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Autonomy, the Critical Journal of Interdisciplinary Autism Studies

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The dominant discourse in Autism since the first appearance of the word in the psychiatric literature, has been what has subsequently been called the Medical Model [1] but in recent times there have been many challenges drawing from the field of disability studies and the emerging field of critical autism studies. This is the story of how I came to start *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* [2].

I did not discover my autism—I prefer the word discovery over diagnosis—during the lifetime of either of my parents. I had not felt any great need for an identity whilst they were still alive and put off many questions I perhaps ought to have addressed whilst they were still there to answer them.

I had been long aware that I related to the world in a very particular way, when I watched others around me as I grew up, negotiate the world with an apparent ease that was foreign to me. In my mid-twenties I took

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on the care of my mother, who was becoming increasingly dependent upon on my help. Eventually she would become completely dependent on a wheelchair for mobility. This roughly coincided with an increasing awareness of disability rights following the International Year of Disabled People in 1981, which first became a focus for our activities. We both had a passion for social justice, she being active in Women's rights and myself being a member of the Labour Party since I left University. She would make public speeches and sit on committees, whilst in addition to transporting her to meetings I would help her to prepare for them through research.

When she passed on, it was not as if the focus for that had gone, but that for the first time I was left on my own to negotiate the social world on which so much of her activity was predicated.

Diagnosis eventually came at the point of crisis, as it often does to both adults and teens. For me the crisis was a middle-aged transition with both parents gone when I first became aware of my fragile status as an adult with no family to base my identity around. It was for me every bit as traumatic as the transition from school to work is for autistic youth.

The foundations of my current advocacy had been long in the making though, something that my mother had encouraged me in when I was struggling with unemployment more than a decade and a half earlier. She thought rightly that I needed a focus in life, some kind of structure to prevent my life from falling apart, and she encouraged me to join her on a course in disability rights.

That is where my purpose started, and although she was unaware that I would later attract the label of autism she had sufficient knowledge of what I needed at that time to give me the confidence to deal with the public at large.

As a disabled person, she too had become isolated from the "mundane" world, shunned and rejected by people who were embarrassed and ignorant of how to relate to disabled people. Our social circle increasingly revolved around newly found disabled friends. These were people I felt most comfortable to be among, and who showed the most understanding of difference.

The 1980s were a time when the social model of disability was developing, and my mother had challenged me to accept myself as disabled. She

realized through her experiences with other parents, that I would by later definitions have been considered as having “special needs” when growing up. The model gave us a powerful tool to confront the inequalities and disabling mores of society by seeing the problem as not being inherently within, but caused by the political and economic systems to accept and adapt for difference. All of the seeds which led me to start *Autonomy* were there at the time. Not just the ideological tools, but some practical ones too. I was an early adopter of computer technology, which I found liberating, and I used it to the full. I used to compile databases of information. This led to my compiling information and publishing it in several editions of a directory of services provided by the City Council, National Health Service, and Department of Social Security.

Whilst the directories told people of what was available, I used those same skills to campaign for what was not, and I started a newsletter for the Coventry Council of Disabled People, an organization my mother and I helped to found in 1983. Thus I learned the skills of editing and word craft that I later put to such use as I have in academia and elsewhere.

Neurodiversity

Neurodiversity itself was not a concept I discovered until after my mother had passed on, however it was something I understood from the medium of disability studies nonetheless, in that I first read Judy Singer’s [3] article in its context as a contribution to a compilation of emerging critiques of existing disability models.

As an early adopter as it were, using computers since the mid-1980s, I finally took the plunge into the Internet in 1996 where I started my exploration into the world of ‘neurodivergent’ identity. I found others like myself on various web sites, mailing lists, and newsgroups. I expect without them I would have remained isolated and unaware but by 1997 I had a website of my own (<http://www.larry-arnold.net/>), and my first domain not long after.

My first practical steps in the world of neurodiversity outside of the Internet came when I started to organize a local meet up for dyspraxic

people under the auspices of the late Mary Colley and the adult group of the Dyspraxia Foundation which I had been encouraged to join.

It was a world of autistics and cousins, a terminology I discovered on joining Jim Sinclair's ANI-L (the mailing list for supporters of Autistic Network International, the organization that Jim had founded with Donna Williams and Kathy Xenia Grant). There were many of us who had multiple labels of dyspraxia, Tourette's syndrome, dyslexia, epilepsy, Asperger's syndrome and autism so "Neurodiversity" seemed to be a convenient banner to unite under, and I founded the Coventry and Warwickshire Neurodiversity Group, what may well be one of the first organizations to rally under the name of neurodiversity. We were a breakaway from a group of students run along the lines of a support group but by a psychologist with a failure to understand the need for personal "autonomy."

I was finding for myself a new role where I could continue the advocacy I had begun with my mother, in support of a community I increasingly felt a sense of being at home among. I took it up with a passion and zeal and Jim Sinclair's writings had a profound effect. They were, as I described them recently, foundational documents, our Declaration of Independence as it were. I did not want to see them lost to posterity because of the ephemeral nature of the World Wide Web.

In 2003 Mary Colley formed a national group under the Neurodiversity heading called the Developmental Adult Neuro-Diversity Association or DANDA for short [4]. This was another important first for neurodivergent-led and—controlled organizations. Although I had differences with Mary over the redefinition of Neurodiversity as purely "developmental" I was one of several people involved with DANDA who went on later to challenge the National Autistic Society (NAS) from the perspective of the well-used disability rights motto "nothing about us without us."

My claim to fame was in breaking the glass ceiling of that society in becoming the first diagnosed autistic person to serve on the board in 2003. Not I humbly add, the first autistic person to serve on the board of an autism charity—both Thomas McKean and Stephen Shore served on boards in the USA—but the first to make a major impact on the direction of the largest autism charity in the UK. For all that autistic people still

have their concerns about the NAS, I believe it is vastly different from what it might have been had I not made my presence felt.

It was around the time that I had become involved in the NAS that I started to go to conferences. I will call them “conferences about autism” rather than “autistic conferences” because the autistic input if it was there at all, was minimal and confined to what Jim Sinclair has called the “self-narrating zoo exhibit” phenomenon, where the only role open is tokenistic, and the only justification in the organizer’s eyes is to talk to the non-autistic audience about how awful it is to be autistic.

I also began to hear the so-called experts on autism speak, and to ask myself “Are they talking about us?” because it did not sound like they were describing the people I had come to know increasingly as autistic in our world. I would suppose a key moment was when I heard somebody ask autism laureate Uta Frith, if she knew whether the sensory sensitivities observed among autistic children persisted through adulthood. She answered that she did not know, “Perhaps they grow out of them” she said. At which point, I, a strapping autistic “youth” of some 46 summers could contain myself no longer. “Not for me they didn’t” I called out, not the last interjection of mine to that conference either.

At this point I need to take a couple of steps back to look at those other parts of the roadway that were leading me toward the establishment of *Autonomy*.

Academia

In 2002 I discovered that the University of Birmingham was pioneering an Internet-based degree course for professionals involved with, and parents of, autistic children. I thought “Why should it not be open for autistic people too?” In the same spirit in which I set about to challenge the NAS from within, I set about to change the course from within the University. I became the first of one of a select few autistic people, along with Claire Sainsbury, David Andrews, and Heta Pukki, to graduate from Birmingham and in so doing we opened the doors for many others to follow. It wasn’t easy being among the first; it never has been.

That being said, it was with growing confidence when I moved from taught master's level studies to Ph.D. research of my own. I had found my niche, and more doors opened for me to engage with academics far and wide on a level playing field as a bona fide researcher, not just a conference attendee with a list of awkward questions.

I had in addition to my autism qualifications, a vocational Higher National Diploma in Media Studies, Moving Image, which I had been studying at the same time as the Web autism course. This was quite a feat as I was studying Psychology at a third college in the evenings as well. Toward the end of media course, I produced a commercially available video with one of the staff there who was also studying media himself. I followed it up afterward with a second DVD, with the same collaborator. The first video was all too much "self-narrating exhibit", but the second one was based on a presentation I had made at the first ever Autscope conference in 2005. This time the video was addressing important questions about the representation of autism, and questioning the diagnostic categories of autism and Asperger's syndrome as they then existed in DSM-IV-TR psychiatric manual [5]. It was perhaps another attempt to talk back to the non-autistic people who were defining us and it was very appropriate material for the first conference/retreat organised in the UK by autistic people, for autistic people. Autscope took its cue from Autism Network International's Autreat conferences which Jim Sinclair had organized in the USA. I have since seen the video described in an academic thesis as "an important autoethnography in this field" [6].

So everything was beginning to come together. I had experiences as a publisher and as an editor since the mid-1980s (service directories and newsletter), and also as an academic presenter and lecturer since 2005. I had become in every sense an academic and engaged beyond pure advocacy into the realms of academic matters which defined the very way in which professionals and clinicians talked about us. I still had a deep and prevailing sense of dissatisfaction with the whole manner in which academia referred to us and continued to consider it as a form of exclusion in which it was still largely a discourse about us without us.

I had answered back with my video, and with my conference presentations but it was increasingly clear that the two worlds which CP Snow had described in the 1950s where humanities did not understand science, and

science had no grasp of the humanities was still the paradigm for today. On the one hand, I was familiar and had engaged with the medical/psychiatric researchers, and on the other with the worlds of sociology and disability studies and I began to wonder whether we were really getting that much respect from either. It was also a question of ethics, not conventional ethics as in getting your proposal past the ethics committee but more teleological in the sense of whom did the research serve.

So summing up, the factors leading me toward “Autonomy” were: a foundation in disability rights and mental health advocacy from a social model perspective; experience of editing and publishing; and experience of academia as a student, as a researcher, and as a presenter. What else did I need other than the will to start it?

The Journal

Eventually, whilst still completing my Ph.D., I thought I might as well go for it and start a journal of my own. I had managed already to capture the essence of video production and publication, and I knew I had the capacity to learn whatever I needed to realize what I wanted to do. I wanted it to be something more than merely another version of the many websites and blogs already on the Internet; I wanted something that looked and behaved like the established journals which academics are used to reading and contributing to. I looked around and found that open publishing was the way to go, and determined that the Open Journal Systems platform which had been developed for this purpose by the “Public Knowledge Project” [7] was the best one for me to use, being as it was free to download and had the right tools to create a professional-looking journal that could sit easily among the existing online journal formats.

I determined from the start that it should largely be a peer-reviewed journal, in order to give it the same academic status as journals such as the *Journal of Autism and Developmental Disorders*, and *Good Autism Practice*. However, I also allowed scope to include articles that had never been published or written in an academic context but which could still be considered, as I said before, as “foundation documents” of our autistic movement and community.

The choice of name, *Autonomy*, suggested itself because not only does it encapsulate what the thrust of my thinking had been, agency and autonomy for autistic people, it contains the same “Aut” root of Autism, which has been used before for organizations and events such as Autreat, Autscape, and Autreach. Of its subtitle (*the Critical Journal of Interdisciplinary Autism Studies*), “Critical” was to embody a questioning and examining of the prevailing paradigms of autism research. “Interdisciplinary” indicated that it wished to include contributions from a variety of academic fields.

I endeavored from the beginning to get some support from established and respected Autistic academics such as Stephen Shore and Temple Grandin, who both agreed to lend their approval to the journal. Closer to home, I sought help and general advice in my editorial decisions from Dinah Murray and Damian Milton, both of whom were associated with the University of Birmingham at the time.

At first I was wary of pushing the Birmingham connection. I had incorporated the University as part of the masthead design for the journal and when the head of the college of social sciences asked to have a private word with me, I was worried that I had committed another academic faux pas. Fortunately it turned out that he wished me to introduce the journal at a plenary session of the forthcoming education graduate conference. I was even presented with an award for my contribution to the research community on the basis of my efforts to set it up.

The Ethos of “Autonomy”

In the words of the rubric: “The emphasis will be on encouraging contributions from autistic scholars who have hitherto had limited exposure to academic publishing. We will feature papers reviewed by respected academics in the appropriate fields, reviews and also feature an opinions section which it is hoped will stimulate a lively interdisciplinary debate. ‘Autonomy’ will appeal to the widest range of the current autism research community and foster cross disciplinary discourse between the fields of medical research, education and sociology amongst others.”

This means in practical terms it encourages, but does not limit itself to autistic contributors alone, as it is important to foster debate and be inclusive. Contributors do not have to declare that they are autistic as there are a number of academics, who for a variety of reasons would find full disclosure difficult in their working environments.

However one early aim of the journal was to highlight and republish pieces that were not written from an academic perspective, but an autistic one. These articles were perhaps familiar to the autistic community but in danger of becoming lost, forgotten or difficult to find as the Internet grows and changes. They were written by people who have had important and pertinent things to say about the autistic community and who have certainly been influential in the development of autistic advocacy, Jim Sinclair's "Why I Dislike 'Person First' Language" [8] and "Don't Mourn for Us" [9] being two examples. I sought to bring these within and alongside the academic canon on the basis of merit, by giving them publication in an academic journal.

"Autonomy" is not without controversy however. Other academics since the debut of *Autonomy* have staked claims to Critical Autism Studies, and some of these have been antagonistic to the original claim, in that they are predominantly non-autistic-led discourses. In the interests of dialogue, it follows that not every article in *Autonomy* will have been written by an openly autistic author. There is room for allies, and for those who are uncomfortable with sharing their status in the public domain for fear of professional repercussions. The main focus however, is on respect toward the autistic community of scholars and the intellectual ownership of ideas that originated within Autistic communities.

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