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From Exclusion to Acceptance: Independent Living on the Autistic Spectrum

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In 1985, as an oblivious and undiagnosed autistic 11-year-old with no idea who I really was or what my life was for, I was introduced to the amazing and captivating world of programmable home computers, who always mean what they say and say what they mean, and expect nothing less of you. Thus I acquired my most central and enduring identity, that of a computer programmer. It was then that my real social life began.

Though I live in the Netherlands, I lived most of that real social life in plain text, worldwide, in English, over a metered telephone line and a modem, at a nice and safe distance from my daily worries. The Internet was still far from accessible to mere mortals, so I used dial-up hobby computer systems called BBSs, bulletin board systems. These BBSs "echoed" personal and group email to each other by exchanging it nightly over the phone during cheap hours, thus forming a slow-lane network called Fidonet.

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Eventually, I became the moderator of two worldwide Fidonet echomail conferences.

While this did gave me a sense of accomplishment, I was living what others call 'real life' without a diagnosis or a clue. As I was growing into a young adult, I deteriorated. Along with depression, I developed what I now know to be catatonia-like difficulties with self-direction, such as taking any sort of initiative [1]. The depression went away later, but that mysterious and near-total inability to "just do it!" never has.

In 1995, as my education and my offline life had fallen apart completely, the Internet became accessible to the common people. On it, my mother and I discovered Asperger's syndrome. Less than a year later, I had a diagnosis of 299.00 Autistic Disorder by DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, [2]) criteria.

With nothing left to lose but my family's love and support, and on a self-discovery high, I went out into the new world of the 'Net. At the time, it was nearly as textual as BBSs, but I was enthralled to find that worldwide communication was instant instead of taking days. I found a few mailing lists (email-based discussion groups) dominated by parents of autistic children and professionals, plus one managed by autistic people: ANI-L, the list run by Autism Network International (ANI), founded in 1994 and hosted by Syracuse University since 1996 [3].

By the time I entered the scene, ANI had developed a vibrant and specific autistic subculture, with verbal stims (in plain text) and various in-jokes involving fipples, llamas, and the like. It was quite wonderful to see this working so well for those who fit in. Here were, after all, people proving for the first time that autistic community is possible! But their ways were not every autistic person's cup of tea, and their community did not seem all that welcoming to those with dissenting opinions. The need for an alternative was somewhat apparent.

But in this pre-social media era, with the World Wide Web still a toddler, starting a group of any description on the Internet was non-trivial at best. No services existed that let you do this at the click of a button. It required the use of server software that usually was very expensive and always needed to be managed by an expert. Nor did I have connections to a university or corporation that could host it for me. So, although there was just the one autistic community, the idea of starting my own didn't occur to me.

Then I was contacted, in early 1996, by the American father of an autistic son, who was advocating for another American autistic man who I shall refer to as X. With a decades-long history of trauma, X had serious behavior problems. In part, this was a conscious decision: he was fed up with being mistreated, so, in his words, "no more Mr. Nice Guy". But it was also clearly the effect of a long history of institutionalization.

So he found himself banned from the few autism communities that existed on- and offline, including the only autistic-run one. But some people went much further: they actively spread the image of him as a direct threat, seriously and physically dangerous, apparently to ensure he would never get another chance elsewhere.

To me it was obvious that traumatized autistic people frequently have problems with bad behavior. Surely, effective advocacy would require at least making an effort to include the really difficult ones, too? It physically hurt to see some of my fellow autistic people not only eject, but also go out of their way to further damage someone who was already broken. My reaction, evoked in part by my own traumatic memories of schoolyard violence, peer rejection, and paternal authoritarianism, was visceral. I felt and understood this man's anger and desperation. Empathy! Much as I disapproved of X's methods, this reaction to them seemed so much more harmful that, despite my usual inertia, I found myself spurred into action.

Starting an Internet group seemed impossible without connections to a large organization, so I suggested that X try starting a BBS of his own, of the old-fashioned dial-up variety. He had some relevant experience and I figured that it might help him to bear the responsibility himself, to achieve something that was his own. Aiming it at people who had been "shunned, hated or misunderstood" due to being autistic or otherwise different, he set up forums on various relevant topics, with a definite activist bend. It was not networked, so I dialed in to the USA to participate at considerable expense. The BBS never had more than five users, and after a month or so, even they stopped coming. Whatever else may have contributed to the lack of interest, it was clear that with the Internet growing explosively, BBSs were on their way out.

Then, serendipity intervened. A new kind of Internet provider opened in the Netherlands, a subsidiary of a UK provider oddly named Demon Internet, after the English expression "to work like a demon" with a nod

to "daemons" as in server software on Unix and similar operating systems. They were special in not only technically enabling, but actively encouraging their users to run server software—to become a full-fledged host on the 'Net alongside giants like Syracuse University. Freeware mailing list server software called Macjordomo had also become available. Power to the people! The puzzle pieces fell into place.

I offered X the position of co-moderator, but at this point he had lost interest in taking an active role. So he took a back seat as I started it as my group. As was customary, the BBS had been divided into various topic-based forums; I decided to keep that aspect by creating several mailing lists dedicated to similar topics. I began to operate these mailing lists together as a set, so members could choose their topics of interest in which to participate.

Thus, the first entirely self-run and self-hosted autistic community on the Internet was born in July 1996, called Independent Living (InLv), with the Internet hostname of inlv.demon.nl (later changed to inlv.org). From then on, until cable internet became available in 2000, I had a routine of actively distributing group mail over the Internet through my dial-up line in batches, a few times a day. The communication was slower than ANI-L, but still much faster than Fidonet.

The group grew quickly. While some members were non-autistic friends and sympathizers, often with other neurological conditions, most of us were autistic—some recently diagnosed as adults, others seeking and receiving diagnoses as a result of their membership, still others content with having self-identified. In finding each other, we found ourselves. The collective process of self-rediscovery as autistic people that we went through as members was so intense, I stopped engaging in computer programming altogether for a number of years. I made friends, and more friends through friends, in various countries. Thus, after that of a computer programmer, I acquired my second-most central and enduring identity: that of an autistic person. It was then that I felt truly accepted in a community for the first time.

The text-only email nature of our community, far from being limiting or disabling, was found to be an advantage. We were able to skip all the social rituals and awkwardness and cut right to the chase, undistracted by body language, timing, sensory or eye contact issues, or any of the other

autism-related difficulties with socializing. In the words of one member, the Internet was where "people can see the real me, not just how I interact superficially with other people" [4]. This helped us support each other more effectively. Email seemed like a natural communication medium for us autistics, like sign language is for deaf people [5].

The notion that we lack empathy was quickly deconstructed as it became clear that neurologically typical (NT) people had considerably less empathy with us than we had with them. A lot of lifelong pain was shared and empathized with. As part of processing those experiences, we started developing our own theories of neurotypicality—of why these strange people, who form the majority, do what they do. We had a bit of fun with it; tongue-in-cheek terms like "neurotypical syndrome" and "social dependency disorder" were thrown around. Some of us also felt inspired to explain ourselves to the neurotypical population using our newly found collective insight [6]. As we were so used to being misunderstood, patronized, and pathologized, it was a relief to have the shoe on the other foot.

But we also started finding things in common with each other, things that were not part of the diagnostic criteria for autism. For instance, many of us had trouble recognizing faces to various degrees, relying on other features such as voice, gait, and hair and clothing style to recognize a person. One InLv member, Bill Choisser (1947–2016), found an obscure medical term for this condition: prosopagnosia. It was thought to be very rare, but the group's experience clearly suggested otherwise. Bill popularized an easier to use term for it: face blindness. Based in large part on InLv discussions, he wrote the first book about the condition, which he published online [7]. The book gained traction and spread knowledge on the condition, and the term is now widely used.

Meanwhile, as people in and (mostly) out of the Netherlands began to take note of my activities, I began to be invited to autism conferences as a speaker. I would warn the InLv members of the impending silence when I was about to travel, then upon arrival I would find places to plug my laptop into a phone line and distribute the backlogged mail.

The feeling, at once grave and uplifting, of having an entire worldwide human community inside your laptop computer, depending on your own continued action to survive, is hard to describe. Wherever I went, they went with me. As I boarded airplanes, the announcement "in the event

of an emergency, you must leave all hand luggage behind" acquired an existential level of fearsomeness.

In July 1997, when InLv was a year old, I met X in person in Minneapolis, Minnesota, USA as the two of us were invited to speak on the new phenomenon of online autistic community and activism at a conference organized by the Society for Disability Studies. In person, he seemed much more timid than intimidating. The conference speech was a success for both of us.

But on InLv, though X continued to prefer his back seat, he was growing increasingly frustrated with the members' self-discovery and mutual support, which he had begun to see as spineless psychologizing. He wanted action. The rest of us were not ready for action. He also became increasingly jealous as I gravitated toward some level of prominence in certain autistic circles. It's understandable: where he had failed, I was succeeding.

Nevertheless, his behavior deteriorated to the point where it became both detrimental to the group and personal to me. Mere weeks after our conference speech in Minneapolis, I had to remove him. He and I both know the exact reasons, and that is enough. I have avoided contact since, but I wish him well. The group had succeeded in including him for a full year. In the process I had learned some hard lessons about both the possibilities and the limits of inclusion, which proved invaluable in later years.

InLv continued without him just as the discussions had begun to gravitate from the purely personal to the more political. A new idea came up in the group, based on the evidence and lived experience that autistic brains are wired differently from the mainstream on a fundamental level. Biological diversity of all kinds is essential to the survival of an ecosystem—so why should neurological diversity, which is one aspect of biological diversity, be any different? The objective fact that neurological diversity exists emerged as a strong argument for the acceptance of autistics and other neurological minorities as distinct classes of people among many, who have something valuable of their own to contribute, and who are as inherently worthy of equal rights as anyone.

In 1998, Judy Singer from Australia, who identified as having "AS [Asperger's Syndrome] traits", turned these InLv discussions into an influential sociological thesis [8] and book chapter [9], citing plenty of group

members with their permission, and adding the requisite academic language to lend it legitimacy. Thus, she is correctly credited with coining the term 'neurodiversity' [10]. However, it may be argued that the American journalist Harvey Blume, who was also an InLv member and whom Singer cites as a frequent discussion partner, first popularized the term [11]. What is certain to me is that InLv, due to the ethos of acceptance, inclusivity, and rejection of social and political conformism that I imparted on it, was able to provide the environment in which the idea could emerge.

It is important to note that InLv's notion of neurodiversity was different from the "neurodiversity paradigm" that many contemporary activists subscribe to. These days it is often held that there is no such thing as a brain that is "less" or "broken" because "all neurologies are valid" [12]. By contrast, neurodiversity as an aspect of biodiversity includes and accepts people with suboptimal neurological configurations. While autistic people who would have preferred to be "cured" if possible were a minority in the InLv community, we never excluded or denounced them.

Meanwhile, the InLv community was joined by the #asperger IRC (Internet Relay Chat) channel for which I took over management in 1998. It had been started in 1997 by a German man nicknamed Nox, who had a diagnosis of schizoid personality disorder. He created the channel to be only for people on the autistic spectrum and related conditions. I disagreed with the exclusion of neurotypical guests and still do, but I did not feel like I could change this after the channel had become established as what it was. In any case it provided a way for autistic people, including many InLv members, to have text-based conversations that are much more direct than email.

Soon, the combination of these two communities started carrying over into the physical world. Many "real-world" relationships resulted, and I would estimate that at least a dozen children were born because of them, including my own three. Amazingly, the #asperger channel survives to this day, though people who join need to be patient as activity is intermittent.

Around the turn of the century, my own catatonia-like inertia problems started affecting my ability to manage the group effectively. As my initial burst of initiative petered out, it became harder and harder for me to manage email requests in a timely manner, and new members had to remind me multiple times and wait months before being added. Some

never received a response, and thinking of that fills me with guilt to this day. Thankfully, as easy-to-use mailing list and forum hosting services became available on the web, other autistic-run communities started popping up. In spite of all this, InLv continued until early 2013. Sixteen years is a good run for any online community.

Probably the most significant real-life outgrowth of InLv and related communities is the yearly Autscape residential conference (see Buckle, Chapter 8), founded after a 2004 InLv discussion on the idea of creating a European equivalent of Autreat. As one of the Autscape organization's directors, it makes me happy to see InLv's spirit of inclusion and acceptance continue there.

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