

Autism is Not a Mental Health Issue-Rethinking Healthcare and Mental Health Legislation

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Introduction

It is somewhat of an irony that, while autism is classified under the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), little is known about its psychiatric aspects. In truth, autism is a neuro developmental, rather than a psychiatric disorder or a form of mental illness. Sometimes the presenting symptoms of autism are not the core deficits of social interaction and social communication, but superimposed psychiatric problems such as anger outbursts, depression and hyperactivity. Unfortunately, these problems are either ignored by professionals as being part of autism itself or, conversely, and perhaps more concerning, autistic behaviours are too often misinterpreted as psychiatric disorders. In the latter interpretation, this can lead to many autistic individuals being institutionalized incorrectly for perceived mental ill health concerns, rather than being correctly interpreted as “negative” autistic behaviours as a result of stress, anxiety or sensory overload.

Sadly, this can lead to autistic young people and adults being detained unnecessarily, often for long periods of time, and being denied access to appropriate support that is more applicable to their autism diagnosis.

Sometimes refusal to consent to medical treatment by autistic adults can be misinterpreted as a form of self-harming, or self-neglect, when, in reality, there has been little or no attempt to acknowledge the sensory and socially communicative difficulties associated of being in a hospital environment.

There have been some alarming cases in recent years in the UK, and elsewhere, where staff in general hospital settings have failed to acknowledge the sensory and social communicative problems associated with being in a hospital environment, leading to behavioural problems in autistic individuals being misinterpreted as psychiatric problems and subsequently leading to detention in a mental health unit. Once in such units, the incidents of challenging behaviours often increase

dramatically, leading to a longer incarceration than would have been necessary if the needs of an autistic individual had been more fully understood.

There is currently no medication that is universally effective in autism. Yet medications are often prescribed inappropriately for both control of maladaptive behaviours and the treatment of other medications such as seizures. All too often, however, autistic children and adults are over-medicated in an effort to “control” rather than manage behaviours.

This article aims to open debate about how best to care and treat individuals with autism when they require medical services. It is from both a personal and professional point of view, as I have autism myself and have children on the autism spectrum, but is also supported by anecdotal evidence from the UK and beyond.

Aim

The aim is to offer clinicians and other professionals involved in mental healthcare provision to consider autistic individuals from a different perspective than their neurotypical counterparts before proceeding with psychiatric and psychological treatments that may have an unintended negative impact upon mental wellbeing.

Case Studies from the UK

Figure 1: Oliver McGowan



Case Study One: Oliver McGowan

In 2016, a young man called Oliver McGowan (Figure 1), who had mild autism, cerebral palsy and focal epilepsy, was admitted to hospital because of seizure activity and his life was cut tragically short. Although not diagnosed with any mental illness, he was prescribed anti-psychotic medication to control his agitation whilst in hospital.

This was despite being informed by Oliver and his parents that certain antipsychotics caused him severe side effects, including increased agitation and seizures. Oliver's condition deteriorated and he died a few weeks later from neuroleptic malignant syndrome—a rare but serious side effect of antipsychotic medication.

Unfortunately, although Oliver's is an extreme case, misdiagnosing autistic behaviours as mental illness, and subsequent mistreatment is not unique here in the UK:

Case Study Two: Alexis Quinn

Figure 2: Alexis Quinn



Alexis Quinn (Figure 2), autistic writer and advocate was detained against her will on numerous occasions, sometimes hundreds of miles away from home, simply for being autistic.

Eight years ago, Alexis was working as a teacher. Life seemed good. However, following the death of her brother and the birth of her first child, her life began to fall apart. So she asked for help from her GP (General Practitioner, family doctor in the UK). A voluntary "rest" in hospital for assessment led to sensory overload. This in turn led to meltdowns, which subsequently led to restraint.

In total Alexis was restrained 97 times, secluded 17 times and endured long-term segregation. She was detained under Section 3 of the 1983 Mental Health Act for treatment. Her daughter was just nine months old at the time. Yet no treatment came because you can't "treat" autism. It's not an illness or a disease.

Like every other autistic person in hospital, she reacted to her new normal in the only way she could: in an autistic way. Staff tried reassurance, but their close proximity, touch and the additional noise

from their talking felt unbearable and led to more meltdowns. Alexis was drugged, restrained and segregated. On one occasion, she was locked in a room for eight days with nothing more than a mattress. Consequently, she had to eat on the floor and had no contact with the outside world.

After three and half years, moving between 12 different hospitals, she became institutionalised, addicted to prescription medication and increasingly isolated.

Eventually, Alexis embarked upon a daring escape : catching a ferry from Dover to Calais, travelling to Paris, and flying to Dubai – before landing in Lagos, Nigeria. She began writing her memoir, "Unbroken", about learning to live with autism and her experiences of detention.

Other Case Studies from the UK:

Benji O'Reilly, a former nurse, described a "prison-like environment" endured by her daughter, during her last admission, in October 2020.

Her daughter was forced to wait 30 hours in an emergency department before being transferred to an infant ward. There, she was "kept in a tiny box-sized, bland side-room for four weeks, with no fresh air, no exercise, no stimulation, no activities, not able to see friends, family, pets". "Unsurprisingly, she had a huge meltdown and started displaying some, what is seen as, challenging behaviour".

By April 2021, the teenager had been an inpatient for seven months, in a hospital "miles away from home", without access to her phone and cut off from friends, home, community, school and hobbies, Ms O'Reilly told MPs (Members of the House of Commons, UK Parliament) in a Committee Meeting on Mental Healthcare Reform "(my daughter)" has been treated like a criminal at times. She has often asked why she's being punished." She said the family does not feel listened to and it "feels like our daughter has just been swallowed up by the system". Ms O'Reilly said restraint needed to be banned: "our daughter's been forcibly stripped and sedated via injection."

Another case introduced to MPs was described by Dr Sarah Ryan whose 18 year old son, Connor, died in a bath , after 107 days in a learning disability unit, where there was a change in medication which increased his seizures.

In all of these cases, the only "crime" -they are autistic!

Like all of us autistics, none of these people can be "treated" or cured!

Many autistic people do not want to be either.

In a 2018 UK survey conducted on 11,521 autistic people by the

NAS (National Autistic Society), 72% of respondents asserted that if there were a cure they would not take it.

Yet every year, hundreds of autistic people and those with learning disabilities fall victim to detention under the Mental Health Act, where human rights abuses are often prevalent and sanctioned by 38-year-old legislation.

This is why. I, and the autistic community in the UK welcome the UK Government proposals to reform the Mental Health Act, which will ensure that mental illness is the only reason for detention, and not autism or learning disabilities, in themselves.

The new proposals firmly suggest that money currently spent on locking up autistic people and those with a learning disability should instead be spent on community services, where people can be treated in their own homes or closer to their families, at a fraction of the cost for inpatient hospital services.

I, myself, have experienced maltreatment and misdiagnosis within my own family, over many years, which I am not at liberty to discuss here, except that this is the reason why I believe this topic needs to be discussed; not to criticise the honourable professions of psychiatry and psychology, but for professionals in these fields to consider the impact of institutionalism and the medical model on autistic individuals and their families. Sadly, the experience in the UK is not unique:

Reports and Case Studies from Around the World

There have been other alarming cases in recent years in the USA and around the World, where staff in general hospital settings have failed to acknowledge the sensory and social communicative problems associated with being in a hospital environment, leading to behavioural problems in autistic individuals being misinterpreted as psychiatric problems and subsequently leading to overly restrictive practices and subsequent detention in a mental health unit. Once in such units, the incidents of challenging behaviours often increase dramatically, leading to a longer incarceration than would have been necessary if the needs of an autistic individual had been more fully understood.

Through my research, I have found a number of disturbing cases from throughout the USA. A study published by the Autism Inpatient Collection (AIC) in 2017 found that a staggering 10% of all autistic youths under 20 were admitted to a hospital for mental health care every year. Many of these spend many weeks or even months in emergency rooms and acute -care hospitals, sometimes sedated, restrained, or confined to mesh-tented beds. Here they may wait for several weeks for beds to come available in specialized autism units.

A Kaiser Health News investigation in 2015 described the case of a 16 year old who spends 304 days in the ER in a hospital in Buffalo. Disability Rights California, sites the case of a 26 year old autistic woman with a seizure disorder who was stabilized after a few weeks in

a Sacramento Hospital, yet she remained there for 10 months, and was discovered in a bed covered by a mesh tent.

By 2014, the number of autistic young people admitted to acute hospitals in the US, according to The Federal Agency for Healthcare Research and Quality, had nearly doubled in five years. Unfortunately, General Hospitals are not really equipped to handle someone who is autistic.

The global COVID pandemic has further exacerbated these concerns, with a virtual “closed” culture developing in healthcare, particularly in the UK, with fewer family or official visitors or inspections.

In an article published in The British Journal of Psychiatry by [1-5], published in 2019, entitled “The Case for Removing Intellectual Disability and Autism from The Mental Health Act,” the authors argue, and I quote, “Since autism and intellectual disabilities are not mental disorders, they should be excluded from the Mental Health Act. Their current inclusion is held to be discriminatory, resulting in unjust deprivation of liberty.”

Unfortunately, too many autistic individuals also fall fowl of the criminal justice system, too . In a study in New Zealand in 2009, by [6-11], they found that “individuals with ASD were seven times more likely to intersect with the criminal justice than those without ASD.”

“Coming Home-A Report on Out of Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs” , commissioned by the Scottish Parliament in 2018, concluded that:

“An individual who is simply communicating their distress may find themselves detained in hospital for prolonged periods and subjected to restrictive practices, including inappropriate psychotropic medications.”

And further “hospital admissions may distress individuals and exacerbate their behavioural problems.”

These actions at home in the UK and abroad, have undoubtedly denied autistic people, sometimes without advocacy, access to appropriate healthcare provision. Such an approach can potentially expose the most vulnerable to abusive treatment.

Autism, although not every autistic people would consider themselves as having a disability per se, is a protected characteristic in the UN Convention on the Rights of Persons with Disabilities.

Studies in the UK have concluded that for autistic people and the learning disabled “liberty is restricted for much longer than for people with “mental disorders alone.” People are compelled to be in environments that harm the person’s rights, and activities such as music or watching films may not be allowed. (These activities can be especially important to autistic people to desensitize within the hospital environment). Too often, the ward environment has a profoundly negative effect on an autistic person’s mental wellbeing; due to sensory overload or confusing

rules and regulations or misunderstanding of medical jargon.

Some may even experience threats or attacks from other patients. For example, a few years ago, whilst working for the National Autistic Society, I carried out a needs assessment and transition for a gentleman coming from a secure mental health unit to specialist autism residential care. This gentleman had been repeatedly abused physically and verbally by staff and patients, had evidence of sustained injuries on his person and screamed and cowered whenever any member of staff was in his personal space. By using low arousal approaches and observing from a distance, allowing him to pace around, he was given time to settle before any attempts were made with personal care or other hands on support. The first night he screamed for much of the night and whilst being showered, but within 48 hours, we were able to wet shave him safely, without any form of restraint or medication.

Statistically, autistic adults and young people have been found to have much higher incidents of co-morbid conditions than neurotypicals, including seizures and mental illness. However, as was demonstrated with the examples of Oliver and others earlier, autistic people may react differently to drugs, and sadly, many are forced to take psychotropic medication for too long, often with significant side effects.

In a report published by the Mental Welfare Commission in Scotland in 2019, more than 50% of autistic people with complex care needs were prescribed antipsychotic medication for “challenging behaviours,” 1/3 had delayed discharge and there was anecdotal evidence of losing skills, interests and independence when hospitalized for long periods. The same report also found that post hospital discharge, suicide rates amongst autistic people were approximately 25% higher than for mental health disorders for the period 2012 to 2017.

All too often an autistic person may be misdiagnosed as having a mental illness or personality disorder, and then be made to take a powerful medication for a condition they do not have. Conversely, in the UK, one quarter of autistic adults are denied access to mental health services due to a diagnosis of autism. This figure is pre-COVID; I dread to think what the percentage is now. Every week, I receive phone calls from people asking for mental health referrals or crisis help, but due to COVID, less services are open, and less phone lines are being manned.

The Care Quality Commission (which oversees health and social care provision in the UK) latest report published in October 2020, concluded that the proportion of services rated as inadequate had rose from 4% to 13%. In independent providers, in the private sector, this figure raised from 5% to 22%.

In April 2020, there were almost 100,000 fewer mental health referrals than for April 2019 (a 31% drop).

Concerns have also been raised that “closed cultures” may be developing and increasing abuse and human rights violations due to “services restricting families from visiting because of COVID. Samantha

Clarke, Chief Executive of Learning Disabled England (LDE) which represents people with learning disabilities, carers and self-advocacy groups, has stated “people are still being traumatized for life by the very places that are meant to help them.”

So the questions remain why this problem is, and what needs to be done?

There has to be a way to separate autism and learning disabilities from mental health disorders. In the UK, only people with an intellectual disability or autism can be detained for socially inappropriate or aggressive behaviour. This is wrong on two counts. Firstly, why should autistic or intellectually impaired people be detained under Mental Health Legislation, when this rule does not apply to anyone else in society; and secondly, it allows for poor practice and misdiagnosis. Challenging behaviour as a response to sensory overload, miscommunication, trauma or abuse; including institutional harm, may be overlooked by seeking a psychiatric and medical response, rather than a normal autistic response to a stressful environment or situation.

A DOH report entitled “No Voice Unheard, No Right Ignored” in 2015, concluded that autistic people were being detained because of autism-associated behaviour, even when no appropriate medical treatment was available, or deemed to be medically necessary. In a survey completed as part of this report, 77% of respondents wanted a change in the way that autism was treated under the Mental Health Act. 6 years later, the promised review is finally being undertaken .

Internationally, the United Nations Convention on the Rights of Persons with Disabilities is changing the landscape for Mental Health Legislation.

Conclusion

Undoubtedly, autistic adults and children can have co-morbid psychiatric disorders. Sometimes, these can be dismissed as simply being a part of their autism presentation. However, sometimes autistic behaviour is incorrectly misdiagnosed as psychosis or neurosis, when the individual may simply be reacting to a stressful situation or environment.

Unfortunately, the mishandling or failure to provide adequate provision for autistic adults and children; especially since the pandemic, may not simply be a case of a few bad apples, but a feature of the inpatient system.

To conclude, autism is NOT, a mental health disorder or condition, but rather a “lifelong condition that affects how people communicate, relate to other people, and how they experience the world around them.”

Inevitably, some autistic individuals may need to be institutionalized. However, due to inadequate service provision, too many autistic people really struggle, eventually hitting complete crisis; and facing being put in a hospital that doesn't meet their needs.

Legislators and mental health professionals need to listen to the growing number of voices, especially amongst the autistic communities themselves, so that autistic people aren't inappropriately detained or sectioned, and are afforded the same rights as their neurotypical peers.

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