

ACCESSIBLE ACTIVISM: WHAT, WHY AND HOW?

1. Structure and Acknowledgements

This talk is about accessibility in relation to activism – what it means, why it matters, and how to achieve it. The quality of my laptop’s inbuilt microphone, as you are starting to notice, is substandard. Please excuse its shortcomings. Let’s start with a quick overview of the structure of the presentation, so you know what lies ahead.

Firstly, I’ll present myself. Then I’ll define the terms accessibility and inclusivity and explain why they are desirable features of activist groups and events. Once we’ve cleared these basics, I’ll dig into different aspects of accessibility and inclusivity to consider when organizing events and meeting people who want to join your cause. Next, I’ll introduce you to two concepts – the social model of disability and the neurodiversity paradigm – which are crucial to expanding our understandings of accessibility.

Having discussed all the necessary theory, I’ll then offer strategies and practical tips for making your activism more accessible. I’ll finish with some remarks on in-group dynamics and provide a list of useful resources and my contact details. A transcript of the talk is available, I am literally reading it out as I am recording this presentation, and it contains links to some of the resources I make use of. Get in touch with me or the organizers of the event to receive a copy of it.

I want to take the opportunity to thank the organizers of the Bookfair for inviting me to create this talk for the event. Doing research can be a solitary occupation in the best of times, let alone during lockdown. Being given the opportunity to share my research with others in hope it might inform their practice means a lot.

Over the course of the past couple of weeks, I have been in touch with activist friends and fellow researchers to develop my ideas more fully and include examples from their experience and work in this presentation, so as not to speak from a single-person perspective. My heartfelt thanks and appreciation for this go to Mie Jensen, Marion McLaughlin, Camilo Torres, Janet Mortimer and the members of the Scottish Women’s Autism Network.

2. My Background

Hi, my name is Ekaterina, you can call me Kat. I’m currently completing a master’s degree in policy evaluation looking at the ways in which autistic activists play a part in the Scottish Strategy for Autism. I have several years of experience in the care and support work sector working with vulnerable members of my local community. Activism-wise, my experience is of participating in environmental initiatives and protests in my native Bulgaria as well as in social campaigns in Aberdeen. Over the past year, I have been examining forms of activism based on making social research findings more readily accessible in community and institutional settings.

3. Definitions of Accessibility and Inclusivity

I like to think of accessibility and inclusivity as two sides of the same coin, the two ways in which we can make social groups and events more open, welcoming and diverse. Accessibility is the physical aspect and has to do with whether our events are easy to reach, attend and participate in. Inclusivity is the social aspect which has to do with whether people feel invited, included and accepted within our groups.

One without the other won't do – an event venue decked out with wheelchair ramps, hearing loops, quiet rooms and adjustable lighting might be physically accessible, but if the members of the organizing group don't know how to use it and lack the social know how which will make disabled people feel welcome in the environment, the event won't be truly inclusive. And vice versa, if a group explicitly makes verbal statements of how inclusive they are, but fail to make reasonable adjustments to their environment so as to accommodate all of their members, their accessibility is compromised.

The above examples sound commonsensical, but even so, organisations with international representation, substantial budgets and plenty of access to expertise still manage to get these wrong. There are autism and mental health charities which adopt patronizing attitudes towards the very people they seek to support. There are development organisations which use neocolonialist stereotypes to represent the communities they purportedly seek to collaborate with. There are environmentalist campaigns which promote behaviour change strategies which neglect the socio-economic realities of the poor, disabled and elderly. Such mistakes are often made despite people's good intentions of bringing about positive social change. And though lack of resources and funding is a problem facing many, if not most activist groups, the main drivers behind mistakes made in terms of accessibility and inclusivity are lack of access to the right information and decision-making by homogenous groups. Accessibility and inclusivity are features of all interactions that take place in activist circles. Their beginning does not coincide with the start of an event, but with its very conception and all stages of its planning.

4. The Importance of Accessible Activism

A quote from one of my research interviews with Marion McLaughlin stuck with me over the past few months and has shaped much of my thinking about the topic at hand. She said '...whenever you make an environment appropriate...for anybody with a disability, you're making it more appropriate...for everybody.'

If activism is about introducing constructive change in society, then it must be open to all the kinds of people who comprise it. Making your organisation more accessible is a way of learning about your community and the needs of the people in it. Inclusion is not about exoticizing or tokenizing people from the fringes. It's about ensuring that anyone who would like to join your group is able to do so.

Different people will have different needs regardless of how much in common they have ideologically. In 2016, there were 13.3 million disabled people in the UK, roughly one in five people. 7% of all children, 18% of working age adults and 44% of adults over state pension age were identified as disabled at the time (<https://www.dlf.org.uk/content/key-facts>). Those are the numbers according to the official statistics, which do not include the thousands disabled people wrestling with their local health providers to be tested, diagnosed, and supported with the difficulties they experience. Bearing these numbers in mind, it is obvious that making activists spaces accessible is not a luxury but a necessity.

In addition to disability, there are multiple other types of sensitivities and vulnerabilities which need to be acknowledged and addressed in activist contexts. I'll cover these in more detail in the upcoming sections. But for now, I wish to emphasize that all people have support needs, all people have a state of mental health be it good or poor, and that all people go through fluctuations in their wellbeing. When we make our social circles and activities more flexible and

accommodating, we are not doing it for a select few of those amongst us. Everybody benefits when accessibility and inclusivity are improved.

There is a growing body of organizational research which shows that more diverse teams make better decisions, refer to facts more frequently, work faster and are more creative compared to homogenous groups (<https://hbr.org/2016/11/why-diverse-teams-are-smarter>). The better we are at including people of different backgrounds in our decision-making and planning process, the better our work becomes. Which is a strong incentive not only to welcome people with diverse needs and sensibilities to our activist groups, but to actively reach out to them and invite them to contribute.

5. Accessibility as a Journey

To expand my definition of accessibility, I'll use the metaphor of a sailing journey. Travelling can be enriching and pleasurable, but it can also be stressful and draining. Levels of accessibility are crucial to people who find it harder to navigate new spaces, and whether their experience is one of anxiety and struggle or exploration and enjoyment has a lot to do with the ways in which we set up our events.

When we speak about accessibility, we mostly think about adjustments made to the physical environment such as rails, ramps, baby changing facilities, etc. So if people are going to be coming along on our ship, we need to make sure to tell them what's already in there and what isn't, so they know how to ready themselves and what to bring. Some of us might be able to pick up our day bag and feel prepared enough to go to an event just with its contents on our person, but for others, preparing for an outing can involve considerable amounts of effort. So try to provide as much information as you can in advance about your venue – is it on a ground floor, does it have elevators, is there a hearing loop installed, are the toilets segregated or gender neutral, are there facilities for making drinks and food, and if any refreshments are provided, what do they consist of? The list goes on and it would save you time to come together as a group and make a written list of relevant features of venue and events, which you can then fill in appropriately and use for various gatherings by making it available to participants ahead of time.

A second important aspect of accessibility is logistics. Providing detailed logistical information to help your attendees plan their journey is the equivalent of giving a clear map to a traveler. Event location and timing are the most significant elements of event logistics, but are by no means sufficient for those who find travelling difficult. Don't assume participants will be able to intuitively navigate the layout of the space. A PhD friend of mine knows five languages and does multiple forms of art in her spare time. She also gets massively stressed about going to conferences because her sense of direction is poor and she can't always tell left from right. She sometimes finds it difficult to ask for more orientation cues as she worries this might compromise her status of a competent researcher. Such unnecessary stress can be avoided by providing more logistical information beforehand – how to access your venue by car, public transport and bike, whether there is dedicated parking space, and in case the event is longer – where are nearby shops, restaurants and what are convenient options for accommodation? Think of logistics inside the venue as well. Make signs indicating the locations of discussion rooms, toilets and kitchen facilities, and whenever possible, declare a doors open time some 15-20 minutes prior to the start of the event to allow people to explore and settle in the space. Outdoor events and moving marches pose their own set of challenges – if possible, make the organizers and event support members distinguishable in some way. If that is not possible for

safety reasons or the event is too dynamic to keep track of others at all times, allocate support buddies to people with accessibility challenges who can stay close to them throughout the duration of the event and assist if need be.

Some are intuitive travelers, while others enjoy meticulous research and planning as part of their journeys. Providing context for your event as well as clarifying its structure and content is of great use to people who like feeling prepared. It's like having a guidebook and a list of useful phrases in the local language before you arrive. Access to information is the third element of accessibility. It can be achieved by giving people a heads up about the structure of the discussion, the planned breaks in the activity as well as by uploading a short paragraph or key points of the content which will be covered and/or activities planned. While not all people need such detailed breakdown of what's happening, increased clarity benefits those who struggle with social anxiety and a need for control of their environment.

By thinking of your event as a journey rather than a fixed location, you can target and improve the aspects of accessibility which make it easier for people to arrive, settle and participate in the activities you're organizing. Smooth sailing!

6. Facets of Inclusivity

Both accessibility and inclusivity have to do with anticipating the needs of people and being responsive to them, but while accessibility focuses on the environment, inclusivity emphasizes the personal experience of people in a group. I present you with a provisional list of personal characteristics you might want to consider when planning and attending events. It's by no means exhaustive and the specific ways in which these factors can play out in the context of your activist circles are for you to consider.

1. Age
2. Gender
3. Sexuality
4. Ethnicity and Race
5. Religion
6. Political Convictions
7. Socioeconomic Background (such as family background, level of educational attainment, employment status, being an ex-convict or refugee)
8. Physical Condition (temporary change in physical condition not caused by disease or disability such as menstruation, pregnancy, hormonal replacement therapy or the recovery process after injury)
9. Disease
10. Disability (Physical or Learning)
11. Mental Health Condition
12. Neurological Difference (such as being autistic or having ADHD)
13. Dependents (whether one has children, looks after elderly relatives or is supporting a spouse through a period of poor mental health)
14. Past Trauma
15. Skills and Experience (the level of familiarity one has with the activist environment, one's knowledge of the area and the language of the event, etc.)
16. Personal Circumstances (sudden change in areas such as family relationships, housing and employment)

I've chosen the image of a gem for this slide because the characteristics listed above are all aspects of a single person, just like polished stones have many facets. Such personal characteristics are intersectional – they intertangle and affect each other, the way we see ourselves and the ways in which others see us.

Two of the most straightforward ways to improve the inclusivity of your group is to address people on their own terms and to learn how to hold safe spaces for those who have past experiences of being denied voice and agency. In smaller groups, starting events with a round of introductions helps break the ice and highlights which aspects of their experience a person identifies with most readily. In larger groups where personal introductions are not feasible, name badges with the person's preferred pronouns and any other terms used for self-identification enable smoother conversation. While some activist spaces are explicitly created for specific groups, such as forums for neurodivergent people, support groups for survivors of abuse or empowerment workshops for women, others are organized around cause rather than identity. In both cases, it is crucial for the group and its events to be explicit in stating their policies on inclusion, circumstances in which attendees would be asked to leave or be removed from the discussion, and to provide the contact details of a group member to whom a person feeling unsafe or under attack can turn to for support.

Inclusivity is about removing barriers to self-expression and equally, it's about accepting limits – our own and those of the people around us. Individual knowledge and experience are finite. Be humble and give credit where credit is due – if somebody's work has shaped your thinking on a topic, name them. Learn to forgo opportunities to be center stage in favour of passing them on to people who are better qualified for the job. Sometimes the best answer you can give is: 'I'm not sure, but this other member of the group has plenty of personal experience with this, better ask them.'

Accepting the identities of other people means not only having appreciation for their strengths, but also respecting their limits. Disabled people, new parents, working students and night shift workers may be tremendously enthusiastic about your cause, but their ability to attend your events may be curtailed by their personal circumstances. The correlation between levels of dedication and frequency of attendance is not always linear. Think about appropriate channels of communication to make people feel included in your activism even if they're not always able to attend your events in person. Uploading videos and transcripts of select parts of your events online will make them available across a much wider stretch of time and space.

7. The Social Model of Disability

I would now like to turn our attention towards possible ways of expanding our thinking about disability. In the education and practice of medical professionals, disability is regarded as something undesirable and in need of fixing. This view of disability represents what is referred to as the medical model of disability. Within this framework, the bodies of disabled people are seen as lacking in comparison to (big scare quotes here) "normal" and "healthy" bodies because of their impairments and differences. The medical model views disability as an objective stable condition originating within the body of the disabled person. It promotes the use of prosthetics, surgical procedures, and assistive technologies in the efforts of making disabled bodies more functionally similar to able bodies.

With the rise of the Disability Rights Movement during the second half of the past century, the thinking around disability started to evolve in new directions which eventually led to the

postulation of the social model of disability by the disabled British academic Mike Oliver in 1983. According to the social model, disability is a fluid phenomenon which fluctuates with relation to the surrounding environment. The impairments and differences some people experience with regards to the functioning of their bodies, sensory processing, learning capabilities and moods are not inherently bad. They become disabling when the social environment does not adapt to these differences and purposefully or unconsciously excludes those affected by them. Hence, within the social model, disability originates in the ways in which an impaired person negotiates access to spaces, services, and social groups. The higher the levels of accessibility and inclusion are, the less disabling the environment is. The social model of disability is useful in activist settings for several reasons. Firstly, it destigmatizes disability and empowers differently abled people to accept themselves as they are and celebrate their identity. It gives us footing in critiquing the institutions, groups and practices which systemically oppress differently able people. Finally, being a dynamic model, it allows for growth, and invites us to consider ways of making our settings more enabling and supportive.

8. The Neurodiversity Paradigm

The Neurodiversity Paradigm is one of the most recent introductions to our thinking in terms of identity. Coined in 1998 through the correspondence of the autistic sociologist Judie Singer and the journalist Harvey Blume, the term 'neurodiversity' refers to the natural variations encountered in the brains and nervous systems of different people. Just like hormonal levels and physical traits can vary from person to person, so our neurology has different setups, and each setup and brain has its own way of processing sensory information, emotional cues and recalling memories, amongst other things. Neurodivergence is the quality of having a significantly different neurological setup to that of most people around you. Some forms of neurodivergence are congenital, which means they are present from the time a person is born – like autism, ADHD, dyslexia and dyspraxia. Others are acquired – such as PTSD and some types of epilepsy. Neurodiversity dispels the idea that some people are “normal” and the rest somehow deviate from that norm. Instead, we talk of minority and majority neurological variants.

Neurodiversity is a biological phenomenon with profound socio-political implications. Just to emphasize, neurodiversity is not a hypothesis but factual reality – as you can see from these photos juxtaposing a neuron from the brain of a non-autistic person and that from the brain of an autistic, there are observable structural differences between the two. There is a working estimate that 15% of the UK population is neurodivergent (<https://archive.acas.org.uk/neurodiversity>). The Neurodiversity Paradigm postulates that neurodivergent people are not deficient and their neurological constitution is fine as it is. However, confronted with a social and physical environment adjusted to the processing needs and social habits of other neurological setups, neurodivergent people struggle.

The medical, psychological and psychiatric disciplines still view neurodivergence as a form of impairment. Neurodivergent activists, especially the autistic community, oppose this view and insist on presenting a more balanced view of neurodivergence, which takes into account the strengths of neurodivergent people as well as their challenges. For instance, many neurodivergent people are capable of extended periods of unbroken focus on a single task and have passionate interests of which they develop an expert knowledge. Autists, for instance, are often very sensitive to sensory stimuli such as sound, light or the texture of clothing and have difficulties picking up on certain social cues. The flip side of this coin is that their sensitivity allows them to focus on details with great accuracy and their different ways of processing make

them original thinkers. Making activist spaces accessible to neurodivergent people is a matter of collaborating with them to ensure that the sensory environment is appropriate for their needs and that they can engage through means of communication which feel comfortable and natural to them.

9. Strategies for Accessible Activism

I divide my practical suggestions in three categories: attitudes, participation and practice.

Attitudes

Flexibility, inquisitiveness, and humility are key attitudes to cultivate to be more inclusive. Since we can't predict the exact needs of everyone who'll take part in our activities, we have to be prepared to change aspects of the environment as we go along. We need to commit to making reasonable adjustments for the people who request them – it's easier to think of them as puzzles which require creative problem-solving rather than hurdles in our way. This is where inquisitiveness comes into play: ask people how their needs are best met, and do your research if you come across sensitivities you knew little about previously. The process of educating yourself need not be a solitary effort - contacting other activist groups, charities and research organizations for resources and training can lead to unexpected collaborations. As a rule of thumb, only reach out to organisations which have representatives of their focus group on their committee. A charity which claims to support autistic people but does not have even one autistic person in an executive position should be regarded with suspicion.

Different needs result in different lived experience. It's not just a matter of learning how to help and assist – learning about the different ways in which people live in the world is humbling and expands your understanding of the human condition. For instance, did you know that there are over 80 different types of synesthesia? (Synesthesia is the blending of senses where a stimulus registered by one of your senses leads to an involuntary response from another, such as hearing colours or tasting sounds - <https://synesthesia.com/blog/types-of-synesthesia/>).

Participation

As previously discussed, the more diverse your decision-making and planning team is, the better. Ensure that campaigns or events which address the experiences of a particular group of people are always headed or co-hosted by representatives of that group. If you're trying to make an event accessible for people with specific impairments, get them on board as soon as possible. They might have suggestions about appropriate venues and will be in a position to give you specific practical guidance how to meet their needs best and let you know if there is any accepted etiquette in the community as to how to offer assistance. A blind woman I work with told me last week that if you're providing support to a visually impaired or blind person by walking with them, you should not grab them by the hand but rather give them your elbow, so they can hold on to your arm right above it. This type of information should preferably come to you from the lived experience of a person you're talking to rather than a text you're reading, because your interpretation of the information might not be attuned to the priorities of people with different needs and you might miss important information.

Don't go to the same one person for advice on all your consecutive events. Say, if you have a trans man on your planning committee, don't tokenize him as a spokesperson on all things trans. Ask him if he knows other trans people who would like to contribute to your activities, or

get in touch with a trans activist group for more input. A single person cannot stand for an entire community – it's too demanding of them and doesn't do justice to the diversity of the group. As the saying in neurodivergent circles goes 'If you've met one autistic person, you've met one autistic person.'

Practice

Begin by thinking about the ways in which you can diversify modes of engagement with your activism. Are you making enough use of virtual and remote forms of participation? People who cannot make it to your events or dislike the sensory environment of protests and large gatherings might still like to contribute to your work. Graphic design and creating online content, research, fundraising and establishing contact with other organisations are all significant activities which can be performed remotely.

Work towards normalizing information dissemination practices about and throughout your events such as:

- Making detailed venue descriptions available beforehand. These can be accompanied by photos of the interior spaces, a map of the location and instructions how to get there by different means of transport and information on parking facilities.
- Schedules of the events including break times and information on internal facilities such as accessible toilets, kitchen facilities, hearing loops, types of seating, ramps and railing.
- Provide trigger warnings for sudden sensory stimuli such as loud noises and bright flashing lights as well as for trauma, violence and abuse-related content.

Designate a space for decompression and processing where participants can take some time out on their own such as a quiet room, a prayer room or a garden.

Make it known that you are willing to make adjustments to the sensory environment and in case the venue itself does not have things like dimmable lights or readily accessible heating control, get some lamps from charity shops, blankets and cushions and single-use ear plugs or ear defenders to allow attendees some control over the levels of light, sound and the texture of their environment. Always have a first aid kit to hand.

In the case of bigger events, try to have signers for deaf people and provide transcripts and captions wherever possible.

Invite and collate anonymous and in-person feedback of the accessibility and inclusivity of your events to get an idea what worked well and what could be improved in future instance.

10. The Importance of In-Group Dynamics

Our activist groups, as small as they might be, are microcosms which reflect trends in society at large. As soon as there are two people in a room, there is a shape to the relationship between them and a distribution of power in the ways in which they interact with each other, give each other or deny one another space, voice and agency in making decisions.

The organizers of activist events need to check in with each other to establish comfortable, consistent, and clear paths for collaboration. People who are ill at ease themselves have a hard time welcoming newcomers into their social environment. To make our events and spaces more accessible and inclusive to everyone participating in them, the core group of organizers of an

event can consider the following suggestions:

- Purposefully keep a balanced perspective on world events. Activism is a response to the injustices we see in the world and the desire to rectify them, but if we allow anger, frustration and despair to become the leading tones of our rhetoric, that will breed distance and coldness. We need to seek out and spread the good news. We need to encourage the feelings of joyfulness, solidarity and creativity within our circles. Think about striking a balance between activities based on constructive criticism of the status quo through direct action, demonstrations, and educational activities, and events which celebrate people's identity, allow them to envision a better world and create stronger bonds with each other. In addition to promoting resources on current events and activist theory and practice, seek information about advocacy groups and therapeutic services which your members and attendees can make use of.

- Many activists have first-hand experience of marginalization, oppression, and social stigma. We often find ourselves overstretched, on the brink of burnout, dealing with a lot in our personal and professional lives. Expectations of everyone's contributions and dedication should be realistic, and there needs to be a distribution of responsibility such that people should be able to take breaks from their activist engagements without facing judgement or putting the continued existence of the group in jeopardy.

- To facilitate the even distribution of responsibilities, keep an ongoing record which includes meeting minutes, event planning documents, relevant resources, contacts of people and organisations you collaborate with, as well as feedback from past activities and ideas for future ones. Select a platform in which information can be arranged by topic rather than the chronological nature of group chats, so files are easy to retrieve. This move, although requiring a substantial initial investment of effort, has multiple benefits. It saves time in the long term and makes it easier for new people to step into organizing positions even if it's at short notice. A centralized database also means that fellow activists who can't join your meetings in person can still make substantial contributions to your work. Having a backlog of data on your activities makes it easier to spot patterns in your group dynamics which you can take into account when making future decisions.

- My friend Mie shared some writing on the topic of inclusivity with me, and I think she raises an important point: ' Sometimes, activists can be hard on each other. There's almost a competition to be the most righteous...It's easy to think we have to be perfect, rather than saying we give what we can... Inclusion is not saying 'you can only be part of this group if you tick all these boxes'. I agree with her- self-discipline and resilience do not exclude gentleness and understanding. Activism is challenging work which asks of us to change our ways of seeing the world and being in it. We are bound to make mistakes, and we can only do as much with the time we have. Yes, it's important to be self-critical and avoid the pitfalls of becoming arrogant and presumptuous. It is equally important to acknowledge that personal change is a slow and gradual process, and that even the fruits of small victories should be enjoyed. I invite you to take a moment now to think about the growth you've seen in yourself and others, and to be grateful for the valuable lessons you've learned through your activist engagements.

11. Summary

In conclusion, most of what I've said so far can be summarized by a single principle:

Activist communities have the responsibility of representing the type of social order they seek to evoke

12. Resources and Organizations

Though we've covered more ground than this, I will only make recommendations for resources and organizations relating to neurodiversity and autism. It's the area I specialize in and can guarantee that these are high-quality sources of information produced by autistic activists on autism

In print:

[Loud Hands: Autistic People, Speaking \(2012\)](#)

[The Real Experts: Readings for Parents of Autistic Children \(2015\)](#)

Online:

[Neuroclastic](#)

[Autistic Self Advocacy Network \(ASAN\)](#)

Scottish APOs (Autistic People's Organisations):

[Autistic Mutual Aid Society Edinburgh \(AMASE\)](#)

[Triple A's Aberdeen](#)

[Scottish Women's Autism Network \(SWAN\)](#)

Thank you for your time!

You can contact me at: e.anguelova@yahoo.co.uk