements and rigidity about what they can eat.

*“I was ill with COVID-19 at the beginning of lockdown and a friend went to Sainsbury’s for me but got different versions of the items I would have bought, and this set off some of my reactions. It was a similar item but had extra ingredients that I wouldn’t expect, such as apple in tropical fruit juice, which made me ill, and they weren’t able to get the milk substitute etc that I needed. It was months before I went to Waitrose and then only in the early morning.”*

There were many of these types of problems around others shopping for members and about finding the supermarkets stressful with queuing, social distancing, people not being able to help with bag packing and reduced opening hours etc. For some people this caused high anxiety and panic attacks when shopping.

## How did members find the move to technology-based support?

Asperger’s Voice changed to having Skype sessions twice monthly, but members found this challenging due to connection issues and the fact that *“we need to see people face to face due to our condition”*. Using Zoom reduced the connection issues, but virtual meetings are still a much harder sensory experience due to the loss of social cues and body language and *“find it difficult to express what we need”*. They have begun to learn how to interact, for instance, only one person speaking at a time, but it is difficult as only able to see head and shoulders. There are also more distractions, so it is harder to focus.

*“I cannot go to my GP and can only have a telephone conversation - this is not supportive for me. Medical appointments at the hospital are now by video conference and I find this very challenging as with technology I cannot create images in my head, so it is really hard.”*

## How has COVID-19 affected the Group's finances?

Impact Initiatives provide a facilitator for the group. They help us apply for funding from grants and to set up financial accounts which would have been difficult. One challenge financially during the pandemic has been that we are spread across the county and our filing cabinet is in Brighton. Our members are in Horsham, Crawley and Mid Sussex so writing cheques has been an issue. Normally, our Impact Initiatives facilitator attends a meeting and brings the invoices and cheques for us to sign. It took four months to find a way to pay for things, though it's still a challenge to keep track of our finances and we need them to be audited so we can apply for funding to keep the group going.

## How has COVID-19 affected the Members?

There have been many challenges for the members in many areas. Anxiety and mental health issues have been greatly exacerbated and although the lockdown has been difficult for the population, *"COVID-19 has not been good for our mental health, we need to interact regularly so that our anxiety does not increase."* Some members are terrified to go out and the people who are normally there to support us are not available so there is an increased risk. Some members will not use the Community Hubs and do not know where to go or who to turn to for support. There is anxiety around what they should and should not be doing, including going out in general for exercise and shopping, which can be tremendously difficult *"I have anxiety of people judging me - the guidance states that you can only go out once a day, but not for how long - people think it's one hour - it says only 1hr on Facebook and Social Media - but if I go out for 4hrs I am being irresponsible, so I had to take myself off of social media."*

There have been many problems with health-related issues.

*"I had a problem with my antidepressant medications, and I had a meltdown in the pharmacy - they kept asking me to go back as they didn't have the full supply and when I did, they did not have the meds. I was told they had stopped stocking this brand and would need another prescription to go to another pharmacy. It was really difficult for me to cope with."*

Difficulties around the issue of Personal Protective Equipment (PPE) and our condition have been identified with members commenting that they would not be able to cope with wearing PPE themselves - the sensory impact of wearing masks around faces and/or behind ears. There is also the issue of NHS staff and support workers wearing PPE and the need of members being able to see people's faces to be able to read their expressions and understand what they are saying.

*"PPE on Healthcare Staff - I am not going to hospitals as seeing people wearing masks is unnerving. I am not sure how I will convince myself to wear one as it will increase my anxiety."*

There have been loads and loads of challenging things for group members and the group as a whole. The positive is that virtual meetings have enabled us to share things and we have put together tools and techniques to help people/members with Autism and mental health problems and provided useful suggestions to help with the psychological effects of lockdown and COVID-19 in general.

**“** *I fell ill with suspected COVID-19 at the start of lockdown. I phoned the COVID-19 line and was on hold for 80 minutes. I then spoke to someone who referred me on to a healthcare adviser, who then referred me on to a nurse, then eventually a doctor who was able to prescribe the pain relief I needed as we were told not to take ibuprofen and I can't take paracetamol, so had been in agony for days. It then took another two days to get the prescription because the late-night pharmacy was in a supermarket that shut earlier than it was supposed to. The doctor told me I did not need to go into hospital - I would have been terrified if I had to - auditory processing difficulties are a real issue for me especially if I can't see people's faces. I'm not sure how I would have coped with being in hospital overnight and with the PPE etc.* **”**

## Contact details

To learn more about Asperger's Voice contact:

Sam or Harriet on 07471 353062, email [aspergersvoice@gmail.com](mailto:aspergersvoice@gmail.com) or visit our website [www.aspergersvoice.org.uk](http://www.aspergersvoice.org.uk)



### *Supporting community action across Mid*

During this time of uncertainty, we have undertaken a range of different activities to support our members.

**General Enquiries:** 01444 258102

**Learn more from our website:** <http://www.msva.org.uk/>

**Admin Hub:** Delmon House, 36-38 Church Road, Burgess Hill, RH15 9AE

**Registered charity number:** 1158780

We have a simple ambition at Healthwatch West Sussex...  
to make local health and social care services better for  
people that use them.



We are here to listen, take action and influence positive change for local people  
living in West Sussex.

We record what people tell us and share this anonymously with those who make  
decisions about our health and care services.

#### **You can contact us in several ways:**



Telephone - 0300 012 0122



Email - [helpdesk@healthwatchwestsussex.co.uk](mailto:helpdesk@healthwatchwestsussex.co.uk)



Website - [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

You can also follow our social media channels to always be updated with the  
latest in health and social care news across West Sussex: [Facebook](#), [Twitter](#).

If you have questions about the content of this update, please either call 0300  
012 0122 or email [cheryl.berry@healthwatchwestsussex.co.uk](mailto:cheryl.berry@healthwatchwestsussex.co.uk)