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Gille de la Tourette Syndrome

Abstract :

An autobiographical account of the experience of mainstream education and comparable experiences of segregated education.

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Introduction

According to mainstream science Gille de la Tourette Syndrome (TS) is a condition which one in five thousand people are "diagnosed" as "having". The condition affects three times as many boys as it does girls, and is present in all racial groups and "social classes". This is a condition in which the person makes frequent and involuntary noises and experiences differing degrees of motor tics, occasionally (in around a third of affected people) the person experiences the involuntary utterance of obscenities (coprolalia) Roberts et al 1994.

This paper breaks away from the mainstream psychological and psychiatric description of TS in order to give the reader an "insiders account" of the experiences of TS with a focus on education. With detailed introspective description and excerpts from initial interviews carried out as part of an M.Phil/PhD research degree this paper will bring the reader close to moving accounts of how a commonly intolerant society can inflict harm on those seen as "abnormal" and brings to light issues surrounding the concept of inclusive education.

You are sat in a classroom surrounded by strange people and a teacher you do not know. As you sit there you experience that all too familiar build up of tremendous energy in your body and you know "its" going to happen and to your dread you find your head suddenly twitches violently to the side, simultaneously you feel your rib cage contract, your throat tightens, you emit a loud sudden screaming type sound, a sound that causes a multitude of heads to turn, including the teachers.... it's happened again, another group of people now wondering "what's wrong with him", "what the hell is he doing that for". From these reactions people sometimes think you are mentally ill, drunk, on drugs, or are doing "it" on purpose; when in fact you really hate this involuntary movement and sound, it has just brought about the need for another round of explanations to strangers who might or might not believe you. You feel "on trial" like your entire social being and worth is brought under the scrutiny of strangers, and why? Just because you make an involuntary noise that other people find upsetting.

This paper is written for people who have an interest in the fairly uncommon condition that mainstream science has named Gille de la Tourette Syndrome (TS). This name for the condition was given to it in recognition of George Gille de la Tourette, a French Scientist who in 1825 documented nine cases of a condition in which people made loud and involuntary noises and in

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some cases swore inappropriately. This paper is written bearing in mind the specific interest of any person who may be entering teaching and thus may in the future meet a young person who has been diagnosed as "having" TS. (My reason for placing "having" in shock marks is because I personally disagree with promoting the notion of ownership of any condition).

The structure of this paper, I hope, will assist the reader by first presenting autobiographical accounts of experience of TS along with a review of the scientific literature on TS, this is necessary in order to appreciate late how people with TS have been pathologised by mainstream psychology and psychiatry and how this literature has influenced how people "with" TS are educated. Along with autobiographical information I have included excerpts from interviews which provide accounts of segregated education and includes moving accounts of the damaging effects of segregated education and its subsequent effect on the social development of one person in particular. I have also included an account of the implicit politics that operate within a support group for parents of children "with" TS, as we will see below it is occasionally the case that some parents expect and demand segregated education for their children believing that this provision will be of help to their child. It has become apparent during my social research of TS that some people believe that provision of "social education" is in some way beneficial. This notion is questioned, one could ask for instance as to the ultimate result for the young person once having been segregated from their society for a number of years. We then look at the difference as some authors point out between an impairment and a disability. The paper then finally asks the reader to question some key issues that arise during the paper.

To describe the feeling that usually precedes a tic, and to give an initial insight to the experience of TS I will draw upon an interview with a person whom I interviewed in 1996, Chris:

People will often ask me "what does it feel like to have a "tic"?"

This is a very difficult question to answer. For example: If you sit in one place for too long, you will have the urge to get up and walk around and stretch your legs, and you will probably feel relief from doing this. However, if you stay seated, you will get more and more anxious emotionally as well as physically to move around. This example is intensified ten-fold when suffering from the Tourette's Syndrome overwhelming "tic or compulsion".

You could view it as though "normal" people are on "automatic pilot". Everyday movements and words are

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acted upon naturally without thinking about them. Whereas with the more severe Tourettes sufferer with motor and vocal tics, every movement and word have to be thought upon, as though on "manual pilot". Imagine yourself with two broken arms in plaster, and then along comes an "itchy nose" that you just have to scratch. Or if I asked you to stop blinking for five minutes. Yes, the frustration would probably drive you mad. I'll say no more!!!!.

My own experience of being educated was fairly plain sailing up until the age of 12 or 13 years of age when I was in the first year of secondary school. Prior to this time I had only made the occasional bout of grunting noises which my family had termed "just a bad habit". I can remember very clearly the first time I started to make noises that caused me embarrassment in front of my friends at school. It was in a chemistry lesson and I was sat on a long bench like table and the teacher was talking about the structure of "the periodic table", whilst I was sat I suddenly made a high pitch and low volume screeching sound. I did not know why this was happening, I was only aware of my stomach and rib cage tightening in an unpleasant way and then feeling my throat tighten causing the noise. I was very embarrassed. My friends noticed and started to mimic me, to which I reacted with a very stern warning not to make fun of me, but I nonetheless felt really upset inside because I did not understand **why** this was happening. For some time after during school I got the occasional mimicking from other people which was almost always responded to with aggression on my behalf because I was determined not to stand for such treatment (at the time I was very much part of the non-racist "skinhead" culture which looking back, with my aggressive propensity, probably prevented me from becoming a "victim"). Things were different though at home.

At home I can remember being told time and time again from my mother and step father to "**STOP IT!**". This added tremendously to the confusion I felt as to why this was happening to me. I was sent to my room after a few warnings and I can recall the immense feelings of injustice and humility as I sat wondering what the hell was going on. This kind of event resulted in me deciding that this was something that I could not talk to my mother and family about and that I had to discover the reason myself. The only way I could describe the feeling you get with TS is that it is similar to when you know you are going to sneeze, you are aware of the "build up" but there is not a lot you can do to prevent it, it's like an uncontrollable burst of energy that intrudes on you, usually at the worst possible time.

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The problems at home though were not as severe as some young people I have met have had to persevere, a moving account of home life was given by Chris:

My mother, a nurse, used to imitate my symptoms as she had said that "they frustrated her intensely". She would shout for her daughters to come for lunch and then shout "and where's that bloody lad". I used to often think that they were not my real parents, as real parents would have loved their children equally. I was often treated like the black sheep of the family..... At the age of nine I was bribed and coerced by my parents into living in a children's home run by Lancashire County Council for children with severe behavioural problems. What with my father being an alcoholic, and on occasion violent, and me suffering from some mystery illness, it was too much for the rest of the family to handle. The child Psychiatrist had recommended that "one of us had to go". However, with my father being the bread winner and as the Social Service didn't have the support for single parent mothers back in the 1960's I reluctantly allowed them to give me away, only yet to realise that in hindsight, I was about to lose a family that I never really had in the beginning.

The home used what was referred to as the "Pin Down" service. For being compulsive I would be made to stand on a coloured tile on the floor, in the dark, I would be on my own for hours before being allowed to go to bed, missing my dinner and supper. Upon reporting them to my parents, I was accused of lying by the staff and pinned down again for telling my parents in the first place.

I was given the option of going back home if I didn't like it after a 1 week trial period. However, after being birched with a trouser belt along with five other pupils for talking after lights out, and expressing my concerns to my parents of physical abuse to the other children in general, I was accused of false fabricating the 7 day trial period and left to stew there for the next seven years of my childhood without any further visits from my family. In hindsight becoming a forgotten child, lost in the system.

This moving account given by Chris is unfortunately not untypical, a number of the people interviewed express similar experiences, maybe not as severe as Chris's but many include the harmful effects of segregation and marginalisation. In my own case things at school were on the whole fine, as I mentioned above the occasional mimicry was usually resolved by aggression or violence in order to prevent what I perceived would be an avalanche of mickey-taking if I let as much as one incident pass without retaliation. This aggression soon became noticed by teachers

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and thus I realised how aggressive behaviour can often go misunderstood in school. I was as I saw it protecting myself, but the aggression was construed differently by the teaching staff. Only on one occasion did a member of the teaching staff comment on the tic-like movements I made: my head used to shake side to side quite often and in one maths lesson the female teacher commented loudly "Must you really twitch so much!", the feeling of immense humiliation was indescribable, the only way out I could see was to react, I stood up and walked to the front of the class up to the teacher and shouted "Don't EVER take the p*** out of me!" and at that I left the classroom and never returned. Eventually I agreed to sit in another class.

Again drawing on Chris's experience we are able to see the degree of mimicry that he was subjected to:

After finishing at the special educational unit, I started to study at St. Bernards Junior School where I had by that time developed the "Hitler" walk compulsion. Crowds of children would line up behind me in single file to copy the walk, only to have the teachers look down on us from the staff room in fits of laughter - whilst no attempt was ever made to stop it. Also, when a few children tried setting fire to my school clothes as I had told them that I thought I was possessed by the devil. "These memories will never leave me".

It is frankly a horror and outrage that this level of humiliation could have been experienced in the presence of so called teachers. Thankfully, not all people I have interviewed have had the same degree of problems, in my own case at school in other classes it was very different. In art classes for instance my friends and I sat and made posters reflecting our music taste and political views, the noises were as bad as ever but the other pupils did not mimic and the teacher used to carry on as normal, I felt safe. If the lesson was particularly boring to me I used to go into the other room and make something out of clay and practice firing and glazing. The pottery teacher and art teacher seemed not to care about the noises I made and I felt relaxed with them, hence I worked hard at pottery and art and produced some pretty good material. I also loved drama, the teacher here too just used to carry on as normal. I used to get the odd comment from other lads about my keenness in drama but I didn't pay much attention, in these classes too I felt good and I enjoyed them. Looking back it was only where being still and quiet were required that I used to experience problems, when I could engage in practical tasks I was fine. My English classes were also fine as we used to read out plays and the teacher again used to carry on as normal. So it seems now that the attitude of the teacher and how they reacted to me was crucial to me participating in the class.

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What is important to mention here is that at the time I did not know why these noises and tics were happening. If on the rare occasion it was commented on by family members it was usually described in terms of a "Bad habit" or "Bad nerves". Again looking back I wonder what the emphasis of "BAD" was about. To me it just happened and there was nothing "good" or "bad" about it.

After leaving school I worked on a farm for two years and then joined the Medical Corp and later the Parachute Regiment as a medic. Throughout recruit training and training in the Paras' the recruit staff made the occasional comment and the rare humorous comment which I completely ignored unless phrased in a polite manner. The rest of the recruits just ignored the noises and seemed to evaluate me on my physical fitness and skill which I was told was excellent. This, with hindsight seemed a strange thing to do; I had a strange condition and experienced some mimicry at and after school, and then I joined the Paras'. But this is where I feel I can make an important point. For all the macho tendencies of army life, people seemed to evaluate me on my physical fitness and my skills as both a paratrooper and a medic; this emphasis taught me what I consider to be a very important lesson: "judge me, if you must, on what I do and say rather than superficially". During the four years I spent with the Paras' I served in Northern Ireland twice and in the Gulf conflict of 1990-91. In fact, though I now have very different beliefs on the whole concept of armies, aggression and politics, it was only when I left the Paras' that I encountered serious problems in employment.

After leaving the forces I started work for BUPA in Manchester in their claims department whilst I was waiting for a place in higher education. I wanted to enter higher education as I thought that my first stab at education was not particularly fruitful and that I had just spent four years out of civilian society and education was a good place to start my new life. Whilst working for BUPA however for two months I was called into my managers office for a "review" after some superficial praise of my performance I was told that a number of the staff had noticed that I make noises and did I know why. For the first time in ages I felt that horrible dread feeling, these people could not see past this problem into ME, they were hung up on something that was "abnormal"-**different**. After telling them that I would try to give them an explanation they suggested that I might see my doctor. To this I told them that I was not ill but conceded that I would. My doctor referred me to a councillor not because of the noises I was making but because I felt really worried about losing my job and

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my new house that I had just secured a mortgage for. I felt really angry at my employer, in my opinion they had created a big problem.

Another few months passed and again I was called into my managers office. This time I was told that the noises were now "affecting the productivity of the department", and for the first time since school I felt an indescribable sense of injustice and anger. At the time I was in a relationship with a person who suggested to me that if I was getting unfair pressure at work I might leave and go to college despite the extreme financial hardship it would cause me, so I applied for higher education. I decided to leave my job and fortunately I had just completed an evening access course in psychology and had (very timely) received an unconditional offer from Bolton Institute - I can remember jumping around the house with pleasure, I was out of that horrid job and had the chance of higher education. Although unconventional I would like in this paper to acknowledge that piece of advice from Rachel as being probably the most important thing any person has ever suggested to me, in the light of the understanding of myself and others that that change has brought about. Thank you.

During my appointments with the councillor he asked me if I had heard of TS and gave me a questions and answers booklet printed by the Tourette Syndrome Association. I read this leaflet when I returned home and to this day I can remember the feeling of reassurance I got. As I read the leaflet which was describing the "symptoms" of TS it was like I was reading a description of myself written by someone else! Whilst being a positive experience by knowing that other people made the same involuntary noises as me and that these type of behaviours were known to medicine as TS I was cautious that the leaflet seemed to be written in the tone that TS was "everything to the person who "had" it". I did not and still do not want to put forward TS as being accountable for every bad day or problem I experience. But all the same I did contact one of the doctors familiar with the condition and made an appointment. At the appointment with the consultant he told me that in his opinion there was no doubt that I "had" TS. This was useful in that I could now rationalise what was happening to me, I was offered drug treatment for the tics and noises but I was dead against taking tablets in order for me just to "fit in" with the rest of society, I had come this far without tablets and I didn't see myself as "suffering"; from something that needed treating or curing. I was at this time very much looking forward to starting college.

When I started my degree in psychology I began to experience a whole new world of change and what I would now call empowerment. I stopped seeing the reasons and explanations for TS (and

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other conditions) as being the lofty realms in which only top academics and doctors could occupy, I belonged there too. I could write and challenge these views if I disagreed with them. I also became familiar with the mainstream literature of TS which briefly holds a very pathologising view of people "with" TS. You will see that this literature often terms people as "subjects" rather than people, and if you read between the lines of this literature you might sense that this type of investigation appears to be written by academics **for** academics and ultimately, how has this kind of literature made any difference whatsoever that has benefited any person "with" TS? If you choose not to read this rather "solid" review please continue where you see "*" below on page 11.

Origins

Over the last hundred and fifty years a neurological condition has been identified in which patients exhibit a wide range of symptomatology involving motor and verbal tics and is referred to as Gille de la Tourette Syndrome (TS). The first description of TS was made in France in 1825 when Itard documented the case of a French noblewoman, the Marquise de Dampierre. In 1885 Geroges Gille de la Tourette documented nine cases of a condition where a *triad* of signs and symptoms including coprolalia (the involuntary utterance of obscenities, occurring in around one third of cases) and echolalia (the involuntary repetition of utterances, occurring in around two thirds of cases) were noted in addition to motor tics and facial tics.

The case studies made by Gille de la Tourette formed an early framework of study and he noted that all the above symptoms waxed and waned over the course of the patients life. He recorded that during wakeful states and during sleep, people with this condition appeared to be "gripped" by uncontrollable tics in the face, neck and other limbs. The collection of data made by Gille de la Tourette proposed that TS has an onset before 21 years of age (with a mean of 7 years), the condition affected three times as many males as females, the condition was hereditary although not always "full blown" and that the tics usually start in the face and progress to be manifested in the upper limbs and torso over a period of years and into adolescence. Subsequent research by Comings (1992), Apter *et al* (1992), Robertson and Trimble (1989) and Robertson (1994) has identified that the motor and vocal tics are exacerbated by stress, anxiety, boredom, social pressure and fatigue, but are decreased by relaxation, fever, alcohol and concentration on an enjoyable task (e.g. painting) and physical exercise.

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Recent Research

The recent research by Robertson (1994,1995) illustrates the dramatic increase in prevalence of TS. There is debate in the literature as to the exact prevalence of TS which is made problematic by the commonly held assumption that many cases of TS never reach diagnosis. Abuzzahab & Anderson in 1973 cited 174 cases in the USA and 53 in the UK. With an increased clinical and academic interest in TS over the last twenty years interest in the prevalence of TS has been shown to be highly disparate from earlier studies. In 1984 Brunn conducted a large epidemiological study which identified 110,000 cases in the US and 25,000 cases in the UK. Robertson (1994) has supported the early observation by Gille de la Tourette that TS is three times as common in males than females and she cites research by Apter *et al* (1992) in which a study suggested that the prevalence of TS in the general population is 5 per 10,000. TS occurs in all racial groups and social classes (Apter *et al* 1992).

As notable as this increase in prevalence is the documentation of the highly varied clinical characteristics of TS. The manifestations of TS as mentioned above have an onset of around seven years of age, initially involving the face, mouth and eyes such as excessive blinking, grimacing and jaw protrusion. As the patient grows older it is usual for the early tics to disappear and new motor tics and coprolalia to appear. Robertson and Trimble (1988) and Comings (1992) agree that the above symptoms occur as the person reaches adolescence and the syndrome becomes fully blown. The clinical characteristics of TS make the diagnosis extremely difficult especially when TS individuals are able (albeit with great effort) to temporally suppress the tics for a considerable length of time. Diagnosis is also hampered by the many associated conditions such as Obsessive Compulsive Disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD) that occur more frequently in females with TS (Robertson *et al* 1988).

Investigations by Robertson and Trimble (1988) into the associated conditions of TS concerned psychopathology using a phenomenological analysis. In comparison to controls they found that patients with TS had a high incidence of hostility and depression. In their detailed study they found that neurological and electroencephalological abnormalities were minimal. They proposed that the feelings of aggression and depression arise as a secondary characteristic of having a "socially disabling and stigmatising condition". However, it is observed that many people with TS lead normal lives and the above suggestion is based on the considered severity of symptoms. In

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addition, psychophysiological studies, computed topography, sensory evoked potentials and neural imaging techniques have not produced any significant differences to controls (Robertson 1994, Obeso, Rothwell and Marsden 1982). The interesting study conducted by Obeso *et al* (1982) provided evidence for the involuntary nature of the tics in TS as they were found not to originate in the "Normal cortical pathways utilised for willed human movements" (Obesco *et al* 1982).

Problems of diagnosis and aetiology

All data gathered on the performance of TS individuals is open to the extraneous effects of neuroleptic medication. The above investigations of TS have made attempts to control for these effects by selecting subjects on low dosages or by accounting for the possible side effects of medication by using controls. The effects of medication on general psychological functioning still remains a methodological concern and this led Bornstein and Yang (1991) to conduct a study using two samples of TS subjects; medicated and unmedicated. Their paper concludes that "The patients taking medications did not differ from those not taking medications on any of the neuropsychological, intellectual or educational measures". Bornstein and Yang (1991 p. 468).

The research on TS has in the past decade provided a small number of descriptive neuropsychological investigations which have identified both a general broad deficit and other more specific deficits. Bornstein, King and Carroll (1983) used a comprehensive battery of tests and gathered data that constituted evidence that TS subjects demonstrated poor visuospatial attention and performance. In a follow up study in 1991 Bornstein *et al* again conducted research which duplicated their original findings and indicated deficits in visiospatial ability. Similar research has been carried out by Dyskens, Leckman, Riddle, Hardin, Schartz and Cohen (1990) who found the predicted reduced ability on visiopatial tasks but also relative strengths and advantages on abstract and logical thinking. The reduction in general and average performance in TS on visual sensory and motor tasks has lead a number of authors (Shapiro, Shapiro, Young and Feinberg 1978, Incagnoli and Kane 1981) to implicate broad right cerebral hemispheric dysfunction in TS. This proposal was tested by Lanser *et al* (1993) using a sample of TS children and a sample of children with a lesion in the right cerebral hemisphere. The data from this investigation indicate no significant difference in neuropsychological performance between TS children and children with a lesion in the right cerebral hemisphere. Researchers in the above field therefore suggest that these findings are evidence of right cerebral dysfunction in TS.

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In addition to the above techniques there has been much interest in a possible genetic transmission of TS. A possible abnormality on chromosome three was identified by Robertson and Trimble (1993), however there remains much debate with some researchers supporting a dominant autosomal transmission. There is evidence that a female with TS stands a 50% chance of her offspring developing some form of TS, commonly Obsessive Compulsive Disorder (OCD) in female offspring and TS in male offspring (Robertson 1994).

Biopsychological neuropsychological and cognitive psychology (collectively referred to here as the mainstream literature) have taken what could be described as a pathologising and biased approach to the study and "diagnosis" of psychological "abnormality", this is particularly noticeable in the event of a practitioner believing a person has more than one "disorder" and is illustrated by the frequent re-organisation of categories listed in the DSM-R. Following "diagnosis" a psychiatrist reported in a conversation that their view was that a person often leaves the consulting room with hypothetical psychological diagnosis baggage.

Mainstream psychological notions of "Co-morbidity" with "attentional deficit".

Channon *et al* (1992) were interested in the effects of attention deficit disorder (ADD) on the day to day life of TS subjects/participants. The interaction and co-morbidity of ADD, Attention Deficit Hyperactivity Disorder (ADHD) and OCD in people with TS has been a recent source of investigation for a growing number of researchers (for example Golden and Greenhill 1981, Robertson 1989, Comings 1990) and specific visiospatial deficits have been particularly implicated. In their investigation, Channon and her colleagues used cognitive experimental measures in an attempt to identify more clearly the cognitive processes in TS. Using adults (mean age 32, SD 13.1) with TS and a control adult sample (mean age 29, SD 10.7) they found TS subjects performed significantly poorer than controls on serial addition, block sequence (forwards), and letter cancellation (particularly when two or more targets are being sought). The mean scores on the serial addition task showed that the TS sample made significantly more errors; 6.63 (SD 7.69) compared to 30.05 (SD 2.32) for controls. On the conflicting colours stroop test the TS and controls took a mean time of 101.26 secs (SD 40.47) and 85.95 secs (SD 14.98) respectively. In a trail making test the TS sample took a mean time of 93.00secs (SD 52.69) to complete the task compared to 60.82 secs (SD 23.44) for controls. Overall the TS sample performed less accurately than controls and the variance of Performance within the TS sample was greater on all but one of

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the experimental measures. The results from Channon *et al* (1992) on the trail making test and conflicting stroop test also provided an interesting result showing significantly poorer performance in the TS sample which led to follow up research by Baron-Cohen *et al* (1994).

*** Cont:**

In reference to this body of so-called knowledge we could put forward the notion that:

"The simple accumulation of facts does not equal progress" (Parker 1995)

The only problem I had at college arising from the noises and tics was trying to concentrate in the lecture theatre. When the noises were bad I used to worry about distracting other students, as I was trying to stop making noises this used to distract my attention from the lecture material considerably. I used to have a quick chat with a new lecturer before the first lecture to explain about TS. Looking back though I imagine the lecturers discussed this between themselves which could have only been natural and of benefit. With only one exception, I had no bad experiences with any of the lecturers or tutors. I can remember feeling relaxed the majority of the time and I think the staff did an immensely good job if I consider I might have been the first student they had met who made such noises, and to be realistic it must have been difficult to lecture a large group of students if one makes loud noises every now and then. I also asked for a separate room to sit my exams as I did not want to disturb anyone whilst they sat their exams. This might sound defeatist but in my opinion it caused no problem and it put my mind at rest regards sitting exams. My third year dissertation was concerned with a cognitive psychological investigation of TS, although I now seriously question cognitive science as a whole and it's fundamental assumptions I did enjoy this time and graduated with a 2:1 in 1997. But now came a change in my thinking,

I looked at mainstream science again on TS. And became aware of critical psychology which unfortunately cannot be justifiably described within the scope of this paper. However suffice to say that I came to consider the mainstream literature as contributing to the marginalisation and pathologised image of a person "with" TS. This literature always talked in terms of "deficits" and "chemical abnormalities" and "attentional problems", nothing seemed to be focused on **abilities**, just **disabilities**. This atmosphere seemed carried on at Tourette Syndrome conferences that I attended. I decided to challenge this mainstream literature with the central argument that it is **not** tics and noises that disable a person it is **HOW** other people treat you and their lack of

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understanding that cause the social stigmatisation. Being all too familiar with the social consequences of TS Chris proposes that:

I feel that my most important goal is to raise social awareness, particularly amongst the carers of people like myself, and the small minded people that give people like me such a hard time, hence I occasionally travel out and about giving presentations on Tourette's to hospitals and universities. Though I still get thrown out of the odd pub occasionally for being misunderstood as being drunk.....People often view Tourette's sufferers as being rather weird, but it's only weird to the people that are frightened of it, can't understand it or refuse to accept that it exists.

I am now engaged in research looking at educating people about TS. What is important here is that people are first and foremost **included** from the outset in their society. If we look at the dictionary definition of "civilised" we note that to be civilised refers to the acceptance of diversity, this in my opinion would be difficult to achieve if we segregate those people not fitting any definition of "normal". We have of course to look at the sources of this marginalisation though, as I have experienced in TS conferences it is occasionally the very people themselves who see themselves as disabled because of TS, and when I have challenged this construction, my suggestions have been met with a considerable measure of resistance. Families of children "with" TS have begun to expect and even demand special provision and that their child be taken out of mainstream education. I have attended meetings where families have presented their "struggles" for the provision of special education for their children.

It is common sense and quite evident from the material presented here that segregation leads to intolerance of diversity which in turn perpetuates further segregation and marginalisation of minority groups. From the material concerned with Chris's experiences and my own we could further argue that full inclusion leads to acceptance which perpetuates an advancement as a civilised society.

As a final point I would like to briefly address the important concept of "disability" in reference to TS. An impairment in TS could be for example the fact that some people experience severe pains in their muscles as a result of continued bouts of tics in their limbs. But the noises and other tics do not disable. To be disabled infers a social context. If I "have" TS and live on a desert island, am I disabled? To be disabled you need a comparison, a context. This context usually involves

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comparison to the norm. The norm in our society has been used to oppress people into disempowered and marginalised identities, education being one scenario where this is evident. If we accept a social model of disability (Oliver 1990, 1995, Goodley 1997) then we could begin to address this imbalance and marginalisation by first challenging segregation and fully including people in the educational setting. A closing comment I would like to make to the reader is that people "with" TS may show some kinds of behaviour that are strikingly different from other people, behaviours which are outside our cultural norms. But difference is no justification for segregation and marginalisation. People who differ in any way from societies oppressive norm have highly valuable contributions to make to our understanding of each other and ourselves. If we can contribute in any way to our society overcoming its sensitivity to diversity we would have accomplished an important goal; **together**.

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References

- Apter, A (1992) A population based epidemiological study of Tourette Syndrome. Tourette syndrome genetics, neurobiology and treatment. *Advances in neurology*. 58, 61-65 Cited in Robertson (1994)
- Baron-Cohen, S. (1993) Can children with Gille de la Tourette syndrome edit their intentions? *Psychological medicine*. 24: 29-40
- Bornstien, R.A. (1991) Neuropsychological performance in medicated and unmedicated patients with tourettes disorder. *American journal of psychology* 148: 468-471.
- Bruun, R.D. (1984) Gille de la Tourette syndrome: an overview of clinical experience. *Journal of the American academy of child psychiatry*. 23, 126-133. Cited in Robertson (1994)
- Channon, S., Flynn, D. and Robertson, M.M., (1992). Attentional deficits in Gille de la Tourette syndrome. *Neurpsychiatry, neuropsychology and behavioural neurology*. 5: 170-177
- Comings, D.E. (1992) *Tourette syndrome and human behaviour*. Hope press
- Dyskens, E., Leckman, J., Riddle, M., Hardin, M., Scharz, S., and Cohen, D. (1990)
- Gille de la Tourette, G. (1889) La maladie des tics convulsifs. *La semaine medicale*. 19, 153-156 Cited in Robertson (1994).
- Golden, G.S. and Greenhill, L. (1981) Tourette's syndrome in mentally retarded children (review) *Mental retardation*. 19: 17-19.
- Goodley, D. (1997) Locating Self-advocacy in Models of Disability: understanding disability in the support of self-advocates with learning difficulties. *Disability and Society* Vol. 12, No 3, pp 367-379.
- Incagnoli, T. and Kane, R. (1981) Neuropsychological functioning in Gilles de la Tourette's syndrome. *Journal of Clinical Neuropsychology* 3: 165-169.
- Itard, J.M.G. (1825) Memoire sur quelques fonctions involontaires des appareils de la locomotion de la prehension et de la voix. *Gen. Med.* vol 8 pp 385-407 Cited in Comings (1992)
- Kurlan, R., Lichter, D., and Hewitt B.A. (1989) Sensory tics in tourette's syndrome. *Neurology* 39: 731-734.
- Lanser, J.B.K., Van Santen, W. H. C., Jennekens-Schinkel, A., and Roos, R. A. C. (1993) Tourette's syndrome and right cerebral hemisphere dysfunction. *British journal of psychology*. 163, 116-118.
- Luria, A. (1966) *The higher cortical functions of man*. Basic books. New York. Cited in Baron-Cohen *et al* (1994)
- Obeso, J.A. (1982) Gille de la Tourette syndrome *Advances in neurology*. 35, 105-114. Cited in Robertson (1994)

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- Oliver, M. (1990) ***The Politics of Disablement***. Basingstoke, Macmillan.
- Oliver, M. (1995) ***Understanding Disability: from theory to practice***. London, Macmillan.
- Parker, I., Georgaca, E., Harper, D., McLaughlin, T. and Stowell-Smith, M. (1995) ***Deconstructing Psychopathology***
- Robertson, M.M. (1994) Annotation: Gille de la Tourette Syndrome - An update ***Journal of child psychology ad psychiatry*** vol 55 pp 599-611
- Robertson, M.M. (1995) The relationship between Gille de la Tourette syndrome and obsessive compulsive disorder. ***Journal of serotonin research***. vol 1. pp 49-62.
- Robertson, M.M. Trimble, M.R. and Lees, A.J. (1988) The psychopathology of Gille de la Tourette syndrome - A phenomenological analysis. ***British journal of psychiatry***. vol. 152. pp. 383-390
- Robertson, M.M. Trimble, M.R. and Lees, A.J. (1989) Self injuries behaviour and the Gille de la Tourette syndrome: a clinical study and review of the literature. ***Psychological medicine***. 19: 611-625
- Shallice, T. (1988) ***From neuropsychology to neural structure***. Cambridge University Press
Cited in Baron-Cohen *et al* (1994)
- Shapiro, A., shapiro, E., Young, J and Feinburg, J. (1988) ***Gilles de la Tourettes syndrome***. Raven Press, New York.
- Sternberg, S., Monsell, S., Knoll, R and Wright, C. (1978) The latency and duration of rapid movement sequences: comparison of speech and typewriting. In: ***Information processing in motor control and learning*** (ed G. Stelmach). Academic Press. New York. Cited in Baron-Cohen *et al* (1994).

Bibliography

- Burr, V. (1995) ***An introduction to social constructionism***. Routledge
- Denzin, N. and Lincoln, Y. (1994) ***Handbook of qualitative research*** Sage.