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Autscape

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In the Beginning, There Was a List

I am currently the event manager for Autscape, an annual three-day residential event for autistic people. It is autistic-led, though not exclusive. I was there the day Autscape was conceived, and I have had a major role in organizing the event for 12 of its 14 years. Here's how it happened.

Soon after I first discovered the Internet in late 1996, I sought out autism-related groups and immediately went to spending hours every day on autism chat rooms on Internet Relay Chat (IRC) and email-based support groups ("lists") such as Independent Living on the Autistic Spectrum (InLv; Martijn Dekker [1], see Chapter 2) and Autism [2]. Through these activities, I heard about Autreat and joined ANI-L, the list run by the organization responsible for Autreat, Autism Network International (ANI, www.autismnetworkinternational.org). In those days, it was common to use an online "handle" or nickname rather than one's real name,

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and mine was 'Kalen.' Then in its second year, Autreat was an annual conference organized by and for autistics and their "allies." I would have liked to go. At that time I had only met two people I knew were autistic, and I wanted to see if others were similar. I also wanted to see for myself what people were talking about so much on ANI-L. Unfortunately, as I lived in western Canada, and had very little money, the trip to the eastern United States was too daunting and expensive. When I emigrated to the UK, any hope of making it to Autreat all but disappeared.

One of the email groups I belonged to in those days was Independent Living on the Autistic Spectrum (InLv), run by Martijn Dekker. On InLv, we occasionally talked about Autreat, as some members had attended while others wished to, and we longed for someone to organize such an event in Europe. Eventually, in July 2004, tired of all the talk and no action, one member asked who would start a list (email group) to get started organizing such an event. I had some relevant experience running email lists for autistic parents, partners, and adults, so I volunteered. Considering myself radically disorganized, my intention was only to manage the technical side of the communication while others got on with the organizing.

Initially, the list had around 20 subscribers from all over the world, and it took some time to settle into a focused group of organizers. I was both flattered and astonished when a Finnish member, Heta Pukki, suggested that I should be chair. No one else came forward, so eventually I agreed. As a somewhat strange side effect of all of this coming from the online community is that my online name became my name within Autscope, so there I am still known mostly as "Kalen" except to my family and friends. Charles Burns was our first Treasurer, and Heta served as the first secretary. Various other people also helped with website, printing, and sharing thoughts and ideas, but I have such a poor memory for people I don't know who all of them were now. Jim Sinclair, the founder and main organizer of Autreat, served as an advisor to the committee. We chose a name and I created a website. We devised a list of features we needed in a venue, and Charles and his wife, Kazumi, found one that seemed viable, Ammerdown Centre in Somerset, England. They negotiated a discount, got us penciled in for 3 days in the summer of 2005, and put forward the initial deposit. Kazumi served as our first venue coordinator, managing liaison with the venue. However, interest waned and progress slowed, and

we started to consider having a smaller event just for the organizers to learn about organizing events, with a view to doing a full-fledged conference the following year.

A pivotal moment came when early in 2005 Heta announced that she had secured a grant of £5000 to pay organizers' expenses and childcare, as several of us had children, and to bring over the leader from Autreat, Jim Sinclair, to assist and train us. Inspired by this change, we suddenly went into full swing organizing the actual event. I managed most of the general coordination, registration, program, and writing. I sent out a call for proposals for the program by email and made an advertising brochure. I also developed a rudimentary online booking form that would allow participants to send us essential information by email. Remarkably, people registered! Charles managed payments and banking. We didn't yet have a proper database for managing participant details, so I kept them all in a spreadsheet on my computer.

Autistic Space

Planning an event around autistic needs is complex due to their diversity. Because the event included room and board, Kazumi liaised with the venue staff at Ammerdown to obtain extensive details of bedrooms, bedding, meeting rooms, lighting, and menus. Although we had catering for special diets, we had a small number who couldn't cope with centralized catering, so we also had to arrange self-catering for them. We had to train venue staff in understanding autistic needs. We visited and took pictures of meeting rooms, social space, and bedrooms. To help those with sensory hypersensitivities, we banned scented products, camera flashes, and any touch without explicit consent. We scoured the venue for flickery fluorescent lights, squeaky doors, air fresheners, and noisy fans, and, wherever possible, had these switched off, fixed, or removed. We also advised participants to use sunglasses, earplugs, or other devices to suit them. Ammerdown had a lounge area with a bar where we could socialize in the evening. It had a similar feeling to a small pub, but without the background music because dealing with a room full of people talking is hard enough without music as well.

We adopted and adapted Autreat's interaction badge system, large colored badges optionally worn by participants to help regulate social approaches. They were:

Red: Please do not approach me. I do not wish to socialize with anyone.

Yellow: Please do not approach unless I have already told you that you may approach me while I am wearing a yellow badge.

Green: I would like to socialize, but I have difficulty initiating. Please feel free to approach me [3].

On each of the badges was written the name of the color, to help those with color blindness, and its use, in case participants forgot what it was for.

We decided from the start that the event should be three days long so participants would have a chance to settle in and still have some time left to enjoy being there. Coffee and meal breaks were extra long for similar reasons. Because many autistic people appreciate structure, there was a full program of scheduled activities such as presentations and discussions. The program also included a leisure time after lunch when a variety of activities were on offer, such as music, dance, and meditation, and we had an exercise session early in the morning for those who wanted to join in. We knew that many of our participants would not drive and public transport to the venue was poor, so we arranged transport by bus from the nearest train station, 13 miles away. Because autistic people have a wide variety of gender identities and expressions, we now gender neutralize toilets in public areas when there isn't already a gender-free one, but we didn't know to do that at the time.

One thing that makes a space autistic is that autistic people are ordinary, not special. Autscape is a prime target for researchers and journalists, and while some autistic people are eager to take part, others wish to be left to be themselves in peace. We have had some journalists, filmmakers, and researchers on site, but we give them strict guidelines disallowing filming in public places and to only use material from people who proactively offer to contribute.

Having put time and effort into organizing all this for the first event, we then hit a snag. The venue decided we would have to provide one carer for

every three autistic people. Most of our potential participants were independent adults who didn't have or need someone to care for them. From this came one of our first principles: participants are presumed competent. If they need help to manage in Autscape's environment, it is up to them to bring someone, although as it turns out, people who usually need a carer when away from home sometimes don't need one at Autscape. Thankfully, an emergency meeting with venue staff was sufficient to convince them that we didn't need to dictate a specific carer-to-participant ratio. Autreat organizers had warned us that some difficult behavior from participants was likely and Jim provided some training just before the event.

Possibly the most helpful adaptation for autistic people is the provision of information. Before Autscape, we sent out a comprehensive yet concise information pack with details of the venue and program, expectations, packing list, and transport details. We were, as always, late producing it, only 3 weeks before the event, but one participant has said that after some considerable anxiety, it was the information pack with its detailed information that told her she was coming to a place where she would be understood.

Most of the bedrooms had two single beds, but demand was so high we needed maximum occupancy, so we arranged to match up roommates and assign rooms ourselves based on sensory and social preferences. We filled all of our designated bed spaces in the venue, which was shared that year, for a total of around 45 people. The first event was a stunning success. Participants seemed happy, organizers were coping, the program ran well. There was no sign of the difficult behavior we'd been told to expect. We had a meeting at the end to consider whether Autscape had a future (and who would run it if it did) and the response was overwhelmingly positive.

Autscape continued in much the same way for the next two events, but with sole use of the venue so we could fit in about 85 people if we used every space. In two of the years, we even had people camping in the grounds in order to come. By 2008 we had outgrown Ammerdown, and it had become too expensive as they no longer gave us the discount for new groups. We searched through hundreds of retreat centers from web searches and recommendations, but all were unsuitable. We eventually settled on Giggleswick School in North Yorkshire, England. As we were told to expect based on Autreat's experience, numbers dropped by about

a quarter when we changed venues. Giggleswick is on a steep hill and bedrooms and facilities are scattered among several buildings. We didn't know how to get a coherent sense of community in a dispersed venue, so to many who had been to Autscope before, it felt more distant and detached. In 2009, we returned to the retreat center format at Emmaus Centre near London, and then back to Ammerdown for the last time in 2010. After the moves, numbers increased back to Ammerdown's full capacity. Since then, we have become better at choosing venues and managing their different strengths and weaknesses, so different needs are met each year and we are better able to provide social opportunities even in dispersed venues.

Autistic Participants

Inclusivity is a central principle of Autscope. In order to be inclusive, Autscope has to be accessible. The main criticisms Autscope has received over the years have been from two views of accessibility. One is that it is insufficiently accessible to people with mobility impairments, and the other is that it is too expensive for autistic people, who very often have a low income. Unfortunately, we have not yet been able to solve both of these at once. Venues with full wheelchair access, adapted bedrooms, en-suite bathrooms, etc., are expensive. Fees would have to be considerably increased to cover such venues. Autscope has to pay the same fee to the venue whether the person is a participant or a personal assistant, so allowing assistants to attend for free would also substantially increase fees. Inexpensive venues are usually boarding schools that are hundreds of years old. They tend to be more difficult to access, work with, and navigate. They have a less polished appearance and provide fewer luxuries, so participants have to bring their own towels and use communal kitchenettes for making coffee and tea. Rather than being compact like most conference centers, schools are often on sprawling sites with long walks between activities, dining areas, and houses of residence. Within the houses, they have many stairs, convoluted corridors, awkward height beds, and few or no en-suite bathrooms. Although the external door to each house is locked with a separate code, the bedroom doors usually don't lock. However, these venues usually have great outdoor space, lots of separate rooms to meet

in, and far more single bedrooms, which many of our participants need. Our best solutions to these problems for now are to keep our program and advertising costs to a minimum and to rotate between venues with different features to prioritize different needs in consecutive years.

Even in the cheaper venues, the total cost for Autscope is still high, but such a high proportion of our participants have a low income that lowering the fees for them would put an unfair burden on the few who don't. Until 2017, we offered a very small low-income discount. The discount had to be small in order to cover a large number of people. We never required proof of income to avoid disadvantaging those who struggle with organization and paperwork. This discount was not helpful to those who had the least and struggled to afford to come even at the lower rate. In 2018 we tried a new approach. We stopped having that low-income rate and instead have a grant scheme which is more flexible and allows us to give larger discounts to a few people rather than a very small discount to many. It is more expensive, but as a more mature organization, our finances are in better condition than they were in the early days.

Some of the issues with access could be solved by diligent fundraising in order to lower all the fees or provide more substantial subsidies for people who can't afford to come. Unfortunately, people with the ability to fundraise effectively appear to be rather rare in our community. We had three large grants in the early years. The first, as described earlier, funded organizers and childcare at the first event. After the second grant we had the misfortune of being randomly selected for an audit of the spending. The stress of the audit was enough to put us off seeking further grants. Funding for ongoing running costs of an organization is virtually impossible to find, but we did apply for one more grant in 2008 to support Autscope's development as an organization. Since then, Autscope has been entirely self-sustaining, with no external funding other than the occasional personal donation. Fees are set at a level that can sustain operation, and prudent management of the finances has allowed Autscope to remain well above the minimum necessary to operate since the first event.

Another aspect of being as widely inclusive as possible is Autscope's decision to be explicitly non-political. That includes party politics—which is not allowed under UK charity regulations in any case—and “autism politics” such as lobbying for changes to law or policy. The sole exception

is that Autscope supports the view that autistic people have a right to exist. Autscope was set up exclusively to run the annual Autscope event. If we become distracted from that, we risk failing at our core purpose. We also risk losing some of our inclusivity. If we adopt a political position, then we alienate those who disagree with it. Autscope has provided a platform for more politically oriented activities to take place. Participants have run discussion groups about the Labour Party's Neurodiversity Manifesto and about autistic activism. Out of one of the latter, the London Autistic Rights Movement was started, which later evolved to be Autistic UK, an active autistic rights organization. One former member, who was involved in another organization for a while, has suggested that Autscope's focus and determination to do one thing and do it well, not to be distracted by other activities like politics and advocacy, is part of why Autscope has lasted so long.

Autscope has had minimal success in attracting autistic people with a wider range of ability. To some extent, this is due to inherent characteristics of people who are, for example, less verbal or less sociable. However, we have tried to include some activities that are more accessible to people who don't handle words as well as most of us, with mixed success. In 2013 I did a presentation on using Makaton, simplified sign language, to communicate urgent needs. We also try to include some sessions that are more experiential, such as meditation, art, music, and movement workshops. To do a really good job of having a program suitable for a wider range of autistic people, we would have to have a dedicated leader and team who focused on only that, but so far all our organizers have been quite busy just continuing to have an event each year.

Being inclusive does not mean making everyone happy. It is common for autistic people to believe that in a hypothetical autistic-only space (which Autscope isn't, but many people have talked about creating) everyone would be exceptionally sensitive and respectful of their needs. In our experience at Autscope, many autistic needs are mutually incompatible, even paradoxical. Some of us are loud, but easily overloaded by noise.

Some are lonely, but only want interaction on our own terms. Some can't stay still and quiet in presentations, but are intolerably distracted by others fidgeting or interrupting. It isn't possible to satisfy all of these at once.

In wider society, many autistic people are assumed, by virtue of their diagnosis, to be at risk of antisocial behavior. Social groups set up by neurotypicals (NTs) for autistic people sometimes require all their autistic members to sign a behavior contract before they are allowed to attend. Such contracts are seldom seen outside of activities for children, teenagers, and disabled people, and it is demeaning. Autescape decided early on that we would not have any kind of general behavior contract. Guidelines are framed in terms of challenges that we can work together to manage. Outright rules are kept to a minimum, mainly around venue house rules and limiting sensory distress to others. We don't require anyone to wear an identification badge, speak in a certain way, or refrain from acting odd or "creepy." We don't tolerate harassment, but when an issue arises, we are more likely to work on ways for both parties to understand each other and to avoid a repeat incident rather than coming down hard on the perceived transgressor. Although we try to limit the negative impact of others' behavior, autistic space is an exercise in tolerance.

Autescape has never excluded non-autistic people. Exclusivity supports the idea that such segregation is needed, that is, that the presence of people from outside our group would be somehow harmful, not "safe." Having inclusion criteria, for example, "autistics only" creates suspicion about whether those in the group are really "us" or may be "them," whether deliberately (infiltrators) or by mistake (falsely identifying as autistic). Exclusivity also lends itself to the spread of prejudice and misinformation about the excluded group, as statements about them can go unchecked, and allows those in the group to foster ideas about their superiority to the excluded one. It is inconsistent to respond to exclusion from mainstream society by practicing it. Some argue that exclusion is justified when the selected group is a disadvantaged minority, but we believe that for all the same reasons that neurodiversity is beneficial to society, it is beneficial to our group.

Herding Cats (Autistic Organizers)

Events for autistic people that are organized by NTs can be autistic-friendly, but they will never be truly autistic space. For better or worse, a great majority of Autscape organizers are autistic. One of the pleasures of working with an autistic team is that we have some communication compatibilities, such as focusing on content rather than the feelings behind it, and being swayed by a well-supported argument. Many Autscape participants don't think they are capable of being organizers, but many organizers didn't either. We have minimum standards of communication and decision-making abilities in order to be able to operate at all, but difficulties, even quite severe ones, are tolerated and accommodated as much as possible, and mistakes, even big ones, tend to be forgiven and eventually forgotten. Some who thought we couldn't work with anyone have done quite well in Autscape. For some of us, it is the only significant contribution we have been able to make to society.

As chair of Autscape, when it wasn't going well, I felt like a cat herder. Autistic organizers have a tendency to get bogged down in details, or go off on a preferred focus, neglecting the priority task at hand. Executive functioning difficulties are very common, and a few of us have severe initiation impairments as well, so we take on tasks and then aren't able to complete them on time (or at all). It is also distressingly common for committee members to fall completely silent when we are struggling. When it was going well, rather than a cat herder, I felt like an orchestra conductor, bringing out the unique features and capabilities of each member. One needs a lot of handholding, another needs an assignment and the freedom to get on with it. Some need constant reminders, others will grind to a halt in response to "nagging." I had to carefully balance demands, responsibility and support to bring out the best in each member.

In 2007, Autscape nearly ended. An interpersonal conflict escalated into a full division of the committee into two factions. It was brutal, messy, personal, and public. Those who believe that autistic people are always honest and loyal, and that groupthink, backbiting, and interpersonal politics are NT failings we are immune to, are wrong. We may not engage in these things with NTs on their terms, but in our own way, we are quite capable of all kinds of bad behavior. By the time the dust settled,

6 months after the conflict started, about half of the organizers had left Autscope permanently. They said that Autscope was fundamentally flawed and doomed to fail.

One of the keys to Autscope's long term success has probably been that it has been a democratic organization from the start. Although the conflict in 2007 led to the loss of many important and hardworking committee members, the organization did not rely wholly on any individual for its survival. That crisis was an essential turning point in Autscope's development that ultimately led to it becoming more mature and robust as an organization. The organizers who remained made some substantial changes to our ways of working that have persisted.

In order to improve transparency and avoid any future allegations of conspiracy or covert bullying, we formalized considerably, possibly excessively. Our informal methods of decision-making and on-list discussion gave way to monthly committee meetings in an online text-based chat, with agendas and minutes published on the website. Meetings have served as a good impetus for those who fail to do things without a deadline, and provide a forum to ask questions of those organizers who don't respond to email.

Our company secretary at the time, Yo Dunn, worked hard with a lawyer and a small group of volunteers to put together our new governing documents and register Autscope as a limited company and a charity. This process was finally completed in May 2011. The company registration was to limit the organizers' liability in case something went wrong. Prior to that, if Autscope had failed to happen for any reason, the individuals on the committee would have been responsible for any financial obligations to the venue. In 2015, we came up against another administrative barrier. If a charity has a turnover of more than £25,000 per year, they need to have an independent examination of the accounts. Our accounts were fine, but our documentation was not up to that, so we spent a year trying to keep our income down while we worked on getting the necessary procedures in place. This threshold has now been crossed, allowing us to choose larger and more expensive venues. It is also now possible to have more than the one event in a year, although that has yet to happen.

Autscope is *autistic-led*, but not exclusively *autistic-run*. We have, from the very start, usually had one or two people on the organizing committee

who do not identify as autistic, but we have maintained an autistic majority without having to make rules or quotas to ensure it. Such a quota would require all board members to openly identify as autistic or not. Most board members already do so, but for various reasons, some people don't, and it is not Autscape's habit to force individuals to do anything. We don't fear an NT takeover, because the whole culture is based on autistic ways of working. In fact, we have had only minimal success at retaining NT members. Our non-autistic organizers are seldom actually neurotypical—they are always family members of autistic people who tend to have other neurodivergent conditions such as ADHD, or significant autistic traits. Having some non-autistic organizers can help with sourcing some of the skills that are uncommon in autistic people. We find they are often better at communicating with NTs, so they have made good venue coordinators, form fillers, and phone call makers. Neurodiversity, which means having NTs in autistic space as much as it does autistics in NT space, is a benefit to the organization.

As organizers, we have had to learn that an autistic Utopia is impossible. We often get suggestions or complaints from participants about things we are already aware of, but due to our disabilities and limited resources, have been unable to act on. For example, it has been suggested that Autscape be longer, that we have more events, that we fundraise more, or that we publicize the event more widely. Aside from any difficulty with doing tasks, advertising may increase demand and we are struggling to keep up with interest as it is. Quite often we have been told that we ought to have web forums instead of or in addition to the email list we provide for social interaction of participants between Autscapes, but doing this properly would require more of our tech people than they have to give right now, when they have other priorities and demands on their limited capacity. One of the most common suggestions in response to our occasional shortage of resources to continually do more and better is, logically, to take on more organizers. It may be counter-intuitive, but so far our experience is that the social and communication demands of a larger team require more resources than what they free up by taking on work.

Where Next

Currently, the biggest challenge to Autscope is meeting the demand. Autscope has been steadily growing throughout its life, but the last two years have shown a sharp increase to over 200 participants. With more participants' fees contributing to the program, we can select more presentations from the increased number of proposals received, which, in turn, cater for a larger audience. The main downside of all this growth is that it excludes those who can't cope with such a large group.

One way forward is to continue allowing Autscope to grow, but a more manageable solution may be to have more events. We have taken a step in that direction by separating the governance of the Autscope organization from the planning of the Autscope event, which will allow separate groups of organizers to manage each event. Autscope could then support events of different sizes, styles, and locations. They could potentially even be in another European country. This has been predictably complicated and, also predictably, is taking more time than anyone thought it would or should. However, we are now more or less prepared for another event when an organizing team is ready to take it on.

I remember at the very first Autscope, now 14 years ago, walking through the venue filled with autistic people chatting, laughing, learning, and generally enjoying themselves, and thinking to myself, "I did this." I found it almost unbelievable, even as I saw it myself. It worked. I didn't start Autscope to be part of a movement or to be an activist. I also didn't do it to be part of a community or to meet other autistic people; I don't even like meeting new people. I do, however, like creating a little autistic space where we can be the ones who are normal, a place where autistic people can meet, learn, socialize, have a good time, and feel they are understood. I started Autscope mostly by accident, but I continued because I wanted to make something that would be a positive influence in autistic people's lives. It is.

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