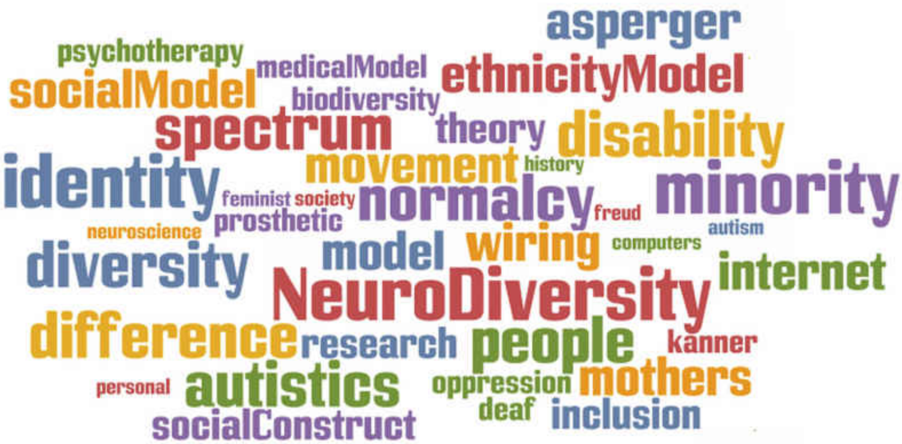
Few people can claim to have coined a term
that changed the world for the better.
Judy Singer can.

- Steve Silberman, Author of "Neurotribes"

NeuroDiversity

The Birth of an Idea



JUDY SINGER

The ground-breaking sociology thesis that
prefigured the last great liberation movement to
emerge from the 20th century

"Few people can claim to have coined a term that changed the world for the better, moving it in a more humane and compassionate direction. Judy Singer can."

Steve Silberman, author, NeuroTribes:
The Legacy of Autism and the Future of
Neurodiversity

"Very illuminating and readable. Through a compelling combination of academic rigour and personal anecdote, Judy Singer makes a strong case for a better approach to helping Aspergers Spectrum individuals make the most of their special talents. I read it in one evening!"

A.J. Eames, Kindle Customer Reviewer

"Judy Singer's book has clarified so much that mystified me about human beings, abilities, disabilities, societies, mental health and illness. I'm shouting out to everyone: Read This Book. It will assist us all, regardless of what our situations are, to understand and embrace the neurodiversity that brings us all together."

*"vve dancer"**,** Kindle Customer Reviewer*

Neurodiversity: The Birth of an Idea

by

Judy Singer

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Dedication

To my mother Agnes Polgar-Gyarmati (1927-2016)

This is dedicated to the memory of my mother Agnes Gyarmati, née Polgar, whose struggles I only fully understood and respected in the final decade of her life.

This work is the legacy of her story, which cries out to be told in full.

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Author's Introduction

Looking back on the 1990s

In 1998, I contributed a book chapter to an academic series on disability, human rights and society, published by the UK Open University Press. My chapter, titled *Why can't you be normal for once in your life? From a 'problem' with no name' to the emergence of a new category of difference,* contained the following lines:

> *For me, the key significance of the "Autistic Spectrum" lies in its call for and anticipation of a politics of Neurological Diversity, or "Neurodiversity". The "Neurologically Different" represent a new addition to the familiar political categories of class / gender / race and will augment the insights of the social model of disability.*
>
> *The rise of Neurodiversity takes post-modern fragmentation one step further. Just as the post-modern era sees every once too solid belief melt into air, even our most taken-for granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) are being dissolved.*
>
> *Judy Singer (1998) p64. Disability Discourse, Open University Press, UK*

It is because of these lines that I am credited with the coinage of the word "Neurodiversity", which journalist Steve Silberman described in Wired Magazine's 20th anniversary edition as the "subversive meme" that became "the rallying cry of the first new civil rights movement to take off in the 21st century"

My book chapter was based on my sociology honours thesis *Odd People In: The Birth of Community amongst people on the Autistic Spectrum: A personal exploration of a New Social Movement based on Neurological Diversity* (University of Technology Sydney, 1997-8)

The lengthy titles of these works reflected my eagerness to draw attention to the exciting new perspectives I was discovering from the dawning of a new type of disability, the "Autistic Spectrum Disorders". A class of people hitherto marginalized as eccentrics and social outcasts were starting to fight back against the exclusion and mistreatment - from ridicule to active bullying - that had been their lot.

They identified as having a “hardwired” neurological difference, not a personality flaw that was their own fault, nor a psychological problem caused by bad parenting. And they were about to shake up the existing orthodoxies of not only the medical and psychiatric establishments, but also of the disability rights movements of the era.

At the time, the term “Disability” essentially encompassed just three categories, which had evolved for the administrative convenience of government: Physical, Intellectual and Psychiatric Disability. This last included “mental illness”, a stigmatized hold-all for anything medical science could not easily explain in biological terms. This is where most high-functioning autistics found themselves. Here, those who could afford it were subject to psychodynamic interventions that delved into the past to hunt for traumas to blame. These therapies delivered few concrete results – neither social acceptance nor the social skills to access employment that would allow autistics a measure of self-realization. This is not to deny the existence of autism-friendly professions such as the science, technology, academia, medicine, and famously, computer science.

Since none of the existing disability categories adequately described High-Functioning Autism or Asperger Syndrome, I described them as “disabilities of social communication” in my thesis. Despite extensive searches of the academic literature on disability, I could find no evidence that sociologists had noticed that a whole new category of disability was being born in front of their eyes. This was hardly surprising since the medical and psychological professions had barely begun to catch up with the new variants of classical autism. And so I embarked on the task of mapping the emerging phenomenon in sociological rather than medical terms. I chose to write a theorised autobiography combining “lived experience” with social research as a participant-observer in an online autistic community.

The intellectual framework for my thesis was provided by the British-based *Social Model of Disability* augmented with the work of American disability theorists. According to the social model, the experience of disability was socially constructed by society’s barriers, negative attitudes and exclusionary practices. Social model theorists opposed what they called the *Medical Model* which locates disability in impairments of individual bodies and seeks cures rather than social change. A brief survey of social constructionist theories can be found under the section titled **A Social Constructionist View of Disability**

Thanks to a renewed interest in my work following mentions in two American bestsellers, Andrew Solomon's *Far from the Tree* and Steve Silberman's *NeuroTribes,* I am republishing the original thesis. I offer it as a contribution to the history of disability rights movements, in the belief that my work was the first attempt to theorise the rise of a truly postmodern phenomenon, the Neurodiversity Movement.

Evolution of the new paradigm

By the 1990s, the idea of autism as a spectrum condition was gathering momentum thanks to the works of professionals like Dr Lorna Wing and psychologist Tony Attwood. Public awareness was growing through personal accounts by Temple Grandin, Donna Williams and others, and through self-advocacy networks initiated by autistic ground-breakers like Jim Sinclair of Autism Network International and Martijn Dekker of the Independent Living Listserv (InLv). The new paradigm was spreading fast thanks to the advent of the internet, which I described in my thesis as “the prosthetic device that binds isolated, socially-unskilled autistics into a collective social organism capable of having a public ‘voice’ ”.

I was drawn to Disability Studies in search of answers to my family problems just around the time the spectrum model was beginning be recognized, although I was unaware of this development at the time. My studies were no mere intellectual pursuit, but an emotional imperative for a life of struggle against bewildering outsiderhood, financial hardship and family trauma. And it was all my mother’s fault, or so it seemed to me at the time. “Why,” I thought, couldn’t she “just act normal for once in her life?”. And to confound me even further, unlike most women of her generation my mother had even made it to university, so “why on earth couldn’t she just use her brains and some common sense?”. It was only when my mother was in her sixties that I began to realize that she did not choose her behaviour, but was struggling with a hereditary issue that affected the female line of our family. I had noticed early in my daughter’s first year that she was not developing in the same way as her peers. While I was searching for answers in the psychiatric tomes of our public library, my blood froze when I read a description of the then dreaded condition, autism. I knew then that I was on the trail at last. But to my great relief, my alarm was ameliorated by my child’s deeply loving and affectionate nature, which hardly resembled the human automatons portrayed by Leo Kanner, the originator of the classic model of autism. I quickly discovered that if I mentioned autism to friends or professionals, I risked being written off as just another “neurotic mother”, so I learnt to keep my hypotheses to myself, developed a thick skin and carried on seeking answers. It was Oliver Sacks’ essay about now celebrated autistic scientist Temple Grandin, “An Anthropologist on Mars” that finally gave me the *Aha!*

moment I had been searching for all my life. Following this up, I rang the NSW Autism Association. I will never forget the life-changing phone conversation that confirmed that there was indeed talk of a new, milder kind of autism, called Asperger Syndrome. And on further reflection, I could see that I, too, had many traits.

A personal, highly emotional turning point for me was reading Ann Shearer's book, *Disability: Whose Handicap*?, which made clear the role of prejudice and social exclusion in turning biologically-based individual differences into "personal tragedies". Disability Studies trailblazers - including Britons Mike Oliver, Jenny Morris and Tom Shakespeare, and Americans Susan Wendell and Lennard Davis - took me deeper into disability politics. They opened my eyes to the history of disability and how the concept arose as part of the 19th century drive to classify, control and regulate the body, the means by which the "classifiers" gained power at the expense of the "classified" - those people who were unable keep up with demand of the industrial revolution for speedy, efficient and conformist workers. I learned how the notion of disability served to distinguish between the "worthy" and the "unworthy" poor, and how the distinction continues to function as a means of social control and punishment in our current welfare systems.

I wanted to know more, and signed up to do further research as an honours student at the University of Technology Sydney, supervised by Professor of Sociology Andrew Jakubowicz. Andrew was one of the leaders of the Australian academic disability movement, together with his partner, Associate Professor Helen Meekosha, whose article *Is Feminism Able-bodied?* was a seminal work for the Australian disability movement. I was invited to join the Sydney Disability Research Network, and at their regular meetings and conferences, I was fortunate enough to learn from the leading thinkers of the Australian and international disability movements.

One of the most interesting questions for me, which I attempted to address in the thesis was, "What social changes in our era have caused this new disability to suddenly crystallize?". I was convinced that Asperger Syndrome was nothing new, and did not believe for a moment that it was caused by vaccination. I could see that the number of children with Asperger Syndrome at my daughter's schools were no greater than number of "odd kids" in my schooldays. My answer to my research question can be found below in the section **Why has the Autistic Spectrum emerged in this era?**

This word *Neurodiversity* did not come out of the blue, but was the culmination of my academic research and a lifetime of personal experiences of exclusion and invalidation as a person struggling in a family affected by a “hidden disability” that neither we nor society recognised for what it was. Nevertheless, we sure knew how to shield ourselves from the critical neurotypical “gaze”, and had developed plenty of strategies to try to pass for normal.

While my focus was on AS, I considered that the scope of neurodiversity was far broader. It could encompass the near-absurdist splinterings of the then DSM IV, even perhaps gender identity and sexual preference, surely properties of the mind.

But as I continued my studies, I was coming to the view that the social constructionist model did not fully suit the emerging autistic movement. I had been immeasurably enriched by the social model and it remained the driving force behind my work. I never forgot that it was because I was “standing on the shoulders of giants” that I could see the terrain ahead. But from my perspective the social model fudged the materiality of diverse bodies and minds, which autistics themselves were saying were not inherently created equal. I understood why the disability movement objected to the language of “suffering”, often well-intentioned but negative stereotypes imposed on the varied experiences and self-images of disabled people. But for me it was a step too far to try to banish the existence of suffering altogether. Like all movements that try to provide a Grand Theory of Everything, the social model had its cultish, fundamentalist tendencies. This came to a head for me at a Disability Research Network seminar when I found myself fuming inwardly that I “might as well be at a Creationist revival meeting” given the movement’s rejectionist attitude towards science, medicine and biology. Yet it was medical researchers, beginning with doctors Hans Asperger, Lorna Wing, Simon Baron-Cohen and Oliver Sacks, and psychologists, notably Tony Attwood, who had laid the foundation that allowed autistic people and families to recognise each other and form their own movement. It was neuroscience that legitimated us, and it was the language of neuroscience and computer science that was the source of empowering metaphors for our movement. I ventured a critique of these tendencies in my thesis in the section titled **Social constructionism vs biological determinism.**

And finally, as a parent myself, I was alienated by an undercurrent of hostility towards parents from within the disability movement. It seemed to me that the disability rights literature overwhelmingly blamed parents for being willing agents of social oppression by trying to "normalize" their children. And as for "parents", I do not think I was being too cynical to read "mothers". While this slur never sank to the depths of Bruno Bettelheim's infamous "refrigerator mothers" calumny, nevertheless the age-old remnants of misogyny were evident. "Suffocating mother" tropes were commonplace before the advent of the women's movement, in the days where doctors and psychiatrists were viewed as gods, when women's confidence in their own instincts was undermined by professional authority and by the fear of being labelled neurotic if they resisted. But as I grew to know more parents of children with autism - and most of the active ones were mothers - I was full of admiration for their dedication, love and courage. These parents refused to be fobbed off by their doctors and psychologists and they had the courage to insist that their children had an unrecognized and unaccommodated genetic difference and not a psychological problem brought on by neurotic parenting.

That is why I placed feminism first on the list when I posed the question "**Why has the Autistic Spectrum emerged in this era?" a**nd answered that it was "thanks to the successes of feminism and identity politics, the decline in the authority of medical practitioners due to the consumer ethos, the failures of psychotherapy, the successes of neurology and the democratising effect of the internet."

These were the circumstances in which I wrote my thesis. I was exhilarated by my new discoveries, but felt ideologically somewhat homeless. It seemed that a new paradigm was needed for autistics, and I could not beat my different drum without accepting a certain amount of personal isolation and conflict, not that either of those had ever been strangers to my life.

As I wrote in my thesis, I had three different subject positions that were not always reconcilable, as

- the daughter of a mother on the spectrum
- the mother of a daughter on the spectrum, and

- a person somewhere on the spectrum myself.

These aspects of myself were nurtured by 3 groups:

- ASpar, a world-first support group which I started for adults who had been raised by autistic parents
- OzAutism, owned by Caroline Baird, a pioneering Australian support group for parents raising autistic children
- InLv, Martijn Dekker's online support group, from which I drew my research data as a participant observer

It was in these groups of extraordinarily insightful and articulate people that I explored my place "on the spectrum" and learned so much.

Language matters

Until something better comes along, I prefer the term “Aspie” to the unwieldy “person with Asperger Syndrome”. Especially now that “Asperger” has been written out of the DSM V despite protest from the Aspie community. My thesis made clear from the start that I was only advocating for people with high-functioning autism, (or the Syndrome-formerly-known-as-Asperger) when I argued that Aspies should view ourselves as a neurological minority, and that our focus should be on minority rights, not medicalisation. Any name for our tribe should emerge from our internal processes and not be imposed on us by the medical model, nor should we collectively bear the name of an individual doctor, however much we might honour him. But on consideration, our removal from the DSM IV may be a blessing in disguise. Now we can fully inhabit our status as a neurological minority and develop our own processes. Looking at the lively communities of self-avowed “neurodivergents” springing up via social media and the sheer volume of their publications, it is clear that this is already happening.

My place "on the spectrum"

At the time of writing this thesis, I was unsure where I fitted in. I saw the gradient as shading from popular culture through to disability, as in *Geek → Nerd → Aspie → Autistic*. The proof of my Aspie traits was in my experience of being always on the outside, looking in at the "normal" people. I was a shy and clumsy kid hovering on the edges of the social hierarchy, barely one step above the more openly reviled outcasts, many of whom I now realize had stronger AS traits than I did. I managed to get by socially because I was quick at schoolwork and proved adept at parlaying my nerdy behaviour into self-deprecating humour, but I suffered humiliations from teachers and students alike when it came to sports. As for the adults around me, I was crushed more than once when I overhead their opinions: "The child is too sensitive and thinks too much". It was clear that sensitivity was a pariah condition to be ashamed of, and one that made me doubt my viability as a human being. After schooling I graduated to hopeless failure at every attempt at a career, despite significant tertiary attainments. I was motivated by the pursuit of truth and knowledge at the expense of conformity and popularity, and did not know how "sell myself". And there was the question that always bothered me: why did I find eye contact so difficult? I was always seeking psychological explanations, all of them unsatisfactory. It was a revelation to discover in InLV how common my experiences were in the Aspie world and how irreducible to anything other than that we were "born that way". Socially I still live with what is now dubbed "Imposter Syndrome". Even at my age, I find myself congratulating myself on my ability to fake extrovert "normality" whenever I go to a gathering and anyone seems remotely glad to see me.

It has taken nearly two decades for the medical model to notice what women in my support groups have been saying since the early days: AS researchers were looking in the wrong place when they spread the idea that only one in four Aspies are female. To the extent that AS is about specialisation, I have often observed that women in AS affected families seem to be exceptionally intuitive and empathetic. Our intuition teaches us when to keep quiet and not show how much we differ from the gregarious norm. In the last couple of years, I have noticed that some women who I would have called Aspies now identify as "Sensitive Introverts" or "Empaths". Having filled out some of their abundant online diagnostic quizzes, I find that nearly all the traits fit me.

During my time on InLv, I found much in common with the members, and once the Australian psychiatric profession caught up with what we pioneered, I received the "official" AS diagnosis. But I no longer identify closely. I was happy to identify as a mild Aspie, but the word "autistic" carries too much heavy freight for me. I would have identified as a geek, but found the word too ugly. The internet empowered me to launch myself more fully in the "real world" and brought me a level of recognition that I had not experienced before. And since others say they cannot see any signs of Asperger Syndrome in me now, all I can claim is a deeper understanding of how it feels to be a devalued outsider, based on the pervasive impact of outsiderhood on my trajectory through life. I still suffer from depression based on my past and I still feel passed over sometimes. But at least I no longer look to psychology to help me hunt for past trauma or someone to blame to explain away every single thing about me that diverges from the Neurotypical Ideal.

Perhaps the best way to describe myself is as a "story-telling" being, based on the theory that our capacity for narrative-making is one of the keys to our humanity. Without having heard of this idea at the time, I wrote in the thesis that the emerging discourse of neurological determinism forced me "willy-nilly, to retell myself the entire story of my life through a new filter". This process was challenging and exhausting, yet ultimately enriching. But I knew it was unlikely to be the last story I would ever tell myself to give my life meaning.

I must mention a significant omission in my thesis and other published works to date. My mother was a Holocaust survivor, and the only one in her family who survived Auschwitz. I chose to omit this fact, knowing it could easily be used to explain away my mother's behaviours as a reaction to trauma rather than as an example of an AS mind. But I knew trauma did not explain everything. Most of my parents' circle were Holocaust survivors, extraordinarily resilient people who came across as neurotypical. Nevertheless trauma had its role, which I hope to explore in further writings.

So, who really coined the word, anyway?

If I go to great lengths to stake my claim, the reasons are twofold. One, on behalf of all us colonials everywhere, is a certain resentment that the Americans, British and Europeans get most of the credit for socio-political innovation. And the other is that I am determined to claim a foothold in the history books on behalf of women who have been forced to abandon their creative dreams and quest for recognition while they struggle disproportionately with child-rearing, paid work, domestic work, community work, financial insecurity, and often, alongside their men, against the injuries of racism and classism.

Google "Neurodiversity" and you will find the same few quotes from American writer Harvey Blume and myself ricocheting around the internet. A consensus crafted from this limited information seems to have emerged about which of us was responsible. For a while I watched, bemused, as Wikipedia's "editors" knocked one or the other of us off our perch. Nowadays, I am generally credited with coining the word, and Harvey for being first in print.

My natural inclination was towards politics, social activism and sociology/anthropology, which led me to disability studies. My thesis research had been extensive, both within print media, academic texts, peer-reviewed journals and online. I joined listservs by and for autistics and their families, which reflected all the current discourses on AS. Articles in the media were proliferating, mostly about children, frequently opening with a reference to the film *Rain Man*, and ending on a note of fascination with the newly discovered "Asperger Syndrome". But I found nothing in either the mainstream media or academia about the social context for the crystallization of this new phenomenon. The only writing with a sociological bent that I had found were some 1997 pieces in *HotWired Magazine* by Jon Katz, on what he called "Geek Syndrome". But Katz had not realised that geeks were the adult version of Aspies.

And then I came upon Harvey's *New York Times* piece "Autistics are communicating in Cyberspace". Amongst insightful quotes from InLv's adult autistics was this arresting phrase "... they are proposing a new social compact, one emphasizing neurological pluralism". From the tone of the article I knew I had found someone who was on the same track as myself. I joined InLv where I discovered Harvey was a member and we eventually began to correspond by email and occasionally by phone.

Harvey is a journalist, a brilliant, incisive writer and thinker, whose work confidently encompasses literature, art, poetry, science, philosophy, politics and more. At the time, he lived in Boston, a few minutes' walk from MIT, one of the engines of the cyber-revolution. For me he provided a window into the exciting centre of the USA's intellectual culture.

What I brought to our conversation was my background in the theoretical aspects of disability politics and activism.

We shared curiosity and an intellectual combativeness. In our conversations, we tossed around a lot of ideas about this new way of classifying humans, but from different angles. We both saw that just as biodiversity was important for species survival, so must human diversity be for humans. We were both aware that the West's faith in the psychotherapeutic model was waning and that neuroscientists were waiting in the wings to take over as a new priesthood. We began talking about the importance of neurological diversity – Harvey was particularly interested in the artistic and literary manifestations of the "autistic spectrum", whereas I, not so much. We talked about the possibilities of human evolution in the cyber age, the possibilities of the emergence of new tribes of humans extending even to cyborgs enhanced with artificial intelligence.

The InLv community drew in people who were, contrary to stereotypes, self-reflective and expressive writers. It was an exciting time as they explored and pushed the boundaries of their new-discovered commonality, and Harvey and I both felt enriched by our membership. I threw myself into the exploration, sharing my family stories, working out where I fitted on the spectrum. Harvey was more of an observer, at least during the time I was there. Every now and then I would chime in with a social constructionist angle when I felt people were taking too much of an individualist, personal growth burden of failure on themselves. And I had stronger reasons to be a participant. I wanted to understand my daughter better, and work towards better futures for her than my mother and I ever had.

I was dreaming of a grand new social movement for neurological marginalised groups in the mould of the feminist, gay liberation or disability movements.

But the term “neurological diversity” was too much of a mouthful to lend itself to sloganeering, until one day I found myself saying that what the world needed was a “Neurodiversity Movement”. I wrote about it on InLv, mentioned it in my thesis, and in my essay, *Why can’t you be normal for once in your life*?

Harvey and I were both writing at the same time. Harvey was published first since the media have a shorter turnaround from submission to publication. I was published in a book, which took far longer.

There was no competition between us. I admire his work, and his example spurred me to try to be a sharper writer. But I took the idealistic disability politics angle intended to lead to a movement.

But in the end, the idea of neurodiversity was out there in the Zeitgeist, waiting for a human vector to express it. I knew that I did not need to put too much energy into defining it. The concept was ready to be populated by a myriad narratives and debates.

Thoughts on the current neurodiversity movement

There have been great improvements for “Odd People Out” since the 1990s. There is much greater community awareness of neurological “tribes” like the autistic, ADHD or bipolar. We increasingly see these manifestations of diversity in terms of their gifts and challenges rather than their drawbacks. There is less stigma, parents are less often shamed and blamed, and educational institutions have begun to adapt. But there is still a long way to go, particularly in the realm of employment.

As in every social movement, contestation and conflict are inevitable, thus any animosity, whether within the neurodiversity movement or against its opponents, should come as no surprise. Some parents claim that their children have enriched their lives, while others claim that they cannot cope. Some autistics claim they are fine the way they are, others claim that life is hard and the neurodiversity movement tries to gloss over their difficulties. Some claim that a lack of empathy is a real symptom of AS while others are outraged by the notion. As for the Curists versus the Anti-Curists, who has ever been able to stop the march of science?

We do not live in a perfect world that grants disabled people equal opportunities. Despite the strenuous efforts of disability activists over many decades, services are declining due to the political Right’s successful onslaught against welfare. Under these imperfect circumstances, every family deserves respect for making choices based on a realistic assessment of their own resources and prospects. When engaging in these debates, we should be patient with each other, however difficult it can be at times, because it is through disputation that we will push boundaries and find new pathways forward.

What I was trying to do in my thesis was to give myself plenty of space to “push the envelope” by putting the most positive spin I could on high-functioning autism. I wanted to see a neurodiversity revolution as potent as the feminist revolution had been. I wanted to see if, given a more understanding, inclusive and supportive environment, whether a new type of human, capable of rising to a new level of human creativity, would evolve. And I was thinking of the difficulties I experienced as a child, as a daughter and as a mother. Could our lives have turn out differently in a more enabling environment? But though I did not mention it in my thesis, I had a darker, more pessimistic view.

At the time, my imagination had taken me no further than a movement based on “Identity Politics”, the first infant steps of all the great social movements of the 20th century. Identity politics excels at gathering the data of oppression and victimisation, but can become mired in simplistic binary oppositions between oppressors and oppressed. In the autistic self-advocacy movement, we naturally focussed on all the ways we had been oppressed, but I was acutely aware that there were many high-functioning autistics in positions of power and influence. We often hear about autistic geniuses, but rarely about autistic villains. I had my theories about some of them but did not have the courage to name them. I certainly hope I never equated autistic/neurotypical with good/bad.

One of my initiatives as the 21st century dawned was to start the world’s first support group, ASpar, for people who, like me, had been raised by one or both AS parents. About 200 people passed through the group before I was burnt out by my role of moderator and unofficial counsellor, and closed ASpar down. Almost every new member spoke of their tremendous relief at finding others who understood what they had been through. We shared our stories and vented our grief. And there was no mistaking the patterns that emerged in our parents’ behaviour. All were consistent with AS traits such as egocentricity, emotional volatility, lack of empathetic insight and heightened need for control. Even though most of us recognised early that our parents were not intentionally cruel and neglectful, the effect was as painful as if they had known what they were doing. We never claimed that every person who had a diagnosis of AS was an incompetent parent. For a start, the diagnosis seems to have been so freely given out but especially if my hypothesis is true that many women with AS traits have heightened empathy, which has to be one of the most important qualification for parenting. Yet just for telling our stories, we were attacked and vilified by some of the angry individuals who policed the dualist boundaries of the movement. Ironically for the vilifiers, we found that it was having the supportive space that allowed us to accept and forgive our parents, and advocate for the supports they needed.

I understand that in America, Ari Ne’eman’s Autistic Self-Advocacy Network has a more nuanced, mature view, and has taken the next step from consciousness-raising into organization, political lobbying and doing the detailed policy work required. In Australia, our own advocacy organization, Aspect, alternatively know as Autism Spectrum Australia, takes a very enlightened view and makes every effort to include autistic people in its paid roles and decision-making processes.

I dropped out of the field shortly after 9/11. Suddenly the exhilarating experimentalism of the cybersphere was engulfed by a tsunami of panic about terrorism. I was not immune. 9/11 was a “Tower of Babel” event which hurled me back to my corner of the globe though I did keep my ASpar group running for several more years. As a sole parent of a teenager. I was struggling financially on a subsistence income and constantly fighting fires on my child’s behalf within an education system that had barely begun to understand the needs of AS children. At the same time, I was trying to support my widowed and isolated mother, who had struggled with unrecognised AS all her life. I had no interest in the intellectual hard labour of an academic career, found the trend towards Cultural Studies and its obscurantist language distasteful and concentrated on finding work in social justice NGOs and the public service. I joined and was active in local AS support groups and P&C associations in the public education system, co-founded a Sydney-wide social club for Aspie teens, became involved in political advocacy for public housing, a bedrock issue for all human rights, and I continue to fight where I can for adequate social security and welfare rights.

The Original Thesis

Odd People In: The Birth of Community amongst people on the Autistic Spectrum: A personal exploration of a New Social Movement based on Neurological Diversity

*by **Judy Singer***

A thesis presented to the faculty of Humanities and Social Sciences in partial fulfilment of the requirements for the degree of Bachelor of Arts Social Science (Honours), Faculty of Humanities and Social Science, University of Technology, Sydney, 1998.

> *"Only when the veil is torn from the bland face of the average, only when the hidden political and social injuries are revealed behind the mask of benevolence, only when the hazardous environment designed to be the comfort zone of the normal is show with all its pitfalls and traps that create disability, only then will we begin to face and feel each other in all the rich variety and difference of our bodies, our minds, and our outlook."*
>
> *(Lennard Davis: Enforcing Normalcy)*

Introduction

As massive tectonic shifts in technology and values fragment the postmodern world along new fault-lines, a hitherto unexamined category of human difference has been “thrust to the surface” of consciousness. As new identities, alliances and movements form and re-form themselves, there are signs everywhere that we[1] are beginning to divide ourselves not only along the familiar lines of ethnicity, class, gender, and disability, but according to something new: differences in “kinds of minds”.

People with all kinds of marginal “disabilities” like ADD and dyslexia are beginning to form communities and produce texts that examine the ways that they have been misunderstood and mistreated. Educational theories have had to adapt to the forces of individuation, and are beginning to cater to different cognitive styles and “multiple intelligences”. All kinds of medical and educational specialists, self-advocacy and support groups are springing up, based on these “neurological” differences.

These new groupings build on the successes of identity and disability politics “trickling down” through society, the spread of computer technology, (both as a source of metaphor, and as communications medium), and on “the march of science”, as it progressively refines empirical observations of human behaviour.

But above all they signal the swinging of the “Nature - Nurture” pendulum back towards “Nature”. Biogenesis is beginning to triumph over psychogenesis, as we increasingly turn to neurology, evolutionary psychology and neuropharmacology for answers in our growing disenchantment with the unfulfilled promise of psychotherapy.

Perhaps these social realignments have found their prototypic expression in the emergence of a coalition of people who have never fitted in anywhere, who have generally been seen as misfits, “oddballs”, “eccentrics”, “nerds”, “loners” and general “weirdos”. These people who, in less loaded terminology, simply lack an innate capacity for social communications, have begun to recognise a neurological kinship. They are gathering together under a variety of labels that have in common the perception that their “social learning disabilities” are on a continuum with classical Autism.

Somewhere in the borderlands between disability and difference, and even, some of them argue, occasional enhancement, these recent additions to the ranks of Autistics are beginning to join together in a new social movement that brings into sharp relief the forces that make up the zeitgeist. In recognition of the wide spread of abilities within their ranks, they identify themselves as being “on the Autistic Spectrum”. Their nascent movement has the potential to illuminate our understanding of our “selves” and our place in the social world, perhaps even adding “neurological difference” to the familiar analytical categories of class/ disability/ ethnicity/ gender.

Linked together by computers and the Internet, the prosthetic device that binds isolated, socially-unskilled autistics into a collective social organism capable of having a public “voice”, autistics have begun to elaborate a new kind of identity. They counter pose themselves against those they have dubbed “Neurotypical” or NT, a term they have coined to sideline the word “normal” with all its prescriptive connotations. Autistics are beginning to see themselves as a kind of neurological “Other” who have existed amongst and been oppressed by the dominant neurological type, the NT, whose hegemony has until now neither been noticed nor challenged.

To identify who these hidden autistics are, think back over all those “odd people out”, the people who “seem to come from another planet’, “march to a different drum”. They are the brainy but socially inept nerds at school, the pedants who defy all attempts to divert them from their special interests. Think of those people who hover frozen and blinking at the edges of conversations, unsure when to break in, seemingly operating on a different timescale from everyone else. They’re the kind of people who have taken shelter under the umbrella of the Autistic Movement.

Then think of how these people have been treated, whether at school, in employment, or in the social arena, think about how they are among the few safe butts of humour left in politically correct times, how their irritating personal characteristics seem to justify their treatment. That’s the oppression.

Finally, try to imagine the kind of society in which NTs and autistics can interact in mutual respect for each other’s differences, gifts and deficits, where communications protocols have been worked out between what are almost different ontological languages, different worlds of body language and expression. That’s the challenge that the new social movement of “Autistics and Cousins” has begun to address.

After a lifetime of puzzling over an anomalous life history, of searching through every halfway rational social movement since the 60’s, none of which addressed my most central problems, I now find myself in the interesting position of being “in at the ground floor” of a fascinating new social movement. I do so from the position of being the middle of 3 generations of women on the Autistic Spectrum. Both my mother and daughter are affected, and I recognise enough traits in myself to make me either an introverted NT or extroverted autistic.

This work serves as an exploration of the rise of autistic consciousness, based on my own personal experiences, and my membership of InLv, (Independent Living) an online autistic community. It manifests a hope that this new movement will have liberatory potential not only for all those who have been marked and stigmatised by difference, but also for all those supposedly “NT”s who have tossed and turned uncomfortably in the Procrustean bed of “what minds are supposed to be like”.

Since this piece will cover an extensive, largely unexplored terrain, it does not aim to present an in-depth analysis. Rather it will be a sampler of all the key social and personal issues around autism which have excited and fascinated me over the past year. And it will be a chance for me to experiment with a patchwork of styles - a polemical mix of personal narrative, theory, critique, futuristic speculation, and social research as participant observer in InLv: an internet community for autistics.

For the sake of an absorbing narrative flow, I would have preferred to begin this exploration in the place where so many social movements start - in a difficult childhood personal “problem with no name”. However, there are a number of ‘housekeeping” issues that must come first. Thus, the essay begins with an explanation of what is meant by “the autistic spectrum”. Then, in order to translate my “private trouble” into a “public issue” (Mills, 1959) I want to situate myself theoretically, and in some depth, in the Social Model of Disability, and methodologically, in a distillation of postmodern understandings of the self, combined with feminist and emancipatory models of social research. The personal narrative which follows aims to make clear just why the emergence of this disability and social movement has come as such a timely relief. A short history of the rise of autistic self-advocacy follows, ending with some ruminations on the meanings of autism as a social movement and metaphor. An appendix gives some background on my participant observation of the InLv forum.

Notes on language

Since the “Autistic Spectrum” is a new category of disability requiring new ways of thinking, I have been plagued by the difficulty that adequate language has not fully crystallised.

I want to make clear that when I used the term “autistic”, I am referring only to people with what is called High-Functioning Autism (HFA) or Asperger’s Syndrome (AS), that is, people who have normal to high “intelligence”, (itself now an increasingly contested term). I have chosen to use the generic “autistic” not only for ease of reading but because this is the term favoured by people identifying as high functioning autistics to describe themselves.

I haven’t been able to decide whether to capitalise the word “autistic”. Autistics have yet to be self-conscious as a quasi-ethnic minority in the sense that the Deaf understand themselves to be. Yet, to use a small “a”, seems to deny their budding movement the weigh it deserves. Thus I have allowed myself to use capitalisation idiosyncratically, while watching for any unconscious meanings that emerge from my choice in a particular situation.

What is the Autistic Spectrum?

As befits a disability emerging for the first time in the postmodern era, the autistic spectrum has fuzzy boundaries. Not even its name has been agreed on, appearing variously as Asperger’s Syndrome (AS), High-Functioning Autism (HFA), Autistic Spectrum Disorder (ASD), Hyperlexia, Crypto-sensitivity Syndrome, Face-blindness, even PDD-NOS (Pervasive Developmental Disability - Not Otherwise Specified), and probably more. The people who band together under this category prefer to name their condition as "AS", and themselves as Autistics, ACs (Autistics and Cousins) and sometimes, comfortably, as “Aspies”, to distinguish themselves from those they have dubbed the “NT”s - NeuroTypicals. The preference for terms like “Autistic Spectrum”, AS, and AC reflects the wide variety of people who are beginning to identify together under the broader banner of “Neurologically Different”.

While Autism is associated in the public mind with images of rocking, emotionally cut-off, intellectually impaired children, and “Rainman” like savants, a range of people who are not intellectually impaired, and may even be intellectually outstanding, are recognising themselves as being “somewhere” on a continuum between “normality” and Classical Autism. What unites these people is an impairment of social communication which makes them look odd, weird, inappropriate, “other”. The emergence of the autistic spectrum rescues these people from the opprobrium of being seen as having poor characters, bad personalities, and even moral defects, by recasting their anomalous behaviour as neurological difference or disability.

The bible of psychiatric diagnosis, the latest version of American Psychiatric Association’s *Diagnostic And Statistical Manual Of Mental Disorders,* the DSM-IV, flags “Asperger’s Syndrome” as, in summary, a qualitative impairment in social interaction marked by inappropriate, sometimes repetitive and stereotyped patterns of behaviour, interests, and activities, leading to significant impairments in social, occupational, or other important areas of functioning, in the absence of significant delay in language or cognitive development (1994:77).

To give an idea of how people on the autistic spectrum look from the outside, I have gleaned this short list of typical interpretations of AS behaviour, from a work highly regarded in the autistic community for its sympathetic view of AS, Tony Attwood's 1998 book, "Asperger's Syndrome":

- lack of empathy
- naive, inappropriate, one-sided interaction
- little or no ability to form friendships
- pedantic, repetitive speech
- poor non-verbal communications
- intense absorption in specialised subjects
- clumsy and ill-co-ordinated movements and odd postures
- unusual prosody, accents, voice control
- insistence on sameness - obsessive routines
- absence of an innate "theory of mind" i.e. a theory of how other minds work.

But from the point of view of autistics themselves, these definitions puts the cart before the horse. They look superficially at autistic deficits, while ignoring their underlying causes. Autistic people argue that autism is above all characterised by a hypersensitivity to sensory stimuli, which necessitates withdrawal from a world of overwhelming sensation. Temple Grandin, an autistic scientist, whose pioneering autobiography *Emergence Labelled Autistic* has made her a spokesperson for autistics, puts it thus:

> *A defect in the systems which process incoming sensory information causes the child to over-react to some stimuli and under-react to others. The autistic child often withdraws from her environment and the people in it to block out an onslaught of incoming stimulation (Grandin, 1996:9)*

Autistics particularly resent the hypothesis that they have no "theory of mind". They argue that what they lack is a theory of NT minds, no different from the way that NTs lack a theory of AS minds.

For me, the significance of the "Autistic Spectrum" lies in its call for and anticipation of a "Politics of Neurodiversity". The "Neurologically Different" represent a new addition to the familiar political categories of class / gender / race and will augment the insights of the Social Model of Disability.

The rise of Neurodiversity takes postmodern fragmentation one step further. Just as the postmodern era sees every once too solid belief melt into air, even our most taken-for granted assumptions: that we all more or less see, feel, touch, hear, smell, and sort information, in more or less the same way, (unless visibly disabled) are being dissolved.

New disabilities do not simply emerge because certain bodily or mental configurations have never existed or been noticed before. Rather, they coalesce as new social formations render these configurations problematic. This section examines Social Constructionist views on disability, by way of background to the understanding of the emergence of the Autistic Spectrum.

A Social Constructionist View of Disability

Countering the Medical Model of Disability

If you ask a random group of people who don't identify as disabled, what they mean by "disability", their immediate reaction is likely to be along the lines of: "Something wrong with a person's body or mind that makes it difficult for them to function in society, to earn a decent living, to participate in community life. A personal tragedy. Although, of course, some heroic individuals, by dint of hard work, expert medical intervention and psychological help can adjust to their limitations and overcome their terrible handicap".

This view has come to be known by the disability rights community as "The Medical Model of Disability" and sometimes as "The Personal Tragedy Model". Disability Rights activists and theorists counter pose their own theory, a "Social Theory of Disability", which grows from the experiences and self-determined needs of disabled people themselves. They are not content to be the objects of pitying interpretations of their lives by those they call the "the temporarily able-bodied". Rather, they insist that disability is a political issue. They have turned the medical model on its head and define disability not as a flaw in an individual, but as an outcome of disabling barriers and social practices. They make a distinction between an "impairment", which may be the property of an individual body, and disability, which, they argue, is a social process. In 1976, one of the early UK disability activist groups, UPIAS (The Union of the Physically Impaired Against Segregation), came up with the following two-tiered definition, which underlines this point:

- *Impairment: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.*
- *Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (Oliver,1990:11)*

Leading Social Model of Disability theorists, such as Mike Oliver, Lennard Davis, and Rosemary Garland Thomson, have begun to provide a historicised account of "disability" as it is understood in

Western society. This brief sketch of the evolution of contemporary disability discourses draws on their work.

Disability in other places, other times.

Although there is a ‘paucity of anthropological cross-cultural studies of disability’ (Oliver,1990:15-17), it is generally accepted that there have been a variety of cultural responses to bodily impairments in non-western cultures. At different places and times, the ‘disabled’ have been placed anywhere on a continuum from sacred to profane: perhaps possessed by a god or demon, perhaps marked by an exceptional destiny, or perhaps reaping just punishment for their sins. They may be anything from exalted, to tolerated, to abandoned at birth, to killed off in adulthood. Clearly there is no innate, ‘natural’ relationship between impairment and the individual’s place in society.

Disability and Capitalism

In order to construct a social theory of disability, Michael Oliver has drawn on a historical materialist framework which stresses the relationship of disability to economic factors and the rise of capitalism. Oliver argues that historical materialism, despite having fallen from grace in recent times, is still a useful tool for tracing the effect of the transition from feudal production to capitalism on the lives of people with disabilities. This development saw a change from the integration of people with disabilities into the daily life of domestic production, to their exclusion from the industrial workforce with its demands for speed, efficiency, and productivity. The institution and the workhouse emerged in this early capitalist stage, as a means of warehousing those who were no longer able to contribute to the productivity of the community, and as a means of social control - a disciplinary spectacle exemplifying the fate of the "idle", meant for the edification of the lower classes.

Some theorists quoted by Oliver (Finkelstein and Sokolowska) add a third stage to this binary division, to create, in effect, an evolutionary theory of disability: they conjecture that we are entering a post-industrial society in which the re-integration of people with disabilities is once more made possible with the aid of prosthetic devices and new technology.

Foucauldian perspectives

All three theorists build on the work of Foucault to agree that discourses around disability arose as part of the 19th century drive to classify, control, and regulate the body, the means by which the "classifiers", (doctors, psychologists, psychiatrists etc.), gained power at the expense of the "classified". Accordingly, disability theorists are critical of what they call the "enlightenment theory of medicalisation" which suggests

> *that medicalisation is a consequence of both the rise of science and the progress of humanitarian ideas. Within this explanation, medicalisation is seen as largely beneficial and progressive, providing treatment to the ill rather than physical punishment for sinners, or deprivation of liberty for the criminal. (1992:49)*

Oliver contends that for disabled people, the result of medicalisation has more often been objectification, segregation, institutionalisation, and powerlessness. For the disabled, the "advances" of medicine have too often been experienced as punitive and coercive. (Oliver, 1990:47; Davis, 1995:3)

Hegemony

Central to an understanding of the social construction of disability is Gramsci's concept of hegemony, and in particular, the "hegemony of normalcy", which is, like other hegemonic practices, made effective by its taken-for-grantedness, its invisibility, its naturalness. (1990:43) (1995:170).

Rosemary Thomson describes the hegemony of normalcy thus:

> *The meanings attributed to extraordinary bodies reside not in inherent physical flaws, but in social relationships in which one group is legitimated by possessing valued physical characteristics and maintains its ascendancy and its self-identity by systematically imposing the role of cultural or corporeal inferiority. (1997:7)*

Disability as ethnicity

To combat the hegemony of normalcy, Thomson wants to “move disability from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity”. (1997:6) This idea has been most completely put into practise by the Deaf movement who do not see themselves as disabled, but rather as a linguistic subgroup[2]. The Deaf

> *feel that their culture, language, and community constitute them as a totally adequate, self-enclosed and self-defining sub-nationality within the larger structure of the audist state. (Davis,1995: xiv)*

Lennard Davis takes up this theme at length in a chapter on nationalism and Deafness, in which he evaluates the usefulness of the strategy of claiming disability as ethnicity, as a symbolic form of group identity based on shared narratives, language and history.

The construction of normalcy

Just as "disability" is a crystallisation of many social and social processes, so too is "normalcy". Lennard Davis makes this point in a chapter on the history of normalcy in *Enforcing Normalcy.* The following paragraphs are a summary of his ideas.

Far from being the universal concept that we imagine it to be, the word "normal" only entered the English language in 1840. Prior to this the nearest approximation to its meaning was the classical notion of the Ideal. While our contemporary understanding of The Normal is not only descriptive, but prescriptive, the Ideal was considered to be a property of the gods, and not something humans could be expected to attain to. Disability theorists repeatedly stress that what we currently call the norm, is actually a rarely achieved ideal.

The concept of the norm emerged in tandem with the development of statistics as a tool of governance. A 19th century French statistician, Adolphe Quetelet, came up with the idea of averaging human features such as height and weight, and by corollary the concept of the "average man". This notion was extended to the idea of a "moral average", a handy justification for hegemonic claims of the rising middle-class. Thus, Davis argues, the "norm" arises as

> *... part of a notion of progress, of industrialisation and of ideological consolidation of the power of the bourgeoisie (1995:48).*

Davis draws our attention to the extent to which the concept of the norm provided the necessary underpinning for the development of the modernist "Grand Theories" of Marxism, Freudianism, and Eugenics. In particular, Davis notes that all the major early statisticians were also eugenicists. This is hardly coincidental, since

> *there is a real connection between figuring the statistical measure of humans, and then hoping to improve humans so that deviations from the norm diminish (1995:30).*

Social constructionism vs biological determinism

The twentieth century has seen Eugenic and Social Darwinist theories being used to justify genocide against both disabled people and ethnic groups deemed to have "inferior" genes. (Morris, 1994:46-47). It is not surprising therefore that disability rights theorists have in common a desire to supplant a perceivedly oppressive biological determinism with a hopefully liberating social constructionism. Concessions to the limitations and negative experiences of lived bodies, or acknowledgment of the benefits of medicine are so minimised, as to become almost invisible.

This polarisation is most marked in the work of Rosemary Thomson, for whom disability seems to be almost exclusively a matter of representation and cultural discourse.

While studying this work, (and wanting very much to be "on its side"), an unwelcome and upsetting idea suddenly popped into my head, and refused to be dislodged:

> *Why, Thomson's worse than the Creationists! Even the most extreme religious fundamentalists are at least prepared to engage with the theory of natural selection, and admit that it exists. And it's not just Thomson - it's all of them!. Their convoluted stratagems to avoid any mention of biological constraints reminds me of the Ptolemaic system of planetary motions*[3]. *I feel a paradigm shift coming on!*

I might not have felt so guilty about entertaining such radically unsettling thoughts if I had known that in that very month, well-respected US public intellectual Barbara Ehrenreich, and her co-writer, Janet McIntosh, had published an article entitled "The New Creationism: Biology Under Attack" (*The Nation*, Oct 1997). In this piece, they take up the very issues that were beginning to exasperate me. They argue that in attempting to counter the misuse by conservative ideologues of biological innatism, postmodernist theorists have fallen into the opposite error, so that like

> *their fundamentalist Christian counterparts, the most extreme antibiologists suggest that humans occupy a status utterly different from and clearly "above" that of all other living beings. And, like the religious fundamentalists, the new*

> *academic creationists defend their stance as if all of human dignity—and all hope for the future—were at stake (1997)*

Ehrenreich and McIntosh make the point that this anti-biological stance, apart from tilting at the windmills of long outdated 60's ideas of evolutionary theory, has stifled debate, limited what can be discussed or incorporated into social theory, interfered with intellectual freedom, and will prove counter-productive. In particular, they warn that we must take our "innate cognitive tendencies" seriously - since surely no-one can seriously imagine we are different from the rest of the animal world, and have none. Failure to do so means we can never determine to what extent oppressive ideologies like racism and sexism do feed off universal categories of mind - and consequently, nor can we determine the most effective ways of countering them. I would make the same argument for prejudice against, and stigmatisation of people who are different by virtue of disability. What if a propensity for stigmatisation has adaptive value, and is "hardwired" into the human organism, as much as a countervailing altruistic tendency to be "inclusive". How then are we to proceed? It seems crucial to ask the question, if we are to come up with effective remedies to "ableism".

This anti-biological stance of Social Model theorists is repeated in their tendency towards overstatement of the case against medicine. While Michael Oliver qualifies, in one or two brief paragraphs, a pervasive anti-medical stance by conceding that there have been "real and indispensable gains brought about by the individualisation and medicalisation of disability", he immediately goes on to insist that these gains must be "transcended" (p50). However reasonable his argument is, there is a message in the unequal weight of argument. Perhaps equally, we need to transcend the construction of binary oppositions such as "Medical Model vs Social Model", even if their use may seem like an unavoidable rhetorical strategy made necessary by the structural limitations of linear text. Or must we concede that we are condemned to dualism by our innate cognitive tendencies?

The dialectical process being what it is, however, my analysis of the process of autistic identity-making suggests that these antithetical entities are already being transformed into a new synthesis. Autistic self-awareness has manifested in an era in which social constructionist ideas have already infiltrated the mainstream. Consequently, Autistics are not constrained to fight so vociferously for these ideas, and have the confidence to take them as given, to go further, to be curious about and inspired by developments in the biological sciences. I will argue that autistics find neither social constructionism nor biological determinism adequate on their own, but prefer to make a new synthesis by picking and choosing from the best of both worlds.

It is out of the conviction that the disability movement needs to transcend its one-sidedness, that I give the last word to Susan Wendell, who in her book The Rejected Body: Feminist Philosophical Reflections on Disability, writes in a vein that is genuinely reflexive and personal, nurturing in tone, and balanced in outlook.

Susan Wendell argues that we

> *... need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognising that there may be much suffering and limitation that they cannot fix. (1996:45)*

As I see it, the ethical challenge for the disability rights movement, as for all social movements, is whether its adherents can see the world for what it is, and still resolve to act with justice and compassion.

Research Methodology

My method for conceptualising and researching this work finds its justification in a number of theoretical strands - feminist research, postmodern understandings of the self, and emancipatory, or critical social research.

From Feminist Research

By making the personal political, Feminist Theory authorises a “blend of intellectual question and a personal trouble” as a suitable choice for sociological research (Reinharz, 1992:259)

Feminist epistemologists have been critical of the false objectivity of the stance of positivist social research, which they dub “the view from nowhere” (Haraway, 1991). Feminist philosophers like Sandra Harding (1991) have instead insisted that researchers must reveal their biases, their standpoints, in what can be called “a view from somewhere”.

From Postmodernism

Postmodernist theory replaces the notion of the Self as a fixed, essential unity, with a decentred, partial, and often contradictory intersection of historical discourses, strategically deployed in the individual's interests (Seidman:1995; Haraway:1985). It reminds us that when we do research, we may well be telling stories primarily about ourselves, that we cannot hope to be separate from that which we observe, and that we need to be reflexive about our biases and standpoints, to reveal 'where we're coming from'.

Putting all this together leads to what Helen Longino calls: "the views from many wheres" (1993:113). It is with this somewhat ridiculous, but irresistibly pithy summary in mind, that I attempt to answer the question, "Who or what is this "I" that has been constructed for the purposes of this exercise in textual productivity? ":

Situating myself

My answer is complex:

- A locus of the historical forces of ethnicity, class, disability, and gender of course.
- A partial self, always in the act of inventing itself.
- A moving point on a sliding scale between free will and neurological determinism, between essentialism and social constructionism.
- The daughter of a woman with Asperger's syndrome.
- The mother of a daughter with Asperger's syndrome.
- "Somewhere on the spectrum" myself, somewhere between low-functioning normate under-achiever, and high-functioning autistic survivor-against-impossible-odds. And a bemused observer fascinated with this latest classificatory schema imposed on an infinitely complex reality.
- Deeply ambivalent as I live out the contradiction between feeling the victim of my mother's deficit, and yet wanting to be the protector of my daughter's right to difference.[4] A contradiction that doesn't automatically lead to an altruistic politics. Not to mince matters, on "Bad Mother" days, retrospective eugenics seems like a good idea.
- Somewhere between a divine spark embedded in universe full of meaning and purpose, and a biological machine, engineered by the purposeless but necessary operations of physical laws.

But lest I fall into the trap of unmitigated self-indulgence, I want to make it clear that what I'm doing is commensurate with the aims of Emancipatory Research.

From the Emancipatory Research Paradigm

Colin Barnes and Geoff Mercer in their introduction to "Doing Disability Research" (1997) identify the characteristics of critical/emancipatory research as

- open partisanship on the side of the oppressed, and political commitment to their causes
- rejection of claims to objectivity and neutrality on the grounds that all knowledge is socially constructed and culturally relative.
- motivated by the need to change the world, not simply describe it - not only the social and material conditions of disabled people, but also the relations of research production.
- reflexive recognition of the power differential that exists between researchers and researched in order to ensure that the outcome is enabling and not disabling.

By definition, all contributors to *Doing Disability Research* have bent over backwards to be reflexive about this power differential:

> *there is a thin dividing line between identification with one's research subjects and their exploitation. (Vernon, 1997:159)*

Mike Oliver asks rhetorically whether researchers are not the main beneficiaries of their own research :

> *What do we think we are doing: pursuing knowledge for the benefit of humankind? Informing policy and practice? Helping Disabled people? Building networks? Developing our own careers? Having a freebie at someone else's expense(1997:16)*

I found myself increasingly uncomfortable with this form of what should have been admirable self-reflexivity, and Michael Oliver himself, in quoting Geoff Lukes on individualism gave me the key I was looking for:

> *But every way of seeing is also a way of not seeing;... and a view of man as essentially... self-interested or 'rational' or concerned to maximise his utility amounts to the ideological legitimation of a particular view of society and social relations - and the implicit delegitimization of others. (Lukes,1973: 149-50) (quoted in Oliver,1992;45)*

One of the frequent claims made about autistics is their honesty, their naivety, their inability to be exploitative (Ratey: 245; ISNT, 1998). Presenting the picture that every person who wants to do research must above all be concerned with social advancement creates “realities” about what people are which leads to the non-recognition of the particularity of the autistic experience, and all the forms of invalidation which flow therefrom.

The production of a research thesis is a highly individualist enterprise, relying on the researcher being

> *“an autonomous producer - self-governing and self-made... [who]... develops within an expanding market economy as a self-controlled individual responsible for shaping his destiny and the social order by competently manipulating his acquiescent standard body with personal skills and technological tools” (Thomson 1997:64)(19:)*

Taking on the autistic identity for me has meant given full rein to the side of me that is none of this, causing me considerable inner conflict. By succeeding at the entrepreneurial activity of doing social research, I seemed to be undermining my resistance to the naturalisation of individualism.

Language matters

The social sciences have been more influenced by metaphors drawn from the physical sciences than is often consciously acknowledged. And not being reflexive about this, they have been dragged along for a surprisingly long time in the afterwash of a long superseded Newtonian science, with its discrete particulate forces, its dichotomies of individual/ society, natural science/ social science, essentialism/ social constructionism, the observer/ the ‘observed’. Vast intellectual energies have been expended in delineating the precise boundaries between these separate entities. But gradually the metaphorical realm of quantum science is beginning to trickle through with its language of paradox, of indeterminacy, of the indivisibility of particle/ wave (read individual/society), of fields, of forces, and of spectra.

And life on a “spectrum” requires words that don’t even exist yet.

If the boundary between the self and the group becomes indeterminate, what happens to the personal pronoun? When talking about the oppression of people on the autistic spectrum, I find myself using the pronoun “they/we” to express the indeterminacy of my position “somewhere on a spectrum”. It feels like cultural appropriation to speak for those whose experiences are further out from the accepted norm than mine, but on the other hand, I’m unwilling to relinquish recognition for my own share in the pain of the oppression.

The word “disability” itself is problematic. It just doesn’t fit. This is not a case of the internalised disability oppression that makes newly disabled people deny that they have a disability. The word ‘disability’ comes from the pre-quantum era, with its discrete boundaried polar opposition between “able” and “disabled”, and fails to encapsulate the situation of people on the spectrum. It has too many connotations of physical and intellectual impairment, and conversely, no association to impairments of social communication for people who are neither physically nor intellectually disabled. The word has too much stigma attached despite the efforts of the disability rights movement to reclaim it[5], too much looking from the line of sight of a debatable normalcy, and too close an association with the modernist paradigm.

Autobiography: From a "Problem with No Name" to a Disability

I offer this autobiographical account of what it's like to live with a "problem with no name" to underline why people affected by the hidden disability of autism greet the opportunity to label themselves or family members with such relief.

But I have another motivation.

I want to generate public discussion on the experience of being brought up by a parent with an intellectual or social learning disability. I want to add my voice to that of US sociologist Carol Rambo Ronai, whose autobiographical piece "On Loving and Hating My Mentally Retarded Mother" (1997) is the only work I have been able to discover that deals with this topic from a child's perspective. Rambo Ronai confirms my experience that there is almost nothing done on this topic at all, from any point of view. What I have been able to discover are "Social Model" works (Booth, 1998) which are so concerned with defending the rights of the disabled that I suspect they tend to play off parent's rights against children's rights. Like Ronai, I want to change a situation in which there exists no public discourse, no shared language, "no common repository of knowledge for dealing with the issue" (1997:417), a situation which regularly places people whose parents have cognitive disabilities into impossible positions.

“Why can’t you be normal for once in your life?”: A Family History.

There was something odd about my family. Of all our acquaintances who arrived here from Eastern Europe in the 50’s, my parents were the only ones who never “made it”. No matter how hard they tried, they couldn’t escape their isolation, marginalisation and relative poverty[6]. Nobody could believe it. How was it possible, in the 60’s, in the richest country in the world??? And Jews too! Weren’t all Jews supposed to be rich and clever?[7]

It wasn’t for want of hard work. My father slaved at low paid jobs his whole life, and my mother worked full-time till I was 20. Neither of my parents drank, gambled, or were in any way extravagant. They were a good-looking couple too, young, healthy, and had prospered in their homeland. My mother had an enviable asset when she arrived here - she spoke “perfect English”, along with 3 other languages, and had a University education - almost unheard of for a woman in this part of the world. Yet, while all my parents’ acquaintances began to prosper, acquiring first TV’s, then their own cars, then making the big move to the suburbs, and finally capping their achievement with their first triumphant return to their homelands, my family remained behind. We couldn’t even raise the money for a television! At the end of the 60s, we were still in our poky, noisy inner city flat, where my parents nursed their sorrow, bewilderment, hopelessness,... and raged at each other. Though my parents made strenuous efforts to participate in community life, personal invitations rarely came, their gifts were never reciprocated in kind, they were overlooked.

My parents ascribed their misery to the losses of exile to Australia, to a lack of family, assistance, and community in what they saw as a provincial, small-minded backwater[8], and above all, to the injustices of Capitalism.

These explanations had their validity, and I spent my childhood drowning in my parents’ grief and nostalgia.

Nevertheless, there was one other factor contributing to the family misery, something that I was certain of, but not allowed to mention. I was convinced that despite my mother’s impressive educational credentials, most of our problems emanated from her.

I was sure she “had something seriously wrong with her”. [9]

From my earliest memories of her, my mother confounded some expectation I had about what a human being ought to be like. I was fascinated with the idea that she came from some parallel universe, similar to the one the rest of us inhabited, but tantalisingly, indefinably, different.[10] It seemed that the rules of this other “universe” were somehow simpler, more stereotyped than ours. And when the real world didn’t fit this simplified schema, she would lash out in frustration, and rage.

I experienced my mother as maddening, intolerable, like a malign force of will, an endless black hole into which all energy was leached from us. [11]

I was fascinated and repelled by her singular oddness[12], her unusual body posture, her harsh unregulated voice, her egocentricity, her inability to sense what others were feeling, or how their minds worked. She couldn’t recognise social cues, she didn’t seem to be able to notice the escalating messages that she was driving others to distraction with her monologues on her favourite topic.

My mother’s day was so consumed by her many obsessive routines, that she could not finish the simplest task, yet any attempt by my father or I to work around her and get on with our lives was met by - blank - there are no words or cultural models, nothing in film or literature to build on - only a flight or fight knot in my stomach that cries out with the voice of a child “nobody will believe me, nobody will ever know what it’s like”. Maybe it was like a field, like an electric fence protecting her compulsions, so that as I approached I was jolted by a high tension current, a high sonic screech that left my nerves jangling.

My mother was a ball of high-voltage anxiety. Both my father and I were kept fully occupied reassuring her as she obsessed about her myriad inchoate anxieties based on her inability to read ‘what was going on” in social situations accurately.

My father copped her wild lashing out, her anger and frustration, and I got her invasive love, a love that seemed not to know anything about me or realise that I had a mind separate from hers.

I experienced my mother as being relentlessly cruel. Not physically cruel, nothing literal like that, for there was no doubt about her love for me, but “cruel” through invasively, relentlessly boring and stupefying me to my wits end, and cruel through her irrational attacks on my long-suffering father. Back in the days before no fault divorce came in, “mental cruelty” was a popular phrase. I remember reading it in a paper, and thinking, yes, that’s her, that’s what she is.

I used to envy my schoolmates. I thought they were lucky. It seemed their parents only beat them, belittled them or ignored them. At least with that, you could hate back, keep your boundaries, I thought. With my mother’s invasions and my father’s martyrdom, there seemed no bottom to the demands made on my energy and my pity. I was eaten up by it.

My father’s response to my persistent demands that he “do” something about the constant uproar in the family, that he take her to a psychiatrist, divorce her, anything, was to deny agitatedly that there was any problem. His response was, “everybody’s just different, you’ve got to accept people the way they are”[13]. Yet he didn’t sound accepting. He spent his life futilely exhorting my mother to “act normal”. Hardly a day went by that one of us didn’t exclaim “Can’t you be normal for once in your life?”

It never once occurred to us that maybe she couldn’t.

As soon as I was old enough, I took myself to the State Library to “look her up” in the psychiatry textbooks. Although I became an instant pre-teen expert on every kind of psychological deviance, I could find nothing, absolutely nothing about “her case”. She clearly wasn’t schizophrenic. Or depressive. Obsessive-compulsive Personality Disorder rang a bell, but those people who washed themselves 100 times a day and couldn’t walk on cracks - surely my mother’s excesses with the colour-coded pegs, the geometrically precise rows of chopped carrot, the perfectly-aligned contents of the cutlery drawer - were hardly in the same league??

What could I do but abandon myself to the conclusion that everyone else had drawn, that my mother was just a “bad, lazy, person who wasn’t trying hard enough”. I decided she had made some wrong moral choice in her life, then got further and further out on a limb of laziness and denial.

Such a life made me a suitable candidate for “therapy”. All of the therapists I went to encouraged me to think that my parents had “chosen” their behaviour. I was desperate enough for any kind of help to cling to this idea and try to stifle my doubts, and, when I couldn’t, feeling even worse about myself: Now I was a “failure” even at therapy. My therapists exhorted me to dump my mother, and abandon her to the consequences of her “choices”. That was going to be the only way she would ever learn! But no matter how desperate I was to shed the burden of a bottomlessly importunate soul, I couldn’t, for my mother had the awesome power of the truly helpless.

I hung in a limbo between escape and responsibility, trying to hang on to the idea that I was a good person, and that one day, understanding might yet come in undreamed of ways.

Eventually, I had a daughter of my own. By the time she was 2 years old, it was becoming obvious that my child was not ‘unfolding’ like the other children I observed.

One day, I read an article about infantile autism. My heart froze. It seemed to be describing my daughter, except that autistics were supposed to shrink from love, while my daughter was deeply affectionate, both physically and emotionally - so surely it couldn’t be autism?

I confided my fears to a friend. The hostility of her reaction taught me to keep my hypotheses to myself. Mothers were not supposed to “compare”, let alone make empirical observations about their own children. Amongst my friends there was only one explanation for behaviour that deviated from the norm: An enlightened version of Bad Mother Syndrome. This theorem states: People from dysfunctional families inevitably pass on the dysfunction to their children. The only way to heal is to start by admitting it.

And I was refusing to admit anything, because I knew I was fine as a parent. My refusal to “confess” meant that I ended up being “excommunicated” from my circle[14].

Meanwhile, it was becoming increasingly clear that my daughter was developing the same behaviours and thought processes that I had found so exasperating in my mother. Till then, staunch social constructionist that I was, I had thought children were “blank slates” to be written on by enlightened, progressive mothers like myself. Now I began to be awestruck by the reality of heredity. It became clearer that we had some kind of hereditary ‘disability’ in the family. But what?

At first I took refuge in the camp of “learning disabilities” like ADD. Although my daughter never quite fitted the paradigm, there was enough overlap for me to at least argue that my daughter had an organic rather than a psychological difference.

My life as a parent was a battleground for various belief systems, all of which had one thing in common: an inability to come to terms with the extent of human variability.

I refused to accept any of these belief systems. I decided to stick to my truth and keep searching. And I developed a thick hide.

It took me a while to re-open the file on Autism. I had noticed Donna William’s autobiographical account of an autistic childhood, but couldn’t bring myself to look. It was not till my daughter was 7 that I got up the courage to read it. I wasn’t far into the book, before I knew that finally, someone was talking about my mother, my daughter. And I discovered Oliver Sacks’ “An Anthropologist on Mars”, which included a profile of Temple Grandin, an autistic scientist. So you didn’t have to be “mentally retarded” to be autistic! I rang up the Autistic Association. My discussion with them was a revelation. Yes, there was a form of “high-functioning” Autism called Asperger’s syndrome. And I didn’t even have to explain what my daughter was like against a steep gradient of suspicion and disbelief. They already knew! My relief was indescribable. Validation after all these years!

This time, I knew at last who my people were, and this time I would not be put off. At the age of 9, (2 years after I had figured it out myself), my daughter was ‘officially’ diagnosed with Asperger’s syndrome. I now had an entry ticket to new world of people whose struggles paralleled mine. It was a wonder to enter a world in which everyone had more or less the same story.

At the same time, I had begun to turn inside out my account of my relationship with my mother. I had not “known” her at all.

Just who had been victim and who perpetrator in our family battles became complexities and finally, irrelevant. We had been but “ignorant armies, clashing by night”.

In the breathing space I found after a lifetime of struggle, a new question arose. Was it possible that I myself “had” “Asperger’s Syndrome”, whatever that was, all along? It was beginning to look like it. Odd bits of my history which hadn’t ever fitted into the race/ class/

gender/ parents-are-to-blame etc. discourses now began to swim into sharp focus.

Why had I never fitted in anywhere?

I went onto the Internet, and joined various email forums, some for autistics, some for parents and professionals. I began to see that my life's trajectory fitted in closely with that of others on the autistic spectrum

Over the past year, I have been forced, willy-nilly, to retell myself the story of my life through a new filter. In doing so I have added a neurological/ biological perspective to my former sociological/ psychological/ spiritual orientation, and have felt both enriched and exhausted by the fullness of my vision

My personal struggles in the middle of three generations of women "on the Spectrum" have been part of the birth throes of a new category of human difference coming to awareness, a new way of perceiving. But what exactly is this phenomenon, why has it constellated in this particular era, and what cultural significance does it have?

From a Disability to a New Social Movement

The Rise of Autistic Self-Advocacy

> *This is where the biggest change will come from. Autistics advocating for other autistics. Up until now it has only been moms and dads advocating for their autistic children. But we are the real voice. We can say what therapy works and what does not. WE are the voice of the future, not a bunch of NT's that think they know it all. Another thing that bugs me is that there are still parents out there that think their child can be cured. They want to find the root cause and hopefully fix the problem.*
>
> *I personally think that being on the spectrum is my gift and I don't want to be fixed. I am so different, that I am like nobody I know. It is hard, but I am learning how to be happy along with being autistic. I don't look down on autism or feel sorry for anybody with it, I think we should all be respected. (L. Bodkin, member of InLv, 13 Nov, 1998)*

The evolution of the Autistic Movement has paralleled the evolution of other movements based on disability or difference: from a social or moral defect in the eyes of the dominant culture, to a "disability", to a counter-hegemonic "Social Movement".

The Autistic movement differs from similar movements such as Gay Liberation in that this process has been greatly accelerated - the process from the initial empirical descriptions of AS to the birth of an international movement has unfolded in just one decade. The Autistic movement has all the characteristics of a New Social Movement as identified by Michael Oliver in *The Politics of Disablement*: the movement is located at the periphery of the traditional political system, offers a critical evaluation of society, puts a high priority on quality of life issues, and with the help of the internet, crosses national boundaries (1990: 110-123). And as Alberto Melucci, a prominent theorist of New Social Movements describes their spheres of action, the movement works on a symbolic level to unmask, challenge and overturn the "dominant codes upon which social relationships are founded" (1998: 138).

From a medicalised disability to a social movement

This brief history of the evolution of the Autistic Movement begins in the 1940's when a US psychiatrist, Leo Kanner used the term Autism to refer to a syndrome that affected people with severe learning and communicative disabilities, occasional savant skills, aversion to human contact, repetitive ritualised behaviour etc. At the same time, an Austrian paediatrician, Hans Asperger, described a similar condition, but in children with normal to high intelligence. Though both used the term "Autism", Asperger's work was unknown in the English speaking world till the 1980's when it was popularised by the UK psychologist Lorna Wing (Attwood, 1998:15). Until then, the prevailing view of autism was that it was a massively incapacitating disability caused by a failure of infantile bonding due to overly cold mothering.

With the gradual dissemination of Wing's work, some people began to recognise themselves, or were recognised by their families, as "having" Asperger's syndrome (Attwood:1998). Because of the difficulties of reconciling their wide spread of abilities despite the common defining features of autism, the idea of autism as a "spectrum" rather than a discrete entity began to emerge. As people with AS or their families began to talk to each other, similar histories began to emerge, histories of misinterpretation and mistreatment by the dominant Neurotypical culture and its institutions.

Despite a common history of what can, with the wisdom of hindsight, be termed "oppression"[15], the limited social, networking, and organisational skills of people with AS together with their aversion to direct human contact, had prevented them joining together to form an effective movement to address their specific issues. All this changed however with the advent of the Internet. Computers are the communications medium par excellence for autistics. A significant number of autistics claim that computers mirror the way their minds work (Grandin, with Blume, 1997). By filtering out all the sensory overwhelm caused by actual physical presence, computers free up autistics' communicative abilities.

Internet communities of autistics began to spring up in the early 1990's - Autism Network International or ANI-L, St John's University - Asperger, PAN-L, and InLv being the most well-known. There are two sort of advocacy groups - those primarily for autistics (InLv), and those primarily for parents and related professionals (AUTINET, and the Australian OZAUTISM). ANI-L, which is probably the most activist of these organisations has separate forums for Autistics and Parents. These are kept strictly separate, so that autistics can communicate amongst themselves without being harassed by talk of "cures" and normalising practices. The advent of IRC technology saw the introduction of the first online chat channel exclusively for AS'ers, #Asperger. In 1996, Barbara Kirby, mother of an AS child, set up the OASIS[16] website which functions as one of the best and most popular gateways into the world of the Autistic Spectrum - with links to other major websites, individuals and organisations. Martijn Dekker, a prominent Autistic activist, and owner of InLv, has set up InternAUT, an international autism self-advocacy organisation with its base on the Internet which seeks

> *to empower people on the autistic spectrum through developing advocacy efforts, educating the public about autism, and bringing autistic people in touch with each other via cyberspace (Dekker, 1997).*

Today there is a huge array of excellent information resources available to anyone who simply types "Asperger" or "Autistic" into any web search engine. [17]

With the advent of these online communities and resources, a strong sense of autistic identity is beginning to emerge. A number of personalities have emerged as role-models for autistics. These include authors Temple Grandin, Donna Williams, Gunilla Gerland whose trailblazing autobiographies have made them spokespeople for autistics. Prominent activists include Jerry Allport, whose life story has been bought by Steve Spielberg's Dreamworks for a record figure, Jim Sinclair, prominent member of ANI, and Martijn Dekker of InLv, InternAUT, and On the Same Page.

Autistics are beginning to elaborate their shared history, search for autistic heroes and celebrities in the history books - plausible claims have been made for Albert Einstein, Bill Gates, Steve Spielberg, Ros Franklin[18], Janet Frame, Nikolai Tesla, Glenn Gould, any number of prominent mathematicians and scientists, and of course, half of Silicon Valley. Although members of the Computer Nerdocracy may not yet be aware of the AS connection, autistics know that Nerds and Geeks are all "Cousins". Autistic villains have been identified too, but out of a desire to avoid further stigmatisation, autistics tend to play them down.’ AS people are beginning to debate and formulate a response to the linking of certain types of crime with “loners”, and to argue that simplistic conflations of good/evil with certain varieties of disability cannot be made.

And autistics are beginning to challenge and invert NT assumptions. A member of InLv, ‘Muskie’, has set up a website “The Institute for the Study of the Neurotypical” which parodies the ways that autistics have been studied, and turns the tables on NT’s by subjecting them to the clinical Gaze:

> *Neurotypical syndrome is a neurobiological disorder characterised by preoccupation with social concerns, delusions of superiority, and obsession with conformity.... NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic and may have overdeveloped areas related to social behaviour. (ISNT;1998)*

Visitors to the site evince pity for poor NT’s with their limited sensorium, ineptitude with computers, and compulsive pursuit of social conformity.

Autistic Movement Objectives

Based on my participant observation of InLv forum[19], I can identify some key aspirations of the Autistic movement. What autistics want can broadly be summarised as:

1. Recognition
2. Civil rights and an end to discrimination
3. Disability services appropriate to their level of functioning on the spectrum.

Autistics want widespread recognition of the reality of pervasive neurological differences, and an end to being expected to perform in ways for which they are simply not ‘wired’. This requires widespread education of the whole community.

Recognition

In the current real world, I am either viewed as totally incompetent or incorrigibly lazy. The presumption in the former is that I'm hopelessly screwed up and the in the latter that I am basically normal. Of course, neither is true. I am somewhere in between.

Education will enhance understanding and hopefully bring about a kinder, gentler attitude towards us.

> *There is no way around it: we have to change the public's perception of autism ("Anna": 4 Nov 1998)*

Civil Rights

Autistics have suffered greatly from teasing, bullying, and discrimination in education and in the workplace. They want zero tolerance for bullying as a basic issue of civil rights.

A lot of highly-skilled and intelligent autistics are living in poverty, through being deprived of the right to earn a decent living by discrimination based on erroneous assumptions about their consciousness based on their lack of social skill. In the work place they want a delinking of practical and social skills in job specifications. “Anna”, a high-functioning autistic who is doing postgraduate study wants a

> *position in which success [does] not hinge upon my ability to schmooze. I should be required to communicate about business issues, but not engage in a lot of small talk.*
>
> *(“Anna”: 4 Nov 1998)*

Lower functioning autistics want an end to intrusive and unsolicited normalising practices: **Susan, who despite making it as far as graduate school, identifies as LF due to extreme sensory** hypersensitivities, has this to say.

> *I feel that people should stop trying to fit autistics into NT molds... As a lower functioning autistic who can't tolerate the strain of hard effort and rigorous learning, I feel that people should stop pushing me to "train myself out of my shortcomings"... if autistics and other disabled persons want to push themselves to the limit and put themselves through tough teaching programs, fine with them. But those who can't shouldn't be put through torture.*
>
> *... I am fed up with being thought of as lazy. I also resent the attitude that anyone could do anything if they only worked at it. I wish they'd realize that some people may not have the wiring necessary to do certain things*
>
> *(“Susan”: 31 Oct, 1998).*

Appropriate Services

A common problem for autistics is that being neither intellectually nor physically disabled they fall between two chairs when it comes to the provision of services. InLv regularly receives SOS messages, when more low-functioning people find themselves in crisis situations, and are shunted from service to service without any assistance being rendered, while being further injured by accusations of malingering, and “not trying hard enough”. Autistics need recognition from welfare and social security agencies that they have disabilities of varying severity and may have high support needs. In her article on the InLv website, “Barely making it in the community” Marla Comm, who finds even the most trivial housework tasks to be “monumental feats” because her “hands and brain refuse to work together and who feels like smashing the whole place up simply because the texture of the kitchen counter irritates her hyperacute touch”, puts the situation bleakly:

> *I wonder how much longer I can go on like this. I dread what might happen to me if help doesn't come soon. I see myself becoming too disturbed to work and too apathetic to look after the few self-care chores I can handle. It hasn’t quite reached that point yet, but I feel myself going bit by bit. If only someone could help me get the proper food at prices I could afford, help me keep the apartment clean, advocate for me when I run into problems with people, find me ways to do the sports I enjoy in safety and offer regular support when I'm upset, I'd be able to remain in society and not only continue working, but be even more productive and less hostile to the people around me. On the other hand, if I continue to left to rot away, I'll have no choice but go to an institution and be an even bigger burden on society.*
>
> *(Marla Comm, 1998)*

The impact of the Autistic Movement

It is difficult to evaluate the impact of the autistic movement, because unlike other movements, it takes place primarily in cyberspace.

Perhaps Autistics will pioneer doing politics in a different way - perhaps the movement will rely more on “discursive” power - i.e. via its internet presence, by all the discussions and information that are disseminated, rather than by its actual physical presence via the usual political means of mass movements, demonstrations, charismatic leaders etc.

Why has the Autistic Spectrum emerged in this era?

People (who know me as the mother of a child with Aspergers) often ask me:

> *"How come this 'disability' never existed before?".*

Translated this means:

> *"What maternal inadequacies are you attempting to conceal by jumping on the disability bandwagon?".*

My answer is usually:

> *"There have always been awkward children like my daughter. And I can still remember how badly they were treated. What has changed, is that parents will no longer sit by and let the same thing happen to their children."*

In this section, I will argue that recognition of an Autistic Spectrum has emerged out of the empowerment of people with disabilities and their families, thanks to:

- the successes of feminism and identity politics
- the decline in the authority of medical practitioners due to the consumer ethos,
- the failures of psychotherapy,
- the successes of neurology, and
- the democratising effect of the internet.

The contribution of feminism and identity politics

In a paper entitled “The History of Ideas on Autism”, Lorna Wing describes how Autism was widely believed, in accordance with the prevailing Freudian paradigm, to be caused by “cold, detached” mothering, with devastating consequences for families. Bruno Bettelheim, who in his book *The Empty Fortress: Infantile Autism and the Birth of the Self* attempted to colonise Autism on behalf of psychoanalytic theory even coined the term “refrigerator mother” to explain the whole problem![20] The tide only began to turn in the late 60’s when “parents who were independent minded enough to reject the idea that they were to blame for their children’s condition came together to form parent’s associations”. (Wing,1996)

It is thanks to the gains of the feminist movement, that mothers[21] have found the confidence to honour their own perceptions[22], and refuse to be intimidated by what Susan Wendell calls “epistemic invalidation” - our invalidation as “knowers and truth-tellers in our own lives - by the cognitive and social authority of medicine” (1996:122), which has the power to validate or invalidate our subjective experiences, and paint us as either the worthy ill, or as neurotics and malingerers.

Decline in the authority of medicine

In email lists for Autistics, at meetings of AS support groups, whether of parents or people with AS, it is common to hear variants of the following anecdote: “I suspected my child had some kind of developmental problem by the time s/he was a year old, but when I consulted my GP, I was told, in effect: “There’s nothing wrong, you’re just being neurotic”. Adult autistics who attempted to self-diagnose report meeting the same response.

Far from being intimidated as an earlier generation might have been, a significant number simply indignantly wrote off their doctors, and kept looking. Whereas the traditional image of “diagnosis” is of something reluctantly sought, dreaded, resisted, and imposed from outside, people with “marginal” neurological differences, clamour at the gates, self-diagnosed, and demanding to be let in. Susan Wendell puts her finger on the reason why people often long to be perceived as disabled. It is ‘because society stubbornly continues to expect them to perform as healthy non-disabled people when they cannot, and refuses to acknowledge and support their struggles” (1996: 25). While there are losses in being associated with disability through stigmatisation[23], there are important gains, through the importance of recognition, of epistemic validation, and through entitlements to necessary practical assistance.

Resistance to Psychotherapy

Even more scorned by autistics than the mainstream medical profession, is “psychotherapy”, and its fixed developmental schemas, its often futile hunt for the causes of current ‘maladjustments’ in childhood trauma, its assumptions about free choice, and its covertly blaming discourses on ‘self-esteem’.

In an age where “self-awareness” is highly valued, people on the spectrum are spearheading neurological, as opposed to psychological self-awareness. Possibly no group has been able to challenge the basis of psychotherapy more effectively than HF autistics, since their social difficulties are so clearly biologically based.

A frequent theme amongst autistics is anger at having their experiences invalidated and their time wasted by expensive psychologists and “therapists”. To the claim that their social difficulties are caused by childhood trauma or sexual repression, they are likely to respond that the difficulty is in their “wiring” (Blume, 1997a) exacerbated by the effects of social invalidation.

“Anna” sums up all these themes:

> *I was lucky to be born into a good home with a caring family. I was never insecure or abused. Yet I turned out the way I did. (I had one tragic event during my childhood—the death of my father—which all the shrinks focused on. It never affected me that much, which no one believed. First mistake.)*
>
> *Therapists/ counsellors approach most patients with the presumption that feelings have been suppressed. They simply cannot envision that someone can be born with a basic emotional deficit. Therefore, they are approaching me on a completely incorrect presumption, which results in their getting nowhere with me. I have wasted a lot of time, energy and money on therapy*
>
> *I got sick and tired of shrinks telling me that what I said was “true for me.” In other words, my thinking was distorted: I was believing something to be true that wasn’t. Makes me sound delusional, which I’m not.*
>
> *“Anna”, frustrated with the mental health profession. (8 Nov 1998).*

Other members of InLv counter some of the major claims of psychotherapy:

- about the value of expressing anger:

  "expressing my anger" only made me angrier and more likely to do something dangerous and inappropriate, not less. Instead I focused on learning to deny the impulses with my body: to train myself to step back when enraged. ("Kate": 09 Nov 1998)(19:)

- about the value of introspection into the past

  *While therapy tried to tell me to look into my past for answers, I found it much more useful to forget about the past and deal with the present. In fact learning to stay in the immediate present was *the* critical breakthrough in my experience of life... ("Kate": 09 Nov 1998).(19:)*

- about 'maladjustment' being caused by occluded incidents of abuse

  [My psychologist] was a very nice guy, and very supportive, and it helped me just to have someone to talk to. However, his interpretation of a lot of things was often wrong. For example, I told him about how I acted in school, afraid of the other kids, hiding under my desk. He said that was usually a sign of being abused. But I know I never was abused. ("Maureen":9 Nov 1998)

- about the Oedipus complex

  And, I described my father, who is more AS than me, and how he is detached, etc. And how my husband is kind of similar. So his interpretation was, that I married Dad. But in reality, I married someone who was more like me than other people. ("Maureen":9 Nov 1998)

- about interpreting factual statements about one's own limitations as signs of "low self -esteem"

  I also remember telling him how I was "weird" when I was a kid. He didn't really believe that, he thought I had a problem with self-esteem, I was putting myself down, etc. But I really was weird. I don't see being weird as a problem now. ("Maureen": 9 Nov 1998)

This sort of "epistemic invalidation" is one of the things that ACs resent most bitterly, and which crops up regularly in online discussions. Jane Meyerding, in an article entitled "Thoughts on finding myself differently brained", available from the InLv homepage puts it this way:

> *People often assume I am lying when I report objectively on my inner workings. Or they think I am putting myself down. That latter reaction infuriates me and many other AS people who have to put up with the same thing. Instead of taking our words at face value, NT listeners ascribe some foreign emotional weight to them.(1998:16)*

Gunilla Gerland, another autistic who has come to prominence with the publication of her autobiography "A Real Life" has written an article directly to the psychotherapy industry in which she passionately castigates its practitioners for disregarding the reality of neurological difference, and for cutting autistics to size to make them fit into what she calls the "Cinderella's Slipper" of psychoanalytic theory. She appeals to therapists to abandon their vested interest in a [universalising grand[24]] theory about human nature that no longer works.

In the wake of similar disillusionments amongst the mainstream clients of therapy, a number of articles in prominent US newspapers and magazines have heralded the decline of psychotherapy at the expense of neurology and pharmacology. The *Boston Globe* recently reported a rapid falling off in the numbers of practising "talk" therapists in Massachusetts, the most psychotherapeutically over-serviced state in the US. One of the reasons given is that "there is less of a need for extensive talk therapy now that potent psychoactive drugs have been developed to target a wide range of specific mental illnesses" (Bass, 1998). In the same month, *Salon Magazine* reports the scramble by psychotherapists to redefine their role in the "greatest economic downturn in the history of psychology" (Lloyd, 1998). Put simply, if Prozac can end in a few weeks the misery that a decade of psychotherapy has been unable to affect, there is not going to be much resistance to easy relief from suffering on the grounds of what Peter Kramer, the populariser of Prozac, calls "pharmacological Calvinism". (1993:274)

The Effect of the Consumer Ethos

However, this preference for neurology over psychology does not necessarily mean that the medical profession will regain its former exalted position. The relationship between doctors and ‘patients’ (a word already hopelessly outdated) or rather “health care providers” and “consumers” has changed forever, through a combination of the consumer ethos and the internet. Consumerism has created a much more demanding and empowered public.[25] and at the same time, the ready sources of information on the Internet break down the monopoly on information with which medicine shored up its power.

With this sense of empowerment, some autistics are in a position to speak with satisfaction about the medical partnerships they have been able to negotiate. For these people, the “Medical model” is not the bogey it once was. Provided that professionals are educated to the reality of neurological differences, they can be of value, as paid support, as partners in experimenting with medications.

It’s all a matter of what “Anna” calls “shrink-hunting”. For her, the process has proven “exhausting and frustrating, but worth it if you can find a knowledgeable and accepting therapist.” (25 Oct 1998)

The Internet and Democratisation of Information

Thanks to the Internet, Autistics are taking diagnosis, scientific speculation, and experimentation with self-medication into their own hands. In a forum like InLv, thanks to the presence of people with significant levels of expertise in areas such as neurology and advocacy, members are extremely knowledgeable not only about drugs and neurology, but about their rights and entitlements, with the latest information regularly being traded. Consequently, the ‘experts’ will be hard put to be one step ahead. Increasingly the experts who gain respect are those whose love and enthusiasm for their topic is obvious, and whose attitude is that of consultants in partnership.

The Autistic Spectrum and its Metaphors

Disabilities and illnesses have always been sources of metaphors with which to critique society, with unfortunate effects on the lives of disabled people. Rather than allow autism to be expropriated for such negative metaphors, I hope to pre-empt the inevitable by proposing some positive metaphors of my own.

If there is one reason why AS can be considered as the metaphoric syndrome for the age, it is the special relationship that exists between autistics and computers, for nothing so defines the age as the ascendancy of the computer, and there is no group of people more at home with computers than HF autistics.

I would even go so far as to propose that computers were largely developed by people with autistic tendencies as a manifestation of their particular characteristics, and to meet their special communicative needs.

Computers as an autistic invention?

Popular mythology has it that computers were invented by “nerds”, and became the favoured domain of “geeks”.

And what are Nerds and Geeks?

Jon Katz, the media critic of the influential online magazine *HotWired* defines them thus:

> *Nerd is a term widely used to describe the sometimes socially awkward, technologically minded, gifted people who built the digital communication structures.*
>
> *Geeks are less interested and skilled in the mechanics of technology. They are more outward, political, and preoccupied with the applications of machinery and technology. If the nerd patches together the wires and software that creates an online community, the geek is the one setting its agenda, arguing about how it’s used, and obsessed with its social applications.*
>
> *Both nerds and geeks have generally experienced outsiderness or worse in one form or another - socially, and often in the context of schools and work. The dictionaries are filled with derisive terms for brainy, individualistic, and independent people. (1997)*

Whatever their own views may be on the matter, for my purposes, Nerds and Geeks are people who fit perfectly into the autistic spectrum. Geeks are simply at the end of the spectrum where asocial interests in objects and abstractions in themselves, become more socialised. Geeks are the transitional subjects between social NT and asocial AC, the people who most epitomise a society built on the interaction between human and machine.

Computers as the essential prosthetic device for autistics?

InLv members regularly sing the praises of the new medium that allows them to have the form of communication they desire, while protecting them from the overwhelming sensory overload and rapid processing demands of human presence. For many, email lists are their first experience of community. Jane Meyerding, a member of InLv makes clear just how much autistics owe to computer technology:

> *Like a lot of ACs (autistics and cousins), I find myself able to enjoy "community" for the first time through the internet. The style of communication suits me just fine because it is one-on-one, entirely under my control in terms of when and how long I engage in it, and, unlike real-life encounters, allows me enough time to figure out and formulate my responses. In real-world encounters with groups—even very small groups—of people, I am freighted with disadvantages. I am distracted by my struggle to identify who is who (not being able to recognise faces), worn out by the effort to understand what is being said (because if there is more than one conversation going on in the room, or more than one voice speaking at a time, all the words become meaningless noise to me), and stressed by a great desire to escape from a confusing flood of sensation coming at me much too fast.*
>
> *(Jane Meyerding - Thoughts on Finding Myself Differently Brained, 1998)*

As this statement shows, for autistics, computers are *the* essential prosthetic device, one which turns them from withdrawn, isolated individuals, to networked social beings, the prerequisite to effective social action, and a voice in the public arena.

Autistics compare the importance to them of computers with the importance of seeing-eye dogs to the blind. Martijn Dekker, who is the 'owner' of the InLv email forum, and a prominent autistic activist foreshadows puts it plainly:

> *For reasons obvious to our HFA/AS community, I consider a computer to be an essential disability provision for a person with Asperger's. (8 Nov 1998)*

Are Computers turning NTs autistic?

In *Enforcing Normalcy,* Lennard Davis plays with the (self-styledly) "somewhat preposterous suggestion that Europe became deaf during the eighteen century" (p51). He argues that transition from a "performance culture" to a text-based culture in which the act of reading required both muteness and attention to non-verbal signs made the hearing become "deaf", while the deaf, as readers and writers par excellence, became the "totemic citizens" of the new age of textuality.

Would it be any more preposterous to suggest that if the 18th century turned the hearing into the culturally Deaf, then the cyber age is turning NT's into the culturally Autistic? Consider how computers force us to deal with an overwhelming onslaught of pure information, minus emotional cues and feedback, how they replace the complexities of intuitive decision-making with simplified, rule-based machine logic. When these simplistic systems cannot respond fluidly enough to complex realities, even NTs can be reduced to the frustrated head-banging rage which is the old hallmark of autism.

Autistics as Cyborgs?

While medical model literature on autism abounds, to my knowledge only one writer has picked up on the significance of autism as a cultural phenomenon. Harvey Blume, a US writer invited onto InLv to generate positive publicity for the movement, has gone on to produce a number of stylish and thought-provoking ruminations on the cultural significance of autism. In one of these pieces “Autism and the Internet, or, It’s the Wiring, Stupid”, he speculates about the links between an upsurge in media representations of autism, and the rise of the zeitgeist-defining triad of neurology, evolutionary psychology, and computers. Observing signs everywhere that we are living through a “romance between human and machine” where “artificial and organic intelligence cross-pollinate as never before”, he goes so far as to speculate that “Neurological man is a giant step toward—and concession to—the cyborg”.

However fanciful the idea of the cyborg may be, it is clear that the internet is able to supply whatever communicative capacities high-functioning autistics lack. It has begun to do what was formerly thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society.

Perhaps it is not too fanciful to suggest that we are entering an era of co-evolution with machines that opens up a new ecological niche for people “on the spectrum”, allowing them to flourish

This argument is the reason for my earlier questioning of the Creationism of the “Social Model”. Biological science has always been a potent source of political metaphor - so far overwhelmingly appropriated by conservative forces to shore up a right-wing, competitive, anti-disablist agenda. But why let the devil have all the best tunes? Why not appropriate metaphors based on biodiversity, for instance, to advance the causes of people with disabilities? Why not propose that just as biodiversity is essential to ecosystem stability, so neurodiversity may be essential for cultural stability.? Why not strategically argue that the nurturing of neurodiversity gives society a repository of types who may come into their own under unforeseeable circumstances, or as Blume puts it:

> *Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may*

> *favor a somewhat autistic cast of mind. (Blume:1998b)*

Donna Haraway, who has argued against throwing out the scientific baby with the feminist bathwater (1991) could only approve of how autistics are fulfilling her “ironic myth” (1985:149) of the cyborg. And she might be reassured to have her worst fear about her cyborg allayed. Far from being the

> *... awful apocalyptic telos of the “West’s” escalating dominations of abstract individuation, an ultimate self, untied at last from all dependency, a man in space (1985:150)*

the autistic cyborg is quite the reverse, a partial self, incomplete in itself and unable to stand alone, yet linked by the internet to form a greater whole. This is not the cyborg as patched-up individual, but the cyborg as symbiotic differentiated colony, creating an ‘Anthropos figure’ a mythological “larger self” of heightened senses and capabilities.

When she attempts to hasten the advent of the Cyborgian age which she fantasises as being

> *... resolutely committed to partiality, irony, intimacy, and perversity... oppositional, utopian, and completely without innocence... no longer structured by the polarity of public and private... defining a technological polis based partly on a revolution of social relations... (1985:151)*

could she be anticipating Jon Katz’ Geeks, aka HF autistics, who transcend their awkwardness, celebrate their perverseness and dream

> *... about transforming society, bringing about a more tolerant and rational civic system.... They dream of developing efficient social and corporate systems and networks that could improve life on the planet. (1997c)*

Whatever either Katz or Haraway intend, it is clear that major mythmaking is in progress as we jockey to read a future in which humanity cuts its ties with biological necessity. Perhaps autistics can blaze a positive mythological trail for all those people who have been kept from realising their potential by myths designed to exclude them.

Conclusion

In this sampler of issues to do with neurological difference, I have tried to depict, demystify, and promote the growing social movement of autistics - my hope is that both ACs and NT’s will benefit when we get used to the idea that our minds are a lot more strange and wonderful than we have lately given them credit for being. People on the Autistic Spectrum are beginning to demonstrate that ‘Neurotypical’ is not the only way to be, or even the best way, and that society can only benefit from learning from the social experiment of those who were once only “Odd People Out”.

Appendix: Participant Observation of InLv Forum

My observations in this essay have been based on my membership of the InLv forum for “Autistics and Cousin”. My aim in this exercise was to demystify the “strangeness” and “otherness” of autistics, and to spread the information that they/we want known about ourselves. Autistics are keen to be recognised, to correct the erroneous assumptions made about their consciousness based on misreadings of their body language.

Method

Bearing in mind that no research is free of bias, that we may well be doing little more than telling stories primarily about ourselves, that we cannot hope to be separate from that which we observe, I have been aware of the dangers of being so enthusiastic about some theory that I want to promulgate that I ignore the realities of people's lives. Fortunately I'm usually brought back to earth by some of those members who identify as LF with something like "These theories about difference, and virtual communities, and geekdom are fine for you HF types, but I have a severe disability, and I need real help and services in the real world". Thus I have tried to give a balanced representation of the needs and wants of people at both ends of the spectrum.

I joined InLv over a year ago at the invitation of the list owner, Martijn Dekker. I initially identified myself as primarily there as a parent of an AS child, the daughter of an AS mother, and as a person who didn't identify as AS though I had quite a few "traits". I mentioned that I might be doing a thesis on some aspect of AS in the future. I soon found myself making online friendships and being fully involved with the life of the community, and the more I talked with people, the more I was surprised to find that my life's trajectory, my minutest idiosyncrasies matched theirs. As a result I began to take on the AS identity more and more fully, experimenting with it, seeing how I felt when I saw myself in biological determinist terms, sometimes strategically switching from NT to AS depending on the needs of the moment.

I have viewed myself more as a participant than an observer, with my research interest being minor compared to my desire to be part of the community. This made me somewhat reluctant to approach people for my thesis, despite knowing that most would be keen to have their issues widely disseminated. However, a few people have declined to be quoted, with healthy suspicions about being "researched".

Since I've been on the list, I have consistently put forward a social model viewpoint, always attempting to shift the focus from locating problems in individuals, to looking at the wider social process. Thus I have not been a neutral observer, but one who has always actively engaged in creating new social realities. I haven't by any means always been successful. Sometimes there is enthusiastic agreement, sometimes polite disagreement, but more often I am ignored!

Since this exercise is for such a limited audience, I haven't wanted to put people to any trouble or work, so generally, I have saved interesting quotes and asked for permission afterwards, approaching each person separately based on my personal relationship with them. I have a file of about 60 key available for perusal.

I only approached two people, "Anna" and "Susan" with specific questions that would require them to make special time. I chose them because they are at the HF and (self-identifiedly) LF limits of the InLv memberships, and I felt that between them they would be able to articulate the range of needs of people on the spectrum. My question was broad:

If you could have an ideal world, what kind of support would you need, and what kind of attitudes would you like people to have?

Privacy issues

I wrote to everyone concerned letting them know that their identities would be concealed if they wished, and that they could change their minds and withdraw at any time. Their permission notes are available for perusal. For those people who requested anonymity, I have given pseudonyms in double quotes. Those who provided their own pseudonym, I have named in single quotes. And for those who want their real names used, I have omitted quotes.

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About Judy Singer

Bowing to the requirements of 1990s post-modernist self-reflexitivy, Judy Singer described herself in the chapter on "*Situating myself*":

- *As a locus of the historical forces of ethnicity, class, disability, and gender, of course, as a partial self, always in the act of inventing itself, a moving point on a sliding scale between free will and neurological determinism, between essentialism and social constructionism*
- *As the daughter of a mother with Asperger's syndrome, and the mother of a daughter with Asperger's syndrome.*
- *As "somewhere on the spectrum" herself, somewhere between low-functioning normate under-achiever, and high-functioning autistic survivor-against-impossible-odds.*
- *As a bemused observer fascinated with this latest classificatory schema imposed on an infinitely complex reality.*
- *And finally, as somewhere between a divine spark embedded in universe full of meaning and purpose and a biological machine, engineered by the purposeless but necessary operations of physical laws.*

In real life, Judy faced many of the career barriers that affect Aspergians. Despite high marks in school and university, she lacked the self-promotional abilities to get a foot in the door with employers. Add to that the barriers that face most mothers trying to establish careers while caring for children. This was more so for her as the sole parent of a child with Aspergers, constantly on call to fight fires in an education system that did not understand this new type of disability. Prior to becoming a mother, like so many people “on the spectrum”, Judy was saved by the advent of the computer age, and found an economically comfortable niche as a computer programmer. When motherhood intervened, Judy survived as a contract worker doing any odd job she could find. During that period she was instrumental in setting up and managing both local and online international support groups for autistics and families. And her passion for social justice, fortified by her family’s personal experiences of hardship, saw her active in the fields of social housing and welfare rights.

Endnotes

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[1] By "we" I am referring to people in Anglophone advanced Capitalist economies.

[2] A distinction is made in deaf circles between small "d" and capital “D” Deafness, or between deafness as disability, and Deafness as ethnicity.

[3] A complicated, ad hoc, and inelegant system of wheels within wheels to explain the observed motion of the planets, made necessary by a fixation on the idea that the earth had to the centre of the universe.

[4] The autobiographical chapter following should make this point more understandable.

[5] At "Pushing the Boundaries" a conference held in Sydney this year for disability activists, the keynote speaker, Jenny Morris, argued that we should use the term "disabled people", rather than "people with disabilities", to signify that disability was something *done to people by society,* rather than being a property of individuals. But though laudable, the idea was not greeted with enthusiasm. Ostensibly, because it undermined "people first" usage, but more fundamentally I think because the word is irredeemably mired in negative connotations.

[6] Lack of money was always the major issue in our lives. I want to establish the link between disability and poverty right at the start. Unsupported disability constitutes a poverty trap by being a massive drain on the energy resources of family members.

[7] Disability does not occur in a vacuum, but interacts with other cultural factors such as class, ethnicity, and gender. Cause and effect may be difficult to disentangle.

[8] I prefer not to name the place, which was neither Sydney nor Melbourne, and was indeed considered provincial, and not only by migrants.

[9] Contrary to disability theory, which considers normality to be a social construct, the certainty of my early experience, suggests that we do have an innate expectation of human parenting behaviour.

[10] Autistics are often referred to as if they were “people from another planet”. Some of them have reclaimed this title : Temple Grandin calls herself and “Anthropologist from Mars” (thus the title of Oliver Sack’s

well-known book) “Jypsy’ has set up a webpage entitled “Oops! Wrong Planet Syndrome!”.

[11] Having expounded at length on the Social Model of Disability, I can hardly belabour everything that was “wrong” with my mother as an individual. After all, it’s retrospectively clear that whatever her behaviour may originally have been, there were exacerbated by social pressure, and lack of understanding. But in the interest of not whitewashing a complex situation, somewhere it needs to be “told like it was”.

[12] In order to determine exactly why my mother fits in with Asperger’s Syndrome and not just “general neurosis” please refer to the list of common AS behaviours on page 11-12.

[13] Autistics were routinely misdiagnosed as schizophrenics (Attwood, 1998:148-50; Ratey, 1977 :266). Schizophrenia was the grab bag for everything that was too “other”, too hard to explain.

There were no shades of grey between madness/ sanity, normality/ mental retardation (as it was known). You were either a deviant to be institutionalised and mistreated, or a normal to be morally stigmatised.

Under the circumstances, my father made the wisest decision he could. - denial.

[14] Obviously I was threatening some deeply held core value of my generation, the shock troops of the sixties who had dragged the world into feminism, but what?

It was only later that I understood that I was undermining social constructionism, the desperate hope that there had to be a social fix for every problem of human suffering and that human progress was inevitable if only society would change.

Davis remarks on the absence of disability from theory: For the “progressive” members of the 60’s generation, “the body was seen as the site of pleasure and resistance to bourgeois culture. The disabled body is an affront to this view,” (1995:93) and the generation who said “never trust anyone over 30” flees from it.

[15] though autistics themselves don't use the terminology of oppression,

[16] Online Asperger Syndrome Information and Support

[17] I am indebted to Roger Meyer, for providing the background reading for this short history of online AS advocacy, in his excellent article “"HF/AS Self-Advocacy in the New Age” (1998). Roger contributes frequently to InLv with a strong Disability Self-advocacy perspective, and has a book on autistic issues forthcoming with Jessica Kingsley Publishers.

[18] Famous for being vilified for her “eccentric and unfeminine” personality by Watson and Crick in their race to beat her to elaborating the structure of DNA

[19] See Appendix for research method

[20] For which he is universally reviled in the autistic community. To be fair to Bettelheim, I wasn't able to find the term in the book, and wonder if this much circulated story is apocryphal.

[21] I used the word "mothers" and not "parents", because in my experience, both at support group meetings and by volume of mail on internet lists, it is the mothers and not the fathers who are the most passionate advocates for their children's rights to be different. It's the mothers who first notice that their children have a developmental problem and not a behavioural problem. (I put this contention in footnotes because of its anecdotal nature, though the volume of contributions to internet parent lists by sex is quantifiable.)

[22] Parallel to the move by schizophrenics to undo the devastation caused by R.D. Laing's vilifications of the so-called "Schizophrenogenic Mother"

[23] No great loss as far as people on the spectrum are concerned, since most have already been heavily stigmatised due to their perceived oddness

[24] (my words)

[25] This is not to ignore the class issues in consumerism, the polarisation between those with choice and those without. Nevertheless, *attitudes* have changed, even if not everyone can afford to act on them. And anyone who attends a support group will benefit from the trickle-down effect of discussions online.