



United Kingdom Human Rights Committee

Human Right Violations Against Parents That Are Autistic, Have an Autism Spectrum Condition

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This report was produced with co-operation by user led networks and organisations in the United Kingdom that advocate, raise awareness and support autistic women and girls.



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Introduction

The number of parents who are autistic, or have an Autism Spectrum Condition, is unknown. There is no available data to indicate how many parents of 'looked after' children in the United Kingdom have a disability. Researchers at the Norah Fry Centre (Bristol University) estimate that parents with a learning disability are up to 50 times more likely to be involved in care proceedings. Autism is a neurological difference that is genetic and heritable. Many autistic or autism spectrum children have at least one autistic parent, or other autism spectrum relative. Reports from peer advocates and support groups reflect the over involvement of autistic parents in child protection proceedings. Some of these families have endured years of professional neglect and abuse, based on misunderstanding and inadequate assessment. Different or unusual styles of family life are seldom respected. Due consideration is rarely given to providing services to support the capabilities of parents with disabilities or neurological difficulties. Disabled parents and their children have a right to family life. Autism should never be accepted as the overriding reason to remove children from their birth families.

In England, the Autism Act 2009 (<http://www.legislation.gov.uk/ukpga/2009/15/contents>) led to the government publishing statutory guidance in 2010 that Local Authorities must have a clear pathway of diagnosis for adults. Despite that guidance, wait times for an adult assessment is dependent on the geographic area of residence with wait time of up to 2 years. This is relevant to the Practice direction 36c under Part 4 of the Children's Act 1989 to conclude care proceedings within a 26 week timeframe. For an autistic, who believes her or her children, are autistic her ability to obtain assessments and provide proof of entitlement to access reasonable adjustments and service provisioning cannot be achieved against a 26 week timeframe. (<http://www.legislation.gov.uk/ukpga/1989/41/part/IV>)

For women, their identification as autistic women is an emerging area of research with the National Autistic Society stating that one in four autism diagnosis are female with 1 in 68 (USA figures) of the general population being autistic (<http://www.cdc.gov/ncbddd/autism/data.html>). Dr Judith Gould from the Lorna Wing Centre stated in an interview with The Guardian that females are being missed and "there is definitely a gender bias towards boys when it comes to diagnosis". (<http://www.theguardian.com/lifeandstyle/2015/jan/05/are-women-with-autism-being-failed-by-nhs>).

In a 2013 survey conducted by Autism Women Matter 61.62% of women surveyed had been formally diagnosed as being autistic with 38.8% of women self-identifying as being autistic. A measure of the effectiveness of the diagnostic pathway can be obtained through the funding support for a diagnosis with 28.7% self-funding their diagnoses, 63.49% obtaining a diagnosis through the National Health Service (NHS) and 7.97% diagnostic funding support through a charity. (<http://autismwomenmatter.com/survey/>).

Five years after the governments Autism Strategy, autistic women were finally included in 2015 in Statutory Guidance after campaigning by autistic led networks and campaigners. The guidance states that Local Authorities must "recognise that women with autism may be missed and misdiagnosed as they may be better able to mask their social difficulties. There can also be a perception that autism is something that men have and this can impact on women being referred for diagnosis. Improved

awareness and training should help overcome this".
(<https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>).

The failures to identify women as being autistic and the challenges in obtaining a diagnosis are still present. Through these failures, women that are autistic but have not been diagnosed, or are unaware of their autism, have entered into child protection proceedings without the reasonable adjustments (accommodations) they would otherwise be entitled to under the Equality ACT 2010 (<http://www.legislation.gov.uk/ukpga/2010/15/contents>). The systemic failure impacting on human rights Article 8, Right to a Private and Family Life of the mother and child's and the right to Article 6, Access to fair trial and proceedings. Autistic mothers are going into court as vulnerable witnesses, unrepresented and without advocacy where the child protection system, without reasonable adjustments, are causing the very harm to children that they claim to be preventing.

Children have the right to be protected from all forms of abuse, neglect and violence and children are also violated by unwarranted removal from their families without their consent. The United Kingdom remains one of the few European Union countries to practice 'forced adoption', the practice of removing children permanently from their parents and the subsequent adoption of those children, following intervention by the Local Authority without the consent of the parents. Further, children are removed from their families as a predictor of 'future emotional harm' where no current or past abuse, neglect or violence has occurred and frequently alongside allegations of Munchausen by Proxy (Fabricated Illness).

In 2000 the Former Prime Minister Tony Blair's 'white paper' ordering a 50 per cent increase in the number of young children placed for adoption from care and provided £20million to councils as incentive bonuses (http://dera.ioe.ac.uk/2241/1/dh_4080512.pdf) to meet targets. MP John Hemming, an Oxford educated scholar, has said the policy led to the unnecessary adoption of 1,000 children every year and stated "It involves corruption in the courts and legal system and a complete failure of our child protection system, which concentrates on getting children adopted rather than protecting them from harm." (<http://www.express.co.uk/news/uk/259355/10-000-children-ripped-from-their-families>)

For autistic women, before obtaining the correct diagnosis of autism they be mislabelled with anxiety, depression and personality disorders through poor understanding of their needs as disabled people. The benefit of user led groups to autistic people has been recognised in England's statutory guidance for autistic adults. Sarah Hendrickx in her book 'Women and Girls with Autism Spectrum Disorder' reiterates this point in context of family life. "Women with autism who had a child with autism spoke of a special bond with that child and of having the intuition to know what their child needed even when it was different to what all the books and advice stated". Sarah elaborates on the positive benefits of shared neurotype (child and parent being autistic) "the inheritability of autism can be a blessing for some girls growing up with autism in families where similar characteristics may be inherent in parents".

Adoption cannot always be considered the best alternative for children that are autistic. The British Association of Adoption and Fostering (BAAF) estimates that one in five adoptions break down and a study by the Maudsley Hospital in London found a

breakdown rate of 8% after one year and 29% six years later. On average, adoptions that broke down did so 34 months after placement. The UK misguidedly refuse to set aside adoption orders even when it is subsequently proved through the courts that the decision was wrong.

From diagnosis, assessments, lack of service provisioning, failure to provide reasonable adjustments and misinterpretation of parent and child's needs, the social services and legal system are breaching Article 6 and 8 Rights.

What Is Autism Spectrum Condition

Medical Perspective

Autism spectrum Condition (ASC) is a lifelong neurological difference defined by diagnostic criteria that include differences in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities About 1 in 68 children has been identified as being autistic (having an autism spectrum condition) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

Autistic Perspective

“Autistics struggle as much with bias and prejudice as with health and disability”

In an international setting such as the UN, it may be easiest to think of autism as akin to being an expat, living in a foreign country with an alien culture for a prolonged period of time. Autism is like being an expat in one's own country, like being an expat all our lives. We live in a continuous state of culture shock.

We find it difficult, if not impossible, to relate to non-autistics and often don't understand social and societal norms and customs even if we grew up with them. As we get older and as things are explained to us or we learn by observation, we may come to mimic others' behaviour, without ever fully grasping why they do what they do. It never feels natural. And far from appearing "normal" to others, they may perceive us as weird or odd, distant or aloof, arrogant or egotistical, when really we are confused and lost.

In our constantly evolving scientific understanding, autism is a neurological difference that is both genetic and hereditary. Many autistic children have at least one autistic parent or other relatives on the spectrum. While common co-morbidities such as anxiety and depression may respond to drugs, medicine has proven ineffective in treating the core symptoms or altering the core characteristics of autistics. There is no cure for autism, and we do not believe that a cure will ever be found. Medical research may, however, result in a reduced level of severity in the most severe, making them less dependent on family and professional care and support.

Autistics struggle as much with bias and prejudice as with health and disability. Challenges and severity vary widely between individuals, but commonly include

difficulties understanding, and using, facial expressions, body language, tone of voice, and non-literal language, unusual speech and eye contact, apparent lack of empathy, dislike of small talk, repetitive behaviours and body movements, reliance on routines and rituals, restricted range of activities and interests, aversion to change, intense focus, perfectionism, dislike of being touched, sensory overload, and coordination issues. (Autistic Minority International)

Autistic Women Underdiagnosed

Autism Spectrum Condition (ASC) has previously been and is currently believed to be more common in males than females with a male to female ratio of 4.3:1 (Fombonne 2003). According to recent research, there are issues to do with this assumption including the following:

- Most research has involved males.
- there are few studies of gender differences in symptoms, and available findings are inconsistent (Van Wijngaarden-Cremers PJM et al J Autism Dev Disord (2014) 44:627– 635)
- Some girls with ASD may not be identified by our current screening instruments (Westman Andersson, G., Gillberg, C. & Miniscalco C. (2014) Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles? Research in Dev Dis Volume 34, Issue 1, January 2013)
- many females with normal to high intelligence could be overlooked or misdiagnosed because they do not present the male phenotype of autism (Van Wijngaarden-Cremers PJM et al J Autism Dev Disord (2014) 44:627–635)

Females on the spectrum have been described as being like swans – appearing to glide across the surface of life but paddling furiously under the surface just to keep afloat. This seeming ability to ‘cope’ is exhausting, can be highly misleading, can lead to feelings of low self-esteem, loneliness and isolation and when females hit ‘crisis’ can lead to their problems being misunderstood or dismissed.

Autistic Females

- may develop ‘cloaking and masquerading’ skills
- may be more articulate with better social (imitation) skills than males
- Are colleagues, friends, girlfriends, wives and mothers.
- May be working, in offices, industry, medicine, academia, art and media; unemployed, students.
- Visit GPs, go to the dentist, attend children's school events and parents' meetings, visit restaurants, cafés and cinemas, join evening classes, take yoga, and go dancing.

ASC women may seem to be fine, 'normal' and coping with life; but every day, all the time, in their daily lives, they are dealing with a range of issues to do with differences and challenges in information processing, communication and sensory issues (Murray et al 2005). These latter include mild, moderate, or extreme sensitivity to noise,

crowds, bright lights, strong tastes, smells, and touch. This is not specific to females but is hugely important. <http://autism.about.com/od/aspergerssyndrome/fl/Why-High-Functioning-Autism-Is-So-Challenging.htm>

Girls and women on the autism spectrum are vulnerable anxiety, depression. They are also highly vulnerable to abuse, both emotional and physical/sexual (Stewart 2011). Girls and women may be misdiagnosed with other disorders, such as social phobia or borderline personality disorder, instead of ASC (Attwood 2007) and therefore not receive the kind of support they need – worse, they may be subjected to inappropriate interventions.

Beyond the aetiology of ASC or sex specific manifestations, cultural expectations may clearly influence both the social expectations on each ASC individual and the coping mechanisms available to them. For example, aggressive behaviours arising out of extreme stress, or challenge, or sensory overload, in adolescent boys with AS may provide the trigger for assessment and diagnosis. However, such behaviour is less likely to be identified in girls or understood.

Despite there being no cogent evidence to suggest ASC women are unable to competently mother their children, there are personal reports from both women and practitioners that mothers may risk being judged and misunderstood on the basis of their 'non-typical' responses or characteristics or even just preconceived misinformation about the nature of autism.

Further, adult women with AS have reported feeling pressurised, judged or excluded on the basis of their seeming lack of what may be seen culturally as feminine characteristics or of displaying male ones (Faherty 2002). Increasingly prevalent personal reports suggest that gender and sexual stereotyping are issues affecting the ASC population widely, with some ASC adults adopting 'non-gendered' or 'transsexual' identities. (Dr Catriona Stewart)

The System Failing To Provide Adequate Support

Mandy Shrimpton is a psychologist, Specialist Social Worker and CEO of Rainbow Autism. Through her experience in health and social care she provides insight into why systemic supports are non-existent, inappropriate and inadequate for autistic women.

Previous 'labels' Stick

Health and social care systems are too geared towards 'ticking boxes', quantitative data and impressed by the medical model. It is therefore biased towards finding labels than offering practical solutions. 'Personality disorder', 'depressive' and some with 'eating disorders' have all been diagnosis/labels frequently used to describe symptoms

of autistic females when they had previously presented within mental health or other services (there is research to show evidence for the differing opinions of diagnosis between clinicians with mental health conditions let alone what this implies for the complexity of autism). Although dual diagnosis is sometimes presenting, many autistic females have experienced inappropriate or no support due to the lack of knowledge of professionals of the condition.

Some professionals displayed an unwillingness to admit failure when they had clearly provided inappropriate services or showed sheer arrogance and refusal to accept it to be anything more than their original diagnosis. Even when an autism diagnosis was given the focus of clinicians can be to prove where it is 'like' the previous diagnosis given to justify their claims. There has been known cases where psychologists were pressurised to undiagnosed an autism spectrum condition. This in itself has influenced women to become depressed, frustrated and angry as they felt let down by the system and made to feel like they were 'attention-seeking' or having other hidden agendas. This has resulted in some women withdrawing completely from engaging in any help later being offered through their mistrust and a lack of self-confidence. Greater multi-agency and collaborative working is required and inclusion from professionals/agencies that have experience and good track record of working with autistic women.

Diagnosis can be important for some but can be limiting for others with the most vital element to explore prior to any diagnosis is to help the person address what it will achieve long-term. Time should be offered to the individual to prepare for a diagnosis - even those considering this to be a very positive action and absolutely sure it was what they wanted had later found the news of having autism being devastating. This was partly the realisation that problems were not going to go away and without diagnosis there was some hope of 'improving' and autism still has some negative connotations attached to it in this society. (M.Shrimpton)

Training and What Professionals 'think' They Know

Professionals and agencies failing to admit their ignorance of autism because they have done a few hours of autism training, 'know people with autism' and therefore believe they have 'expert' knowledge. This results in poor practice and inappropriate help which can do more damage than good in the long-term. Every individual is different and the a great deal of training or professional experience has emerged from what was perceived by those in institutional care, clinical or educational bias or provided by those on the spectrum able to communicate their needs. Those most likely

to be 'in care' can have separate needs to those living in the community without diagnosis and struggling to cope with jobs, family life and general day to day living. They will often be behind closed doors and in the safety of their homes or bedrooms. Greater inclusion from a range of agencies offering practical experience is required in training and a partnership with autistic people should occur for effective training delivery and formation. (M.Shrimpton)

Assessments and Gatekeeping

There are many barriers to getting an assessment of need which is the only way to getting any professional support or appropriate services without the funding for private consultation. Firstly, the process of getting assessment is usually reliant on either individuals having to do their own searches to locate the necessary point of access to get any advice, help or information on support or services available or happen as a result from a crisis situation. This can include having to make phone calls, internet searches or face to face contact, all of which may prove difficult for someone with HFA. Once an access point for possible assessment is found the process through to then successfully being assessed will be dependent on the person providing the initial contact interpreting the situation correctly and the individual making the referring ensuring they clarify the needs in dramatic terms. There is also a good chance of being passed from one team to another as the choices for information, advice and support for autistic people can be limited. Unless there is a clear pathway in ones' county for autistic people, only way to access any help is through the mental health or social services system. Many assessments may be reliant on strict time frames for completion and strict eligibility criteria's to adhere to including needs having to be assessed as critical or substantial before anything can be offered. Historically, eligibility has usually evolved from the needs of those with severe learning or physical disabilities, older people or those with severe mental health conditions (benefits agencies are a point system evolving from such baseline of needs). For an autistic person they can go to crisis point with the right triggers to influence their anxieties and 'meltdowns'. However, bureaucratic systems in contrast can be slow to act, dependent on set processes to adhere to and inflexible to meeting with such complex needs. Public funding constraints also can add to the problems as many professionals can only offer what budgets can allow. (M.Shrimpton)

Consideration of Future Service Assessments

Future services need to consider and introduce a more creative approach to completing assessments and the support on offer if long-term benefits are to be

achieved. For example some health professionals can refuse to allow service users/patients to email them directly due to their policies but this may be a preference for some that cannot deal with face to face contact. Assessments may be more honest and easier to complete if this could be done via email, social media or through the use of other ways than just face to face contact.

Decisions need to consider and fund preventative measures and not just be about 'fighting fires' when things have gone wrong. Specialist agencies/professionals are in short supply but so too is opportunity and the recognition for 'outside agencies' to get into a health or social care systems to promote their services. Brokerage is an area to be investigated as is the system of 'preferred providers' and the processes of public authority and NHS tenders.

Too many support plans are biased towards a need to find the cheapest solutions and to agencies already set as 'preferred providers' instead of considering a person-centred and/or multi-agency approach. Mental health for example are biased towards a 'recovery model' (**you cannot recover from autism**) and so will look to offer a 'quick fix' (so medication may be a chosen option) to promote that recovery. Social services on the other hand are so strapped for funding that they will go with agencies that 'fit' with a local authorities banding of cost and outcomes. There is no 'one size fits all' for autistic people. Pressure of reaching targets and ensuring data bases are set up to identify these do not fit well with the reality of life for autistic people with fluctuating needs. Services can appear to do well but in are not offering the support that is really needed and so fail to make long term positive change. Many services that are target based are time limited so will step out when these are reached but the autistic individual has a life-long condition and the bureaucratic system in not flexible to work with meeting needs adequately. Many clinical assessments are a matter of 'ticking boxes', psychometric tests are all relatively the same in their content but with HFA it can depend on ones' mood of the day, their environment the ability of the assessor to engage the person and to then correctly interpret the information given. This all provides a basis for problems to arise. . . (M.Shrimpton)

Assessment of Mothers

Many mothers we see are terrified of children being taken into care. The general gender inequalities of society can be heightened when the female is autistic and within the health and social care systems (i.e. biased towards male dominated systems and ideals subtly entwined through the tendency of male clinical leads or lead commissioners – being male, middle class values. Female social workers may wish to

affiliate with these values of the 'system' in order to be accepted and valued by their colleagues and to gain promotion. Many commissioners have come from banking, finance or system analysis backgrounds so not really be familiar with the practicalities of motherhood or such things as having to struggle on limited incomes. We need to see more female social workers in top positions and those coming from a range of backgrounds if this is to change and allowing sub-contracting to agencies or professionals that have the specialist experience required.

Females appear good at fighting for the rights of their children but not so for themselves (or recognising their own needs). They are often very vocal when fighting for the rights of their children and can be very honest (even if that means telling professionals what they are not good at). Many are also facing constant battles with fighting for children's needs when many also have children that are autistic and can be so worn down by the battle that do not have time or able to recognise when they need help until it is too late. Some say they also feel 'ganged up on' when a number of agencies are involved (such as schools, social services, health professionals and this can cause confusion, sensory overload and high levels of anxiety. Non autistic do not like having their faults pointed out and people find a constant 'complainer' difficult to deal with (particularly if you have limited time or funding and a very busy caseload) and so this can have an impact for those needing support. Many autistic females are in good careers and may be perceived as successful by others and do well in their areas of interest (such as writers, artists, campaigners) however to the untrained mind this can work against them and consequently see them as attention-seeking or manipulative (far from helpful for mothers being assessed on their parenting skills).

Greater numbers of advocates need to be available and funded (few local authorities and professionals seem to involve independent and adequately experienced autism advocates and there appears little information or funding provided to allow individuals to access these). This would enable better communication and ensure a two-way understanding of rights, responsibilities and limitations. The mother's needs (that can be overlooked) should be addressed more fairly if she is autistic and taken into account of as well as the children in assessments. . (M.Shrimpton)

Autistic Parents and Education

Some mothers can encounter multi levels of disability discrimination during the years their children are in education. Their ability to research what is best for their child, their social communication differences and the way they experience the sensory environment around them can be barriers in accessing appropriate supports and

meetings for their children. The inflexibility and lack of training of professionals can make interactions between school and home contentious and escalate to unwarranted child protection measures. The ongoing 'battles' can be detrimental to all mothers regardless of their neurotype (autistic or not) but for an autistic person, it can seriously impact to their Right to Family Life and Privacy.

In England, Autism Campaigner Anna Kennedy researched bullying and wrote "Children with autism, who often struggle to 'fit in' and to understand social rules, can be more vulnerable to bullying and teasing. I recently conducted a national survey¹ of over 900 parents of children with autism in Britain. It reveals that over 60% of children with autism have been bullied in mainstream schools and the problem is being largely ignored".

In the UK, parents can appeal education provision for their children with "appeals involving autism the fastest growing category and the third largest overall at 11% of the tribunal's case load up from 6% last year" and parents are increasingly unsupported in the systemic fight for their child to receive appropriate and inclusive education with "the number of hearings at which participants were represented by lawyers or supported by charities or parent advocate groups has declined sharply" (<https://www.tes.co.uk/teaching-resource/Appeals-on-autism-are-increasing-fastest-81322/>)

Sometimes parents will home school their children when they have unsuccessfully tried to access supports and bypass the system completely. One mother in the book 'Women and Girls With Autism Spectrum Disorder' wrote of her experience with the system "it's been grim – fighting for diagnoses, fighting for education, fighting with the LA's (Local Authority) for provisions etc. It's like a constant fight that you can't back out of, and it never ends – it's always time for the next Annual Review or IEP (Individualised Education Programme) meeting or Phase Transfer" The impact of the quality of Family Life and their privacy cannot be overstated.

Home educating can be seen by women as the best choice for their mental health and that of their child with one mother stating "because I'm free of the mainstream system, I can meet my own needs much better which means I'm in a better and stronger place to meet the needs of my children and I'm modelling healthy habits for my autistic child. It is really important for the autistic adult to make sure they are on an even keel if deciding to home educate" (D.Hallisworth).

Those children can be the most underdiagnosed and under support children in terms of systemic supports due to a failure of the system to allow meaningful inclusion and cooperative relationship building between parents and professionals. Autistic children can benefit from home school or flexi school (the child attends formalised education part time) arrangements allowing a greater opportunity to develop the child's autistic needs and harness their interests into learning opportunities (see Case Study One, Home School).

Parents that cannot home school and are aiming for inclusive education within the education system can find their autistic differences and unmet disability needs in accessing the system to be wrongfully interpreted as character flaws. Barbara Martin

of Cheshire based 'Multi Sports' is an advocate that has assisted autistic parents within schools. She states "autistic ladies are focused on getting to the bottom of their child's difficulties and having the right supports put in place. They particularly cannot tolerate injustice but their intense focus can be perceived by non-autistic people as obsessive or controlling". Mothers perceived this way can often be accused wrongfully as obsessing over their child's disability to the detriment of the child identity and be labelled (without psychological reports) as Fabricating Illness in their child. Please see Case Study Three, School and Fabricating Illness.

At a recent conference in Birmingham, Professor Tony Attwood, a leading world expert on autism, quoted an 86% anxiety figure in a study of 300 adults. Sarah Hendrickx, author and psychologist on autism issues, states "it is a given to be anxious whether you're a parent or not and parenting, I would argue, exacerbates anxiety many fold due to the 24/7 panic of recognizing and responding to the needs of a non-verbal, non-rational person who is in your care. Particularly if many of the skills required have a social acceptability basis (that you're not aware of), or require people reading or intuition (which you find difficult)." Professor Attwood was also quoted that autistic women have a "pathological fear of making a social mistake" that Sarah Hendrickx further puts into context with autistic parents "for women surely parenting is the biggest opportunity for making a huge social mistake. As women we are supposed to be natural mothers and so any drift from the 'norm' is judged as neglect or abuse more quickly than it would be for a man".

Case Study One, Home School

There are huge advantages to children in the spectrum in being home educated. They can have their learning tailored to their exact needs, take breaks when they need them, study things they're interested in without interruption (thereby enabling them to achieve the mastery required to make a career out of a special interest, perhaps) and extra focus and help can be given to developing social and general life skills. General anxiety levels are lower, there's a closer relationship with their family, especially siblings, and the transition to adulthood and independence is easier. Benefits to autistic mums are huge. The stress of dealing with the school system takes a lot of energy, especially if the system isn't supporting your child as well as it could. Home educating means a more natural, relaxed start to the day instead of the anxiety ridden rushing to get everyone ready and out the door for the school run. So the days start well which sets everyone up for a good day. I can plan activities that involve social connection and give us all a chance to succeed in them, simply because we're not forced to go, or stay, and can limit interaction to a few hours (or less) at a time. This means interactions are positive, so friendships build, confidence is gained and there's a good support base there when needed. I find having the same neurotype useful in that I understand how meltdowns develop so can help my child avoid them and I'm always craving knowledge so find it quite natural to study topics my child is interested in, to the depth my child wants to study them. I like learning, and that rubs off on my children, so they like learning too! It also keeps us connected so we understand each other and relate better to each other. There is a lot of trust there too so my autistic child will push themselves out of their comfort zone more readily, trusting that I'm there and will guide them out of difficulty. Autonomous learning really suits autistic children

and I intuitively know how to strike a balance between individual and group activities that will keep my child learning and growing at a steady rate. (D. Hallisworth)

Case Study Two, School and Fabricating Illness

Mother with autism with a son that was diagnosed with autism at a young age. The mother was concerned at the extreme meltdowns the child experienced on return from mainstream school. Despite the autism diagnosis school were dismissive that additional supports were required and questioned the validity of the diagnosis. The child stated to adults that he wanted to kill himself, hated the noise of the classroom and shouting of the students, had no friends and was traumatized by the noise of the hand dryer in the bathrooms and so did not go to the toilet when at school. This led to bowel difficulties and trauma at the thought of fire alarms and unexpected loud noises. The mother requested I accompany her to a meeting with the Head Teacher of the school whose attitude towards the mother was one of 'bullying' that led to a formal complaint to the Local Authority. Thereafter, there was evidence of institution sharing of information to the detriment of the family that included telling social services that they would find the home in chaos. The mother agreed to schools recommendation for a referral to Social Services to "help" the family. Social Services arrived at the home in a two person team and it became evident they were there to assess not how they could support the family but with the view to remove the children. The home prior to Social Services arrival was calm, children happy and the mother hopeful of obtaining supports for her child. The professionals from multi agencies prevented the mother from having advocate support and met privately to discuss the family without the mother present. An Educational Psychologist judged the mother to have Munchausen's by proxy. The mother obtained legal support that led to Social Services agreeing there was no case to answer and the child was subsequently placed in an autism specific school. (B. Martin, Multi Sports Cheshire)

Case Study Three, Home School interference

"I am a mother with Asperger's and I have two autistic children - who are both female, making it all the more important that they do not ever go through what I have been through.

Before I received my Asperger's diagnosis, I approached my GP for an ASC assessment for myself and my children. The GP decided I was obsessed with autism, I wasn't autistic and that my autistic traits (earplugs for sensitive hearing, "pressure of speech") were instead due to severe anxiety and purely because I was home-educating my children, he decided they were at risk of abuse or neglect and made illicit social services referrals, in breach of guidelines and in complete incongruity to the evidence of visibly well-cared for children.

Social services visited and reported no concerns. Due to my younger child's difficulties, we subsequently accepted a referral to disability social services. Both children were diagnosed with autism within the space of approximately a year of each other. Within that time, disability social services failed to be of assistance to the family, and their involvement was stressful for us. They had no autism awareness, I assumed that being disability social services they would have.

I decided there was no point maintaining a connection with them, their visits to the house were very stressful for the children and I only entertained their involvement for the sake of support for the children, which was not forthcoming. In response to disability social services changing our social worker, I took the opportunity of telling them we no longer needed their service. This changed their approach for some reason and they demanded a meeting.

At the meeting, for which I brought along an independent witness, we were told they would close the file. They subsequently changed their minds and then started saying they wanted to see the children alone, I raised a formal complaint through the local authority. A social worker said I was anxious based on my verbosity. Verbosity is a very well-known Asperger's trait. We were told to bring the children to see them, the children were plainly unhappy at being there and didn't want to talk to the social workers. I found out from copies of file notes that the social workers had outrageously lied on record, by falsely claiming I had prevented the children talking to them at the meeting. I had to get expensive legal advice from a family lawyer. A meeting was held purportedly to discuss the complaint, but they used it instead to criticize me, even though I had previously been assured by the manager that they were "not looking for anything wrong". When I described a behavior of one of my children the social worker said "well in that case we want to know how your Asperger's affects your parenting". I had to threaten social services with legal action if they wouldn't stop harassing us and another professional subsequently spoke on my behalf and the files were then finally closed. We have been scared off from ever asking for support again because we know they lie and misrepresent Autism." (Planet Autism)

Assessments & Meeting Adjustments

Autistic women may experience difficulties responding to verbal communication and require time to listen, process and formulate an appropriate response. Obtaining a response immediately does not always reflect that the mother has been meaningfully included in a meeting. Allowing the mother access to all written reports that will be discussed at least 3 days before the meeting allows the mother to formulate and 'script' her response. This is particularly important for mothers that have an expressive language difficulty or enhanced sensory difficulties that she may also be self-regulating.

As one mother, Catherine, described. "I am given advice and information that takes me days to process the full meaning of ...and once I finally process it all days later I'm often angry and frustrated that the meeting was a wasted opportunity for me" Another mother, Caroline described her inability to follow proceedings as "they had 5 professionals talking and it was really hard to follow what was being said and then they would look at me but before I could say anything they had moved on to talk about something else. But when I was trying to talk they kept interrupting me and then I would have to start again until I just couldn't do it anymore and just stayed quiet"

An autistic mother may appear to not be engaging in the process by choice, be obstructive or uninterested in what is happening. The mother may be self-regulating the way she feels, sees, hears and smells her environment that may be enhanced during periods of stress or anxiety. Her natural response to the sensory stimuli may

be fight (perceived as aggressive), flight (hurry proceedings or leave at perceived inappropriate times) or frozen (non responsive and lost capacity to be verbal).

The mother may appear aggressive or shouting but when she struggles to moderate the tone of her voice and may lack some self-awareness, particularly in times of great stress and anxiety when her adaptive skills are lowered. In planning meetings please be aware of environmental triggers including air conditioning noise, residual noise from hallways or other meeting rooms, a seating position where she can see what is happening behind her, allow natural light to be used, schedule longer meeting times to allow for frequent breaks, and time to process what is being said about her and to her. A mother, Jen, describes the physical effect of failure to account for response to sensory stimuli “the air conditioner was not working so they opened all the windows and the noises from the cars was all I could really hear and the head teacher likes to wear perfume so strongly it makes me feel poorly”

Organisational hierarchies may be difficult for an autistic woman to intuitively understand. The mother may appear to not accept help offered and not coping because she has not been told the processes she needs to engage with. The lack of information creates uncertainty in understanding what is coming next, how long it will last or what her role is. Providing a diagram that shows the structure of the organisation / charity / department and the relationships and relative ranks of the positions/jobs will enable the mother to visually process what stage of the process she is participating in. Paul described how a mother can be engaged in a process without her understanding of their meaning “the social worker said her we would need to get everyone working with (name of child removed) together and discuss what she needed but it was a child protection case conference. We both went home completely betrayed that asking for help meant we were being accused of something we did not do. It went to a child in need eventually but the labelling of the processes and what they meant was hard when you think you are discussing one thing and they have a different agenda”

Autistic women may struggle with social hierarchy and how to communicate differently with people of different status. This can get them into trouble with teachers, bosses, family elders or others in the community. This impairs her ability to access help from the most appropriate person and understand who can and cannot be useful, who can or cannot make decisions, who is or is not influential. Providing a diagram that shows the organisation / charity / department and the relationships and relative ranks of the positions/jobs will enable the mother to understand who and where to access assistance. This can impact on the mother’s engagement with one mother stating “in the court papers they said the Guardian tried to meet with me but I was refusing. There was so much happening and so many people I had to talk with and I did not understand how important the Guardian was. She is like the Queen in chess. If I had known that, of course I would have talked to her!”

Autistic mothers can approach parenting in a research based manner. When a mother experiences communication that is not clear, concise and without hidden meaning she may lose confidence in her own ability to communicate and /or lost trust in the data she is receiving through communicating with professionals. This may lead to her

hyper-focusing and hyper-vigilant on details and appear to not see the situation holistically. This may result in the mother retreating from the process (leaving herself and child unable to access the systems designed to help) or escalate situations without mediation.

Frequently parents are told to “tell the worst day example” in order to access correct supports for their child. An autistic mother may take this literally and not generalise to specific situations and apply the advice in her interactions with all professionals in all situations. The mother uses her attention to detail to focus on changes within the child. She is able to help her child by finding answers to help them. The mother may have researched the child’s difficulties, be able to recall details on reports she has read (photographic memory) and may ask more questions than what makes professionals comfortable. Sometimes the mother may be accused of fabricating illness in her child or overly focusing on the disability of her child to the detriment of the child’s sense of identity. This is usually untrue, it is a communication style difference. One mother says, “I went through a S47 when I trying to get educational statements for my kids and they said I was ‘emotionally abusing’ them by focusing on the problems. For every referral I got for the kids the GP agreed with me to make the referral and as part of the care proceedings the kids were later diagnosed. It was only when a charity paid for my assessment that the professionals started to understand me better and now the kids are on ‘child in need’ and taken off care protection. It does make me wary of going for help now”

Social Services Mislabelling Autistic Traits

Misperceptions can be unmet disability needs of the mother or the mother responding appropriately to the child’s disability needs. Neither warrants child protection measures but may require additional service provisioning to support the family.

Where genuine parenting difficulties exist, they may be resolvable through preventative training and support prior to extreme measures of removal. Parents report the need to prove capability without access to supports through their own caseworker in Adult Social Services. Supports should be obtained through Carers Assessment (as role as a carer) or with a Community Care Assessment (their own needs) both of which are a legal requirement of Local Authorities. Access to an advocate trained in autism spectrum conditions and training of social workers is imperative to ensure women can access assessments and have their needs correctly identified.

The Association of Directors Adult Social Care (ADASS) have written of the recognition that supports may be required for parents and engagement with Children’s Social Services “Understanding how autism influences someone’s life is important - none less so when they have additional needs, such as a learning disability, serious mental health issues or physical health needs. Recognizing how they co-exist is important when supporting someone to manage their needs successfully. Recognition of gender, race, and sexuality are also important when, for example, considering how best to support a woman with autism bringing up a child who requires reasonable adjustments in parenting support; engaging with children’s services, and considering

the cultural and religious beliefs in relation to raising awareness of autism within local communities.” (<http://www.adass.org.uk/blog-new-thinking-about-autism/>)

Wrongful Allegations Of Neglect

Neglect can be attributed to executive functioning delays or sensory processing disorders of the parent and the child. For example, a family that has a restricted diet can be the result of sensory response to the taste, texture and smell of food. This is normal and the family could be supported with nutritionist input or occupational therapy. She may experience difficulty with the planning and arrangement of food shopping with her own and child's response to busy supermarkets, the fluorescent lights, jostling of people, trolleys and managing her children and heavy laden bags. Support through carers and internet shopping could be considered. The cooking of food requires many steps that can overwhelm some parents or they may become overly concerned to ensure the child meets the recommended dietary intake of '5 a day' balanced meals.

Many autistic people do not feel comfortable using the telephone and may struggle to make appointments and then manage their schedule, their children's response to out of the home visits and to keep those appointments when made. Providing text or email for parents to make appointments can reduce pressures as can access to after hours or home visits from GP's.

A mother may be perceived as limiting her own or her child's social opportunities. This can be a non autistic interpretation of needs based on their own value judgements that may not be aligned with an autistic parent or child's actual requirements.

A child may reach a crisis in health or sickness before the parents seek medical attention. This is not neglect, it can be a child that does not outwardly exhibit pain in a way typically observed through the way their body processes pain with a sensory processing disorder. A mother that insists on x rays or medical attention beyond what a doctor thinks is necessary is not an anxious parent or a parent fabricating illness, but a parent that understands the nuances of child behaviour in terms of sensory response to pain.

A mother that does appear emotionally demonstrative to her child can be limited in her facial expressions and body language. This is, in the context of both mother and child, perfectly acceptable as a characteristic they both share. The child and mother may also be managing chronic pain symptomatic of underlying collagen deficiencies including Hypermobility and Ehlos Danlos Syndrome that can be a physical barrier to physical touch

A mother may have a different contextual or social awareness of the role of parenting due to her own social isolation as a disabled person, lack of peer model or have been a product of the care system and not had the incidental learning opportunities required of the parenting role.

A mother who is reluctant to engage with 'the system' may be too frightened to ask for help in case her children are taken out of her care; she may isolate herself and her child in self-protection. This is an understandable response to a very real threat.

Wrongful Allegations of Emotional Abuse

This is can be a woman that struggles with regulating tone of voice and have limited facial expressions that give an impression to others of mood that may or may not be reflective of actual emotional involvement. The mother may also have differences in adjusting her vocabulary (semantics / pragmatics). She may be wrongfully perceived as shouting or being aggressive and be quite shocked in the difference of her intent against others perceptions. This can be part of her disability and difficulties with social communication.

A mother that appears to not respond appropriately to the needs of the children can be based on non-autistic predetermined ideas of what is appropriate. For example, a child falls over and the mother does not rush to assist as she is aware her autistic child (diagnosed or not) requires space, no touching and time to process the pain before other human involvement in incident management. It may also be her difficulty in not recognising the repair role of physical affection that some children require and not respond when required. This is part of her disability in understanding and accepting alternative perspectives.

A mother may go into 'research' mode and sense that her child needs assistance and seek answers. Social communication difficulties and sensory overload when in meetings often lead to breakdown of communication between home and professionals. This behaviour is misdiagnosed as fabricated illness, Munchausen Syndrome. Her perceived hyper focus of difficulties the child experiences that is deemed to be damaging, now or in the future, to the child emotional development is her autistic attention to detail.

Social services may wrongfully perceive violence which is actually an autistic 'meltdown' in response to disability needs not being met. This may occur after prolonged periods of not receiving support or not receiving targeted and appropriate support for the parent and the family. But, the way the system interacts with an autistic family can in itself create incidents of violence / meltdown.

Police & Child Protection Powers

Autistic people are more likely to be harmed than harm others and have a strict adherence to rules. Their homes can be their 'safe place' free of demands from society and where they retreat to deescalate from their experiences with the outside world. Autistic children and adults can struggle with unexpected visitors where they have not been able to manage change effectively into their daily routines that are important for their sense of security and stability.

Under Section 46 of the Children Act 1989, In the United Kingdom police have child protection powers to intervene to safeguard children from "significant harm". Under this law, the police have the power to remove children to a safe location for up to 72 hours and do not require a court order to remove children. A 1998 study of 13 police authorities found that the most common reason for police protection provisions being used was for children "at risk" with 60% of children being placed into Local Authority

care (*Protecting Powers: Emergency Intervention for Children's Protection*. West Sussex, England: John Wiley & Sons. pp. 55–82).

Some local authorities choose to seek assistance from the police when courts are unwilling to hear an application for an Emergency Protection order at short notice (*The Social Worker's Guide to Children and Families Law*.) Some police officers feel that they do not have adequate training or skills to make a judgement regarding exercise of their child-protection powers (*The Social Worker's Guide to Children and Families Law*.) A larger concern of the police is regarding the consequences of not acting; therefore, 'covering their backs'. (*Protecting Powers: Emergency Intervention for Children's Protection*. West Sussex, England: John Wiley & Sons. pp. 55–82).

For an autistic mother, uniformed police officers arriving at her home unannounced when she is managing her child's needs can escalate the family emotionally and trigger an autistic overwhelm that is referred to as a 'meltdown'. She may be unaware of the seriousness of the visit, what it entails and what actions could be taken and find it difficult to manage her emotional responses at the unannounced intrusion on family life. Her response, and the response of the child, may create the impression of 'significant harm' needed for police to take action and / or the police preferring to take preventative action as self-protective measures.

One mother reported that she agreed to her children being removed, under the impression that the children were being taken for 72 hours as a form of respite. She was shocked to be given a few hour notice the following day to attend court. Another mother reported her reaction to the request for intrusive medical examinations of her children and her strong refusal based on her previous history of sexual abuse. To that mother, it made no difference if her children were being examined by a medical officer or being abused, she imagined from the child's perspective they were being intimately touched and looked at and this was inappropriate given she knew no abuse occurred.

Police officers must receive training on autistic families so that they are confident in making balanced decisions before exercising their protective powers. The failure to have the training, and decisions being made to self-protect rather than protect the child, is breaching the family right to a private family life. These situations become 'evidence creating' of perceived harm where the Social Services may not have the ability to meet the legal threshold criteria to obtain court orders to remove children.

Contact Sessions: Children in Care

Contact sessions can be very difficult for parents. It is imperative that social workers supervising contact are sufficiently trained in autistic families to properly assess interactions and into context.

The social element of the contact session - the start and end could be a barrier for these women and drain them before even seeing their child. Training for foster carers is essential in order for them not to judge the mother for her different approach to the child.

From an autistic parent perspective, failure of social services to provide reasonable adjustments impact both parents and child and lead to evidence creating as opposed

to unbiased representation of the parent / child relationship. This misinformation is then collated and used to judge the parenting capacity of mothers. These failures can include:

- Failure to adhere to scheduled times resulting in change management difficulties for autistic parents, the child in care and autistic siblings (if present). Leading to parent potentially perceived as 'challenging' and 'obstructive'
- Failure to provide a room appropriate for autistic individuals with a Sensory Processing Disorder thus increasing the need for coping mechanism and potentially reducing quality interactions Leading to parent potentially perceived as 'challenging' and 'obstructive'
- Failure to provide toys and / or equipment of interest to the child that engages their interest
- Failure to provide social stories or visual supports for the child in care in my experience these are not routinely used by foster carers - unless they are in a specialist agency. Most foster carers have limited or no training in autism to my knowledge. Certainly it does not go into this level of detail and is not supported by social workers (who equally may have limited knowledge).
- Failure to understand the heightened anxiety of an autistic parent in feeling 'exposed' through being watched and assessed in sessions
- Failure to understand that an autistic parent may hear background noise (social workers talking to each other) clearly and be intrusive to conversations that are time limited with their child
- Failure for social workers to correctly 'read' facial expressions, body language and tone of voice of autistic parents leading to misinterpretation and miscommunication

Reasonable Adjustments; Meetings & Court

Mothers with Asperger's who are subject to family court proceedings are being failed and let down by the justice system in breach of their Article 6 rights. They may have developed many coping mechanisms and be difficult to recognise that a mother may have Asperger's and/or a specific learning difficulty. Anxiety and fear can be predominant emotions for autistic females that can be intensified by the experience of court. The impact of being anxious in the Court setting is highly likely to affect the mother's ability to conduct themselves effectively, and she would be disadvantaged due to the impact of her disabilities including, though not limited by:

- Engagement in the process by being given information verbally
- Required to respond quickly and would need to draw on her limited Auditory Processing resources to make sense of all communication in the Court and not just the questions posed directly to her.
- Response to the sensory environment in court with lights and sounds
- Inability to recognise people's faces due to prosopagnosia

- Visual processing stress impacting on her ability to read documents
- Inability to regulate emotions in high stress environment

Guidance for Vulnerable Adults in Courts

- The Equal Treatment Bench Book is a guide for judges, magistrates and all other judicial office holders. (https://www.judiciary.gov.uk/wp-content/uploads/JCO/Documents/judicial-college/ETBB_Children_Vulnerable_adults+_finalised_.pdf)
- The Advocacy Gateway, gives free access to practical, evidence-based guidance on vulnerable witnesses and defendants. (<http://www.theadvocatesgateway.org/images/toolkits/3AUTISM211013.pdf>)

Equality Act 2010, Duty to Provide Reasonable Adjustments

Women with a diagnosis of autism spectrum condition, have rights under the Equality Act 2010. '[Disability] places upon the state (and upon others) the duty to make reasonable accommodation to cater for the special needs of those with disabilities', Lady Hale in *P V Cheshire West and Others* [2014] UKSC 19 para 45.

In *Wiltshire Council –v-N, J and A* [2013] EWHC 3502 (Fam) Mr Justice Baker gave guidance to courts in cases where a person was known to have a learning disability. This case was itself a re-hearing following failures by the Judge at first instance to make reasonable adjustments for the father to deal with his cognitive deficits and vulnerabilities reported in the Court of Appeal reports at [2012] EWCA (Civ) 1905. He set-out as follows:

- a. The duty to identify the need for assistance in responding to questions and giving instructions falls to those acting for the parents. Plainly it is essential that those representing parents consider the question of capacity to give instructions and competence to give evidence at the outset of their instruction. If there is perceived to be a need for support, that issue must be addressed at the earliest opportunity. [para 76]
- b. In a case where it is known prior to the issue of proceedings that there may be an issue about capacity or competence, the local authority or the party's representatives should draw this to the attention of the court on issue. The court will then give directions for the appointment of a litigation friend and give directions for additional measures at the case management hearing
- c. In a case where the issue has not been identified prior to the issue of proceedings, it should be addressed fully at the case management hearing. The party's representatives should, if they consider that expert advice is necessary to identify the existence or extent of a learning disability, apply to the court in accordance with Part 25 FPR 2010. If the court grants such an application, the court may list a further case management hearing after the expert has reported to give directions for an intermediary or such other assistance as may be required. Alternatively, if it is

considered that the case for additional measures can be made without expert assistance, then that application should be made at the case management hearing.

d. The legal representatives should also, by the time of the case management hearing, identify an agency to assist their client through an intermediary or otherwise, in the event that the court confirms that such support is required [paragraph 78] Albeit not 'expert witnesses', a report from an intermediary or deaf relay interpreter in some cases is likely to be able to help in what tailored assistance, additional measures or adjustments the vulnerable witness/party needs.

e. Funding the cost of an expert (subject to the LAA's approval) will fall on the certificate of the appropriate party (or parties). However, the cost of an intermediary, as a type of 'interpreting' service, should be borne by the Court Service.

f. Funding issues should be addressed by the appropriate representative at the earliest opportunity seeking prior authority from the LAA or giving notice to the Court Service that an intermediary may be required

The above guidance was expressly approved by the Court of Appeal in the case of *Re C (A Child)* [2014] EWCA Civ 128 in which Mc Farlane LJ stated "The court as an organ of the state, the local authority and CAFCASS must all function now within the terms of the Equality Act 2010. It is simply not an option to fail to afford the right level of regard to an individual who has these unfortunate disabilities".

Article 6, Access to Fair Trial and Proceedings

Reasonable adjustments that are commonly provided for autistic people include:

- provide information in an accessible format would be to plan questions in advance and for the person to respond with someone to assist them to interpret the information if necessary and then prepare a response
- At least 15 seconds to process the auditory information/question posed to them, before expecting a response. Interjections and prompting to answer is likely to delay a response and force an autistic person to re-process the question being asked.
- Visual prompts, charts and diagrams and being able to draw whilst in court, to aid recall and deescalate feelings of stress and anxiety.
- 15 minute break every 45 minutes/hour of court proceedings. When faced with a stressful situation such as family court proceedings breaks at regular intervals such as 15 minutes every 45 minutes

Case Study, Mother Loses Child to SGO

The mother, the subject of child care proceedings, had made it known to all parties involved (including her solicitor) that she had Dyslexia and Dyscalculia. They all decided to ignore this fact and did not inform the judge at the start of the hearing who would have had to undertake a case management hearing to ascertain the level of the mothers difficulties and what reasonable adjustments she might require. Unbeknown at the time to the mother and others involved the mother had Asperger's (an autism spectrum condition).

This did not happen and the mother was placed on the stand for a very lengthy time without any support or regular breaks. The judge decided because of the way she gave her evidence that her evidence could not be relied upon. The mother was completely overwhelmed by the whole process. It was documented that she had poor working memory and processing speed. She could not follow proceedings, keep up with conversation or find the place in paperwork. She was acutely anxious and highly stressed. The text on pages blurred so that she could not read the material.

She subsequently lost her child to an SGO (Special Guardianship Order with child no longer residing with the mother).

The mother should have had reasonable adjustments made for her throughout the hearing even with the knowledge that she had a specific learning difficulty. The fact that she went through the process as an undiagnosed female with Asperger's made this case even more troubling.

March 2014 and then in September 2014 the mother had a private and NHS assessment respectively. She met the criteria for a diagnosis of Asperger's. In the July of 2014 she went back to the court to make an application to discharge the Special Guardian Order and reopen the Finding of Fact Hearing. The basis of her application was that the new information of a diagnosis of Asperger's meant that she did not receive a fair hearing and that her Article 6 human rights were breached.

The main point being that she did not have reasonable adjustments so that she could fully participate in the hearing. In the initial stages the local authority and the guardian took a stance that having Asperger's would have made no difference to the outcome of the original hearing. They have previously gone as far as saying that the mother was claiming that she had such difficulties to try and get a back door appeal.

During the months from July to Stage 1 hearing in February 2015 both parties maintained that having Asperger's did not make any difference. It was only on the day of the hearing that they softened their stance and did not oppose the reopening of the Finding of Fact. The judge decided that her Article 6 Human right to a fair trial had been breached and ordered a rehearing. The advocacy Gateway's guides proved too invaluable when presenting evidence to the judge on how a vulnerable person should be treated when in the family court.

The next obstacle was who would fund the mother's legal fees. She did not qualify because she was over the threshold for legal aid. The court and all parties agreed that the mother must have representation as a vulnerable party, however she could not get legal aid. The court submitted the case to the president of the family court for him to give guidance on who should fund the mother. The date is yet to be decided. The rehearing had been listed for a date in June. (Warren Bell)

Impact on Parenting Choices

Perspective of a young woman who has suffered abuse and her experiences and observations impact negatively on her future parenting choices.

"I spent my childhood unsupported, unprotected and misunderstood. The social care system, schooling system and medical system all failed to recognize my autism or protect me from abuse both in and outside of the home. If I had a child they would likely be on the spectrum. I am unlikely to ever be in a financial position where homeschooling is an option but I do not trust that state run schools can meet the needs of a child on the spectrum or protect them from bullying or emotional harm. I believe there are many misconceptions about the abilities of Autistic people to parent. I suffer from PTSD and other mental health conditions as a result of my childhood. As a disabled person, if I do reach out for help with parenting, these diagnoses may be used against me. I may lose my children and my children may lose their parent. This is not a risk I am willing to take. I am extremely maternal and would love to have children but know rationally that, particularly as a working class woman without familial support, The environment I would be forced to subject my children to and the risks involved in giving them this life means it is neither safe, kind nor worth it. " (Mercy Charpentier)

Perspective of a young woman who has grown up in an autistic family and is researching and evaluating her future parenting choices.

"I didn't receive my diagnosis until I was seventeen and have not had any post diagnostic support other than a half hour appointment at which I was asked if I had any questions but at the time I was still trying to get my head around what having a diagnosis of AS would actually mean for me in the long term .I have had to find the answers to any questions that have arose later for myself with the support of my family .I see myself as lucky compared to many others as I have other family members with AS .My Mom is diagnosed and so is my eldest brother .I also have a brother and an uncle that are Deaf so have been brought up around those that are considered different by society all my life .

I have been with my boyfriend a couple of years and we are now engaged to be married .He is neurotypical but now has a really good understanding of Autism .As a couple we are aware that Autism has a genetic component but we are also aware that with early intervention, the correct support and adapted parenting styles that a child with Autism can grow into a successful adult who makes full use of their strengths and talents.

I am not planning to have children until I have finished my education and am financially secure however I have begun to think about my health and am taking steps to insure that my body is as healthy as it can be before I contemplate becoming pregnant .Myself and my fiancé have begun to read up on parenting including the needs of children with special needs so that when the time comes that we do decide to be parents, we are fully prepared for any needs that child may have.

I want to be fully prepared to become a parent as it is a great responsibility .Myself and my fiancé both received sex education at school which is compulsory but all it taught was the basics of how men and girls were different and how you got pregnant and gave birth .That was it .No real life skills such as what a healthy relationship was or how to actually parent children once they were here "(Ann Holloway)

Conclusion

Autistic families are being systemically failed and abused through not having their status as disabled people recognised and appropriate service provisioning in violation of Article 2, 1 *“Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”*.

The long term discrimination and failures by officials, and the difficulties in accessing complaint processes, constitute a violation of Article 2 section 3A *“To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity”*.

Autistic families are being violated in their family and home through unwarranted interference in violation of their Article 17 section 1 rights *“No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation”* and by not being able to access advocate support who are trained in autism, their Article 17 section 2 rights are being violated *“Everyone has the right to the protection of the law against such interference or attacks”*.

The judicial system can be compliant in systemic abuse through failing to adequately safeguard women in fair proceedings through not providing reasonable adjustments in child protection proceedings to the detriment of the family unit. This is in violation of Article 26 *“All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”*. This is particularly relevant to families where forced adoption has occurred and subsequently the judicial system was found at fault but refuse to set aside adoption orders in misguided handling of their interpretation of the rights of the child to family life. The police powers of removing children, where a court order does not exist, based on judgement without adequate understanding and training of autistic people and their differences in communication and response to unplanned visits must be considered a breach of Article 26.

Autistic family life is a natural component of society where their rights in Article 23 *“The family is the natural and fundamental group unit of society and is entitled to protection by society and the State”* must be respected with appropriate and adequate supports, where necessary, as reasonable adjustments to protect the child's Article 24 rights *“Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State”*.

No woman should need to consider system failure and rights violations as part of her future reproductive choices.

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www.autismwomenmatter.org.uk