ON OUR OWN TERMS: Emerging autistic culture

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Foreword and disclaimer

This paper is about how many high functioning autistic people are trying to make their own dreams a reality today.

I am an adult with a diagnosis of high-functioning autism. I have now been active in the autism self-advocacy movement for about four years, gradually growing in this world. I sometimes write papers like this one or give lectures, and I am happy to provide my inside experiences and insights for those who find them useful. I also run an Internet-based support group for people like myself, namely those on the autistic spectrum, and it makes me extremely happy to realise that the group helps people and enables to people who help themselves. It is also the best self-help I could have wished for; the contact and friendship I have with my autistic peers is immensely valuable to me.

It appears that providing such and similar things causes many people to respect and appreciate me in a certain way. Parents look to me for advice about their autistic children and I am happy to help if I can. But sometimes, parents expect instant expertise from me because I am supposed to know everything about autism — after all, I live it. But the most I can offer is the personal experience and insight of just one person — me — completed with what I've heard from the many others I've met. That does not make me an authoritative expert on autism (as if anyone really is, with everything that still needs to be researched). I do not provide definitive answers; at best I provide leads so that you can find the answers yourself. This paper should be read in that light.

The paper starts off with a history of the autism self-advocacy movement including pioneer organisations such as Autism Network International (ANI) as well as an overview of autism self-advocacy initiatives currently being set forth around the world. There exist parallels between these initiatives and the larger Disability Pride (e.g. deaf community) and Psychiatric Survivors movements. The autistic community stands with one leg in each of these two movements and is not succeeding in taking much advantage of either. As a result, autistic culture today is largely where deaf culture was a century ago.

The Internet is for many high functioning autistics what sign language is for the deaf. I will describe my Internet support group (Independent Living on the Autistic Spectrum) and will list some key insights this group's members have brought forth over the years, as an illustration of the effectiveness of the Internet as a communication tool for autistic people.

Then, from my experience both in having a relationship with another autism-spectrum person and in having extensive contacts in the autistic community, I will theorise about both similarities and fundamental differences between autistic interaction and "neuro-typical" interaction.

The paper concludes with a vision of the future - what an Autistic Utopia might look like, which will never be achieved but provides clues as to which direction to work towards.

A word about the term "autism". The autism spectrum covers a wide range of diagnoses and a wide variety of individual makeups. The word "autism" is often reserved for the most severe forms of handicaps within the spectrum, whereas so-called milder forms are designated with the terms Asperger's syndrome or PDD-NOS. In my opinion, the terminology and the distinctions between the different terms are arbitrary. It is also cumbersome to have to distinguish between all the categories in a paper like this one. Therefore, in this paper, the word "autism" means the entire autism spectrum, and people who are "autistic" might as well have a diagnosis of Asperger's or PDD-NOS.

This author also does not subscribe to the concept of person-first language as it pertains to autistic people, because most autistic adults report that the condition affects their entire

being, and therefore they would be someone completely different if they were not autistic. Autism is not an appendage, but an inseparable part of a person's makeup.[1]

A note about the author's first name: it is indeed spelt Martijn. This Dutch male first name rhymes with "fine" and "sign".

1. Introduction: Establishing autistic culture through self-advocacy

1.1. Culture requires self-advocacy

As will be shown later in this paper, a culture and community for people on the autistic spectrum is still in the process of being established, currently lagging way behind other disability cultures. The movement did not really get off the ground until the Internet became widely available, as the Internet is essential in the facilitation of communication between adults on the autistic spectrum.[2]

Culture requires community. And for the establishment of a community it is essential that the needs of those within the community be recognised, respected, and that it's being worked on that these needs are met. In other words, advocacy and especially self-advocacy are an essential factor in the establishment of autistic culture.

Self-advocacy is a very new and abstract thing to many people on the autistic spectrum and I have found that many people have problems understanding what it means.[3] So it seems useful to give a more exact definition of the concepts of advocacy and self-advocacy, that allows the reader to see what these words mean, and how the two concepts are different from each other. What's below is my definition; others might define it slightly differently.

1.2. Defining advocacy and self-advocacy

Advocacy:
> *to find and implement methods*
> *to help people in a certain population*
> *lead happy and productive lives*
> *that meet <u>their own</u> needs (allows for **self-determination**)*
> *and, as much as possible (but no more), meet society's requirements.*

Self-advocacy:
> *to find and implement methods*
> *to help <u>yourself</u> and others in <u>your own</u> population*
> *lead happy and productive lives*
> *that meet <u>your own and each other's</u> needs (allows for **self-determination**)*
> *and, as much as possible (but no more), meet society's requirements.*

1.3. Self-determination

It is worth noting that self-determination is an essential part of both advocacy and self-advocacy; if a person is not allowed to have real input in the way he is treated

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[1] Sinclair, Jim (1992): Don't Mourn For Us. `http://www.ani.ac/dont_mourn.html`

[2] Blume, Harvey (1997): Autistics are communicating in cyberspace. New York Times, June 30, 1997. `http://www.nytimes.com/library/cyber/techcol/063097techcol.html` (may require free registration with the New York Times site to access).

[3] Kennedy, Michael et al (undated): Thoughts about self-advocacy. Center on Human Policy (CHP) et al. `http://soeweb.syr.edu/thechp/thoughts.htm`

or helped, then the help will not be effective. For more about this I refer to an excellent *Summary of Self-determination* available on the Web.[4]

2. History of the autism self-advocacy movement

2.1. Early history

The history of the autism self-advocacy movement starts with the recognition, by parents and professionals, of autistic adults who are able to communicate what autism is like for them from the inside. They practice self-advocacy by publishing autobiographical books in which they give their personal view of what it's like to be autistic. Some of them become best-selling authors.

> *Temple Grandin is probably the most famous example of this, as she is not only autistic but has a respectable position in society as a successful animal scientist at the university of Colorado. Other well-known autistic authors publishing in English include Donna Williams, Tomas McKean, Gunilla Gerland, and Liane Holliday Willey.*

These early autistic self-advocates work primarily within the professional medical establishment and parent societies. Their prime audience is parents with autistic children. Autistic adults still have little or no structural contact with each other.

In this early stage, autistic adults who are able to communicate and function on a 'high' level are still thought to be a rare exception. So it's understandable that parents who are desperate to find ways for their children to improve cling with a vengeance to what little insight 'from the inside' is available.

> *One the one hand this caused parents to take the word and personal experiences, however valuable, of the few 'established' HFA self-advocates as universal truth. This happens often even today; for example, many parents think today that all autistics think in pictures and cannot think in words, because this is Temple Grandin's personal experience.[5] But whenever many autistic adults come together, it is found that individual experiences and coping strategies of autistic adults vary widely in almost all aspects of life. While many autistics do think in pictures, others don't do this at all.*
>
> *On the other hand, high-functioning autistic adults who are not 'famous' are not recognised and diagnosed, and their experiences and opinions are not heard, or are often ignored if they are not consistent with the established views. Especially autistic adults who have not managed to be successful are shunned by parent societies, in spite of the fact that one could also learn from their difficulties and the way they manage (or fail) to cope with them.*

This limited supply of personal autistic experience causes parents to get an incomplete picture of what it's like to be autistic; incomplete, because it is too specific and too personal to provide a picture that's representative to the whole diverse population. Parents could also get expectations of their autistic child that are either unrealistic ("my child can become just like Temple Grandin!") or too pessimistic ("Temple Grandin and my child are not comparable, therefore my child will never be able to improve").

2.2. The rise of the Internet and pioneer self-advocacy organisations

In the early 1990s, Internet is becoming available to the general public and starts revolutionising many aspects of society. One of the biggest strengths of the Internet is to unite small groups of people that are thinly spread all over the world; after all, on the Internet, distance does not matter. No other medium previously offered this kind of empowerment.

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[4] Kennedy, Michael et al (undated): Fact Sheet: Summary of Self-Determination. Center on Human Policy (CHP) et al. `http://soeweb.syr.edu/thechp/SELF_DETERMINATION.html`

[5] Grandin, Temple et al (1996): Thinking in Pictures: And Other Reports from My Life with Autism. Vintage Books. ISBN: 0679772898.

> *On the other hand, people who are not fluent in the English language are at a disadvantage, because the vast majority of published material and online meeting groups are in English. But as the year 2000 is approaching, this is improving.*

Parents of autistic children are among the first to profit from their new Internet connections when Ray Kopp, father of an autistic child, and Dr. Zenhausern at St. John's University found the *SJU Autism and Developmental Disabilities List* (AUTISM list) in 1991.[6]

> *A mailing list, the oldest group communication feature of the Internet, is a direct extension of regular e-mail. Hosted by a central listserver somewhere on the Net, it functions as a big virtual meeting room, as all mail sent to the list is forwarded to the e-mail in-boxes of the members, and all responses to list mail are usually redirected back to the list.*
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> *Common subjects discussed on the St. John's AUTISM list range from potty training through fights with the school district to speculation about a cure. Parents who would normally never have met each other find strength in numbers as they find they are no longer alone. The exchange of information and mutual support (as well as regularly recurring flamewars) is unprecedented in its effectiveness and speed.*
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> *The Internet parent collective closely monitors the latest research development, along with the odd researcher or two who also joined in. Unwilling to wait for official approval, they start experimenting. The rise of Applied Behavioural Analysis (ABA) as an intensive method to train autistic children to function within the framework of 'normal' children can be credited largely to online parent groups such as the AUTISM list and its spin-offs. In 1998, the same online groups are instrumental in the discovery and spread of Secretin for treatment of autism, a hormone that is thought to drastically improve the functioning of autistic children with metabolic problems.*

But adults on the autistic spectrum find themselves unheard and misunderstood by the parents who are mostly concerned with looking for ways to make their autistic children "indistinguishable from their peers", if not curing them altogether. Many parents are so preoccupied with finding a cure that they do not think about what things will be like when their autistic children become autistic adults.

Disappointed by the lack of acceptance of the autistic way of being on the AUTISM list, Jim Sinclair and Donna Williams found Autism Network International (ANI) in 1992. ANI is a self-advocacy organisation run by autistic people, for autistic people. It is the first of its kind.

> *One of ANI's services is ANI-L, a virtual community that is 'autistic space'. ANI-L serves the same support and information function for autistic adults as the St. John's AUTISM list does for parents. Even though non-autistic people interested in this concept are also welcomed, the autistic way of being is central to ANI and ANI-L and it is not allowed to disrespect this by insisting that a cure for autism must be found. Instead, the positive aspects of being autistic should be exploited, as well as the negatives addressed.*
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> *ANI also organises Autreat every year, a yearly 3-day conference camp in the US state of New York that replicates the autistic space in 3D life with workshops about specific topics and the opportunity for social get-togethers.*
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> *To avoid having to use the term "normal" to describe people who are not autistic, people at ANI have invented a new term for people without neurological conditions such as autism: NT, which means "neurologically typical". This term has found widespread use in the entire online autism community, including even parents of autistic children. The opposite term is AC, meaning "autistics and cousins", or people with autism and related conditions. This terminology is analogous to similar words in other disability communities, and can in fact help shape a community.*

2.3. Current state of affairs

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[6] http://maelstrom.stjohns.edu/archives/autism.html

Many more online communities have since sprung up that target various audiences within the autism community. An overview is available at <http://www.isn.net/~jypsy/mailist.htm>. One of these communities is Independent Living on the Autistic Spectrum, run by the author of this paper; more about this further on.

There are also autism self-advocacy movements that do not have a strong on-line focus. These include Autism National Committee[7] which is an American organisation that seeks to define and protect human rights for autistic people, and Patrick Frey's activities, based in Switzerland, to make a world-wide society for autistic people.

As with all movements that are in its infancy, the autism self-advocacy movement suffers from lack of unity. Diversity is a good thing, but there are not yet many attempts to avoid duplicate efforts and collaborate in furthering common goals among the various organisations. The autism self-advocacy movement does not seem different from other movements this way; historically, young movements have been vulnerable to political rifts and it has taken time for unity to grow.

3. Parallels of the autistic community with other self-advocacy movements

3.1. Disability Pride movement

People with physical disabilities have been practising self-advocacy for a very long time and have developed lively disability cultures that have left many marks on modern Western society. One only needs to point to close-captioning on TV, traffic lights at pedestrian crossings that also make sounds, and wheelchair-accessible buildings to show how much can be achieved when a disability movement organises and persistently advocates for its members. To illustrate how the autism self-advocacy movement can learn from these achievements, here are parallels with deafness, blindness and other physical disabilities.

The parallel between deaf people and autistic people lies mainly herein that both populations have a communication style that is different from the norm. Deaf people often use sign language to communicate, which has nowadays been almost universally accepted to be every bit as functional and diverse as spoken language. The differences in communication style in autistic people are much more subtle than in deaf people, and often very hard to detect for an outsider. Yet, such differences clearly exist, as autistic people often report that they have very few problems communicating with and understanding people 'of their own kind'. One could thus speak of a culture: communication problems arise when the cultural border is crossed. With deaf people, this cultural border is much more clearly visible than with autistic people.

A parallel between blind people and autistic people could lie herein that both groups of people tend to compensate for abilities they don't have by accelerating the development of other abilities. Blind people tend to have an acute sense of hearing; unlike seeing people, they have to use their hearing to orient themselves in their environment, which puts entirely different demands on the hearing system. This combination of decreased or absent abilities with other heightened abilities is often called *uneven development*. Uneven development is a hallmark characteristic of autism spectrum disorders; the most well-known example of this is the savant skills of Rain Man, combined with his lack of 'common sense'. Savant skills occur only in a small percentage of autistic people, but it is evident that uneven development occurs even in autistic people without savant skills, as their *verbal IQ* tends to differ significantly from their *performance IQ*.[8] Autistic people also often report a

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[7] `http://autcom.org/`

[8] Ozbayrak, Kaan R. (undated): Differential diagnosis of Asperger's Disorder, in `http://www.aspergers.com/`

heightened ability to think in pictures, or to do logical reasoning, as a way of compensating for their lack of 'instinctive' understanding of the world.

ADAPT (American Disabled for Attendant Programs Today)[9] is a grassroots disability rights group with an activist focus. Among other things, they fight for disabled people living in the community and not in institutions. They are fierce defenders of the Americans with Disabilities Act (ADA) and are prepared to organise demonstrations for that. Their membership appears to be mainly comprised of physically disabled people, such as wheelchair users. The autistic self-advocacy movement has a lot to learn from how groups such as ADAPT bring about real change in society. Hopefully, as public awareness of high-functioning autistic adults keeps growing, organisations such as ADAPT will become aware of our existence and resources can be shared.

3.2. Psychiatric survivors movement

Even though autism spectrum 'disorders' are neurological disabilities and not mental illnesses, it is usually a psychiatrist that performs the diagnosis. The diagnoses within the autism spectrum are listed in the DSM-IV, the psychiatrist's diagnostic manual. Diagnosis is performed using behavioural criteria. Essentially, autism is currently diagnosed as if it were a mental illness, even though it isn't one.

Nevertheless, people with autism often experience additional problems that *are* of a psychiatric nature, such as depression, anxiety and stress disorders, in part because of neurological imbalance and in part because of the misunderstanding and hostility society at large still exhibits towards autistic people.

From a self-advocacy viewpoint, this connects autistic people with the movement of 'psychiatric survivors'. This is what those people call themselves who have experienced abuse at the hands of psychiatrists, including accidental or intentional misdiagnosis, involuntary hospitalisation, involuntary treatment with inaccurate medication (sometimes causing horrible side effects up to and including death), inappropriate restraint and isolation, etcetera. World-wide, psychiatric survivors unite in Support Coalition International[10], a grassroots organisation fighting for the abolishment of involuntary, forced treatment (whether in-patient or out-patient), improvement of conditions in psychiatric hospitals, and respect for individual differences even if they are widely met with misunderstanding.

3.3. Position of autistic community

As shown above, it is like the community of autistic people stands with one leg in the Disability Pride movement, and with the other leg in the Psychiatric Survivors movement. It doesn't totally belong in either of the two, because autism is neither a physical (bodily) disability, nor a mental illness; it is a neurological disability.

Consequently, the autism self-advocacy movement is not widely aware of the Disability Pride and Psychiatric Survivors movements, and conversely, the latter are not aware of the former: you won't find the words "autism" or "Asperger's" on the sites of ADAPT or Support Coalition International. This leads to the somewhat depressing conclusion that autistic self-advocates are currently isolated from other self-advocacy groups. But if the autism self-advocacy movement is to have as much success as other disability movements in bringing about change in society, it is going to be necessary to establish mutual awareness, contact, and collaboration between all these movements. In order to accomplish that, the awareness of all forms of autism, especially high-functioning autism, needs to be drastically increased in society as a whole.

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[9] http://www.adapt.org/

[10] http://www.mindfreedom.org/

4. Autistic culture and community on the Internet: Independent Living on the Autistic Spectrum[11]

4.1. History and description

In early 1996, Dean Walker in the US started a bulletin board system with the intention of offering a place where people with neurological disabilities who felt marginalized in society would find mutual support and develop methods for activism and self-advocacy. This online community was divided into forums, each dedicated to an aspect of living independently with an autism spectrum condition. Such topics include social interaction, employment issues, selfcare and household, and others.

Because it was an archaic dial-up system that required a long-distance call to reach, it was not successful in this form. After a few months, in July 1996, Martijn set up a mailing list server on his computer in the Netherlands and replicated the forums in the form of Internet mailing lists as described in section 2.2. This group of mailing list was called InLv, short for Independent Living on the Autistic Spectrum. Dean disengaged from continuing in a managing position, making it Martijn's group. An amended version of Dean's division in topics is still in use today by this group.

As more and more people subscribed to InLv, the group's character started to change from primarily an activism development centre into a primarily centre of emotional and practical support. Members share their lives with each other, ask each other for advice, or want to hear they are not alone. It turned out that it was extremely valuable to most members to find out that they were not alone with their problems, and this alone helped them a great deal, even if the problem itself was not solved by it.

For some, the lack of inclination of the majority members to set up a more activist-type organisation has been a disappointment. However, it should be pointed out that mutual emotional and practical support by the members has been shown to empower them by increasing their mental wellbeing and with that their level of functioning. Thus, mutual validation through emotional support can also be counted as a form of self-advocacy.

As InLv members corresponded intensively with each other and bundled their collective hundreds of years of autistic life-experience, they came to a few insights that are not commonly found in the literature. It is therefore worth summarising some of them here.

4.2. Some key insights from members

Male-female ratio. The first thing a member would notice when he joins InLv is that there are many women on the autistic spectrum who contribute. According to the literature, autism spectrum disorders are supposed to be much more common in males than in females (I have seen estimates anywhere from 4 to 15 [!] as many males as females). But on InLv, the amount of autistic women has usually been about the same as the amount of autistic men; in fact, as of this writing, 45 out of 102 members on InLv who identify as autistic are male, and 57 are female! While this is undoubtedly attributable in part to the fact that women are better communicators and therefore more inclined to join a list like InLv, it should be no surprise that most InLv members feel that women on the autistic spectrum are vastly underdiagnosed. Indeed, it does turn out that women on InLv are often 'self-diagnosed and peer-confirmed' while men have an official diagnosis much more often than women do. Experience on the group shows that there are a number of possible reasons for this widespread underdiagnosis:

> On the average, autistic females tend to be higher functioning than autistic males, thus reducing their chances of being properly diagnosed, as recognition of high-functioning autism is relatively new.

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[11] http://www.InLv.demon.nl/

The autistic problems in females might manifest itself in a behaviourally different way: typically, the autistic female will be the quiet, 'invisible' child in the back of the class who bothers nobody, and therefore the teacher won't notice that she has problems, whereas autistic males are more prone to aggression and behavioural oddities.

Due to scientific prejudice, the autism-related problems in females might be called something else instead, such as 'neuroticism'.

Females might be better able to compensate for the problems that they have than males are, because, like non-autistic females, they are born with better adaptation capability than males are. But being better able to compensate for a problem does not mean one doesn't have the problem, it just means it goes unnoticed, or is 'explained away' (usually as a pejorative moral judgement).

Because problems are still there even if they are compensated for, autistic females are, just like autistic males, prone to develop depression and anxiety if the autism goes unrecognised. The depression or anxiety then treads to the foreground, thus masking the already carefully hidden autistic symptoms even further. That causes the depression or anxiety to be seen as the problem, instead of a result of difficulty dealing with a different problem.

Inertia. Many autistic members of InLv find that they have a particular difficulty that we usually call "inertia". At first sight it looks like laziness: the inertial person has problems getting started with things, such as doing housework, filling in tax forms, or writing a paper for Autism99, even if the motivation to do it is present. It may also be that he ends up doing something different than planned, because this was easier to get started with than the originally planned task. But on the other hand, when the inertial person does manage to get started with something, it is hard to stop again; normal sleeping times are not observed and he gets irritable if interrupted because he is completely immersed in the activity that he finally managed get started with. One InLv member compared himself to a steamroller: "I'm a slow starter, but get out of the way once I'm rolling!". Inertia can thus have its advantages if one manages to use it to one's advantage. The topic of inertia tends to return periodically in the group discussion and always generates plenty of "me too" responses; it seems it's an almost universal trait of people on the autistic spectrum. It has been shown to be very important to one's self-esteem to distinguish inertia from laziness. Inertia and laziness can co-exist in the same person, but they are not the same and do not feel the same either.

Simultane capacity. Another almost-universal trait of autistics that one rarely finds in the literature is lack of simultane capacity: it's very hard to do several things at the same time, or keep track of several things at the same time. An example is cooking and talking at the same time: for an autistic person, maintaining a conversation takes up all of his attention so that the cooking goes wrong. Also, many autistic people have difficulty with driving a car for this reason, especially in busy city traffic: while they are paying attention to that pedestrian coming from the right, they might miss that car approaching them from the left. Especially in countries where driving tests are though, many autistic people cannot get a driver's licence because of their lack of simultane capacity.

Face blindness. Prosopagnosia (also known as facial agnosia or face blindness) is difficulty or inability to recognise faces. Experience of InLv members suggests that prosopagnosia is especially common in people with autism and Asperger's Syndrome, although not everyone has this. But unfortunately, as of yet there has been little scientific research in that direction that we know of. However, there is evidence[12] that suggests there is an anatomically independent area in the brain dedicated to recognising faces. Face blind have a brain dysfunction in that area, so that two people of the same gender and with identical clothes and hairstyle look identical. In 1996 and 1997, the discovery and extensive discussion of face blindness by members on InLv lead to the creation of an excellent website on the subject, *Face Blind!*, by Bill Choisser.[13]

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[12] http://web.psych.ualberta.ca/~mike/Pearl_Street/OSHERSON/Vol2/Farah.2.3.html

[13] Choisser, Bill (1997, 98): Face Blind! http://www.choisser.com/faceblind/

Central Auditory Processing Disorder (CAPD) appears to be another thing that is common, though not universal in people on the autistic spectrum. It is a hearing disorder that is situated not in the ears but in the brain. The ears hear the sound fine, but the processing in the brain is distorted, causing speech to sound like an indistinguishable jumble when there is a lot of background noise or when using the phone. People with CAPD pass usual hearing tests fine and usually have no problems understanding you if the environment is quiet and they can look at you while you talk.

Sense of time. Many autistic InLv members report having problems estimating time in various ways. Many are prone to lose track of time, causing their days to be very unstructured (though, paradoxically, a minority of autistics tend to have days that are obsessively structured - possibly as a way of compensating for this problem). Members also report having trouble estimating the length of a time period, for instance, not knowing whether they've been out walking for half an hour or two hours, and trouble with remembering the order of events (chronology).

4.3. Autistic communication compared with NT communication

Sometimes it happens that autistic people who know each other online in a group such as InLv end up meeting in person, "in real life" rather than online. In 1997, the author of this paper has had the pleasure to make a 2-month trip to the USA where I have met and stayed with several members of his group. I have also met groups of autistics at conferences. I've made a number of observations on how autistic people communicate with each other when they meet, and how that is different from how "normal" (NT) people communicate. I hope they are useful to the readers who are autistic and don't know how to behave around other autistics.

Different rhythm. Where NT people usually attempt to fill silence with smalltalk and experience silence as uncomfortable, many autistic people seem to be okay with silence, especially once they have become used to the idea that other autistic people are okay with that, too. NT conversations have a very fast-paced rhythm of little exchanges back and forth, whereas autistic people usually say what they have to say, in its entirety, then stop talking and wait for the other to respond.

Less non-verbal communication. Communication is mostly done with words, not so much with body language and facial expressions. In that way, autistic communication could be comparable to written communication. However, contrary to popular belief, many autistic people do have an acute sense for the emotional state another person is in. It is only the non-verbal communication that is social in nature that is absent.

Directness. An autistic person usually means what he says and says what he means, and will rarely give hints or practice "white lies". NT people frequently misinterpret this as aggression, but in reality it is a kind of openness and honesty.

Literal interpretation. An autistic person will rarely re-interpret what another person says according to his own constructs about what things "should" be like (for example, if you say that something is painful, an autistic person will never tell you that it's not because "nobody finds such things painful"). An autistic person will also rarely "read between the lines"; he'll be inclined to take your words literally. This poses problems in his communication with NT people, but not with other autistic people, as their words are usually meant to be taken literally.

To summarise, autistic communication appears to occur without much protocol and in a direct way. This does not impair the functionality of this communication as long as everybody has roughly the same way of communicating (which will be the case if all involved are autistic). Indeed, the author has found time and time again that autistic people can make deep and meaningful contact with each other, and may even be at an advantage with this because there is not a lot of social protocol to cut through first.

There has been no scientific research that I know of in the fundamental differences of social dynamics between groups of adult NT people and groups of adult autistic

people; one reason for this is probably that groups of autistic people rarely meet, although this is slowly improving. I believe that empirical research by a social psychologist into the dynamics of autistic social interaction could produce results that would form a very important addition to current insight about autism.

4.4. Characteristics of an Autistic Utopia

To finalise this paper, I would like to theorise about what would be an ideal society for an autistic person to live in; a society designed for autistic people. Since autistic people are a world-wide minority that is geographically diffuse, it is not likely that such a thing will ever happen; yet, speculation about this could provide important clues that help define strategies for advocacy and self-advocacy. Below I am proposing three main characteristics of an ideal society for autistic people; I would be interested if others can think of more.

Listen, accept, respect. The needs of autistic people, in spite of everything they have in common, do vary widely. An autistic person's individual needs and desires should be respected and allowed for as much as possible, with no social pressure to conform to any group norms. Respect for the individual, not for the group, should be the basic value in society; people should listen to each other, accept each other's needs and problems, and respect them even if they don't understand them.

Organised around individual. One main feature that sets autistic people apart from the rest of humanity is that an autistic person is not necessarily a "social animal" and has trouble functioning in groups of people. The individual, not the group, would thus have to be the centre around which an autistic society is organised. In schools, every child should have an Individual Education Plan (IEP), and workplaces should be flexible enough so that each worker can work in the way that suits him or her best. Education and work should also be organised such that each person can work at his or her own pace, and contribute as much as he is up to at any given moment.

No hierarchy but redundancy. A disadvantage of a society organised around the individual is that collaboration is hard without a group to base it on. Since collaboration is essential to have a society at all, a different way to accomplish this is needed. Organisations in NT society are traditionally organised according to a hierarchical, authoritarian model: the boss is on top and controls his subordinates, who in turn control their subordinates, and so on, until the lowest level of subordinates who don't control anybody. This traditional model is clearly incompatible with the concept of respect for individual, the difficulties to function in groups, and last but not least, the intolerance of most autistic people of being controlled. For alternatives, we should therefore look to non-hierarchical ways of organisation. The most successful and famous instance of a non-hierarchical organisation today is the Internet (indeed a "society" in which many autistic people thrive). The Internet is effective and unlimited in its growth precisely because of its lack of hierarchy: it is a distributed, redundant network.[14] Even though the Internet is an organisation of computers, not of humans, this could well serve as a model to organise a new kind of human society compatible with the autistic way of being. Human organisations set up in similar ways that exist today are grassroots activist groups, and the Open Source model of developing software[15] (with the Linux operating system as a well-known proof of its effectivity).

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[14] Baran, Paul (1964): On Distributed Communications: Introduction to Distributed Communications Network, The RAND corporation. `http://www.rand.org/publications/RM/RM3420/`

[15] `http://www.opensource.org/`