

## **An Auternative at Autism Europe International Congress 2019**

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I attended the Autism Europe research conference in Nice recently on behalf of the research project An Auternative: A society for autistics - Sharon Elley, University of Leeds, Cal Watson, David Cowan, Michael Dawson, Panda Mery, Zygy Banks. Our presentation was entitled [Expertise and strategies used by autistics to overcome barriers](#). It discussed some of the strategies identified by our questionnaire to autistic people. In the past the focus has been on challenges and problems or sometimes on strategies that can be used by parents, teachers and other professionals. Very little attention has been given to the strategies that autistics can use ourselves. This makes us seem passive and dependent on others. Looking at strategies used by autistics shows that we can be autonomous and self-determined.

The response to the presentation was positive and I made various contacts as a result of it. There have also been a welcome number of Twitter messages about it, generally positive. However, like much of my life there were complications. I am not sure whether things are generally more complicated for autistic people or just for me. I had tried to change the day of the presentation and ended up have to use strategies to get round the fact I do not use electronic and electrical technologies on Shabbat (the Jewish Sabbath). I ended up giving a bilingual presentation in French and English and trying to project and amplify my voice to deal with the lack of microphone and simultaneous translation. It worked reasonably well, but like many strategies not perfectly.

I would like to thank Rebecca Wood for her assistance in changing the slides which was a great help. It was good to see her presentation the previous day on her research on the use of interests in the education of autistic children and their potential for reversing current educational inclusion. This is something I strongly agree with and am surprised that it is sometimes controversial.

My presentation was at the end of a session on Rights and Participation. The first talk by Soumia Amrani from Morocco was about the Convention of the Rights of Disabled People and the lack of access of autistic people in Morocco to education. This was followed by comments from the audience on the importance of inclusive education. I commented (in French and English) on the importance of inclusive education to allow non-disabled people to learn about autistic people and how to communicate with us.

The other two presentations by Amanda Webster from Australia and Alistair Saviour de Gaetano from Malta discussed the establishment of organisations for consulting and involving autistic people, an autism advisory council in the Maltese case. Both organisations had encountered similar problems arising from success. They were considering changing their structures and employing someone to run the organisation, as the workload was exceeding what could be done on a voluntary basis. I am also grateful to Amanda for discussing self-determination, allowing me to shorten that part of my talk.

The other strategy I used at the conference definitely did not work. This was wearing an An Auternative t-shirt to encourage people to ask questions about the project to get round the difficulties I experience with networking. However, there were too many people and too much else going on for anyone to pay attention to even the very exciting and eye-catching green on purple An Auternative t-shirt.

The conference had a large number of parallel and poster sessions. Unfortunately the chaos, noise and movement of people associated with poster sessions makes them inaccessible to me. From the sessions I was able to attend and examining the programme I got the impression that the conference still has quite a strong biomedical focus and that there may also be an increasing interest in the physiological basis of autism. There were also some more practical sessions on issues such as employment and education, as well as sessions on gender and sexuality.

There were some interesting presentations in the session following mine on adaptations for sensory issues, rather unfortunately referred to as 'sensory peculiarities'. It can be difficult for many autistic people, including me in the past, to accept our sensory differences and that we are entitled to receive adjustments and respect rather than misunderstanding and derision. Strategies will of course still be necessary. However, unfortunate terminology does not help this. Sarah Cuniffe gave an interesting presentation on consulting autistic people to determine their lighting preferences. This is one of the areas where requirements are very varied and it is not possible to make general recommendations. Choices of appropriate lighting are further complicated by the requirement to also consider the needs of other groups such as visually impaired (autistic) people.

Although interesting, some of the other presentations in the session were limited by only consulting teachers and professionals. One of the presenters noted that she regretted this, but had found out too late about ways of consulting e.g. children who do not use spoken language. I would have liked to comment on the need to recognise that it is researchers rather than autistic people who have communication limitations and that most people can be consulted. It can take more time and patience, partly for researchers to learn appropriate communication approaches and skills. However, the chaos at the end of the session made this impossible.

Accessibility for autistic people was poor. There were communication problems, leading to information not being received by several presenters. I still do not know how to access the conference abstracts or even whether this is possible. I only found out by chance about the requirement and mechanisms for uploading the presentation powerpoint in advance. My requested black and white large print documents were all in colour. The staff were helpful when approached, but having to approach them is difficult. My interest in languages makes this slightly easier to do in French. Additional sign posting (include tactile signage) and information about the venue layout in advance would have been useful. It was difficult to find the stairs above the

second floor and the staff seemed not to know where they were. As well as accessibility issues, this could have caused problems in the event of a fire. I appreciated the quiet room with its comfortable sofas, but it was unsignposted as far as I could tell and like a box without any windows. I was also rather disconcerted by people flooding in for the next session while I was still giving my presentation.

There were several autistic presenters as well as some autistic participants. I suspect, but do not know for certain, that the number of autistic presenters has increased compared to previous years, but is still a very small percentage of the total. Overall, I found the conference useful. However, it was unfortunately not an environment fit for autistics. I hope that I and other autistics with expertise in this area will be consulted about the organisation of subsequent conferences.