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Solace studies in therapeutic work with refugees and asylum-seekers

No. 2

Could refugees and asylum seekers be struggling with ADHD and ASD alongside trauma and loss?

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Editor's note: This is the second in a series of working papers reflecting on aspects of therapeutic work with refugees and asylum seekers undertaken by therapists and others working for SOLACE, a regional organisation based in Leeds (www.solace-uk.org.uk), and others associated with it. The views expressed here are those of the author. Anyone working in this area is welcome to submit drafts of short papers (3000-5000 words) to the series editor at Gary.Craig@galtres8.co.uk.

Could refugees and asylum seekers be struggling with ADHD and ASD alongside trauma and loss? Adding a neurodiverse lens to our work

Introduction

At Solace we work with refugees and asylum seekers who have experienced unimaginable losses and persecution, and who face a range of difficulties and barriers in their life here in the UK. We expect our refugee clients, whether adults or children, to be suffering the effects of loss and trauma, of displacement, the stresses of the asylum system, poverty and poor housing, and the racism they encounter in the UK. We look for signs of trauma, and are skilled in responding to this. But do we also anticipate that people may also be struggling with the impacts of neuro-diversity, in particular autism, and ADHD?

I felt inspired to research this area, and find out more about the complexities of the issues it raised when working with a child who I thought had many autistic traits, alongside being severely traumatised at an early age, a sole survivor, brought up by a mother grieving for all her other children. On the one hand it might be that the possibility of autism was the least of her worries. But I also wondered, if she was on the autistic spectrum, whether recognition might enable the school and her family to support her better.

I had few concerns about the school's response, but I did wonder if her mother would be helped by this potential recognition, and I was concerned about her possible reaction. This question has stayed with me, and inspired my curiosity in how neuro-diversity and autism in particular, might be understood and experienced by some of our client groups, recognising that it might well be different between countries, and between urban and rural populations, as well as between individual families. Attitudes towards neuro-diversity vary enormously within this country, and there is still stigma around, despite the huge efforts of many support and campaigning organisations.

At a recent workshop on Understanding Autism, the presenter said that if he saw a child experiencing extreme anxiety, his first question would be whether they were neuro-diverse. When we meet an extremely anxious refugee child, we imagine that this is the result of trauma, loss, displacement and issues around integration. So my interest and curiosity is in where these two perspectives meet, to see if this can deepen and broaden our approach.

In this paper I look at the following questions:

- To what extent might we expect to meet refugee clients who are neuro-diverse, or are concerned their children may be neuro-diverse: what is known about the incidence of neuro-diversity in other countries, and in refugee populations?

- What might indicate neuro-diverse traits and how might these present differently or in addition to those resulting from trauma, loss and displacement?

- How does understanding and awareness of neuro-diversity vary around the world and what stigma is attached to ADHD and ASD?

- How might this affect our therapeutic approach to the individual child, and what might we need to consider in working with the family, school and wider system?

Throughout this paper I hold the refugee and asylum seeker clients I have worked with in mind, curious as to the insights that these questions may offer.

Neuro-diversity: what are Autism and ADHD?

To start with, it is useful to outline what is understood by Autism(ASD) and ADHD. These are both defined, albeit in slightly different ways, by the DSM 5 (US) and ICD 11 (Europe), so what follows is a basic summary of what we might notice.

Autism

Autism is a developmental condition, i.e. a neurological difference, which may be associated with learning difficulties. It is a condition that exists on a spectrum, from very serious impairments (defined as level 1 or level 2 in the DSM 5) where life-long support may be needed, through to high functioning autism (also referred to as Aspergers). It is a defined as a triad of impairments:

- Problems with social interaction (e.g. difficulty with social cues, emotions)
- Problems with communication and language (e.g. delay in starting to talk)
- Problems with social imagination (i.e. struggling to imagine what the other person might be thinking).

Some of the traits associated with ASD are rigid thinking, obsessive special interests, susceptibility to sensory overload due to heightened sensitivity, high levels of anxiety, difficulties with self-regulation, and recognising and expressing emotions. Self-soothing may be achieved through “stimming”; a repetitive movement or sound that effectively blocks out other inputs. When the anxiety builds up, the rigid thinking is challenged, or there is just too much, the release from this overwhelm may come in the form of a meltdown.

Meltdowns can be scary for all concerned, and they may come out of nowhere, but they are not tantrums (which is how they may appear to the parent who feels their child is being naughty) and they need a careful and measured response.

Whilst many of these behaviours and responses may also indicate trauma, it is the combination of issues that defines autism, which has a slightly different quality. As I write this, the child I worked with comes to mind – they showed all these traits and others, and the question remains – would this knowledge have helped?

The impact of gender

In the UK, autism is recognised as being under diagnosed in women: the ratio of boys to girls diagnosed with level 1 and 2 autism is 4:1 (1) and Attwood (2) suggests the ratio for high functioning autism is even higher at 10:1. So it is much less likely that a girl with high functioning autism in particular will be recognised as such. However, this is changing, as we start to understand the ways many girls successfully mask their social difficulties. Autism is also associated closely with gender diversity(3).

ADHD

ADHD is also a neurological condition, slightly more commonly diagnosed in the UK (2.5%) (4) than autism at 2% (5). ADHD stands for Attention Deficit Hyperactive Disorder, and it includes what was known as ADD, i.e. the attention deficit without hyperactivity or impulsivity. Like ASD, ADHD is much more commonly diagnosed in boys. It is also more widely diagnosed in the US, about 6-7% in children, due to the DSM V diagnosis being broader than the ICD 11 view.

The diagnostic criteria in DSM V require having six traits of inattention, and/or six of hyperactivity and impulsiveness. Hallowell6 describes the core symptoms as “excessive distractibility, impulsiveness and restlessness”. He goes on to describe many advantageous characteristics, such as creativity, original thinking, humour, stubbornness, warm-hearted and intuitive behaviour, and at the same time, their struggles to turn great ideas into actions, explain themselves to others, and chronic under achievement. They may get easily frustrated, can be very disorganised, forgetful, can be alternately highly empathetic or not at all, and may self-medicate with alcohol, drugs or other addictive behaviours. People with ADHD can often be highly sensitive as well. ADDitude1 suggests two hallmarks of ADHD are emotional dysregulation and executive functioning, i.e. a real difficulty in regulating their emotions, and bringing in their thinking to support themselves.

How likely is it that a client might be neuro-diverse?

This is an interesting question because world-wide rates of diagnosis, and within the Middle East, in particular, vary widely. There is a viewpoint that the higher rates in the developed world are linked to diet and lifestyle – indeed ASD is known as “the Western disease” in Somalia.

However where there is no capacity to test, or tests are inappropriate, or there is limited capacity to provide appropriate care, numbers will necessarily be lower.

So we don't know whether latent neuro-diversity rates are the same around the world, or greater in some places than others. However we can look at the potential likelihood that our disturbed and distracted adult client, from say Iran, might be undiagnosed. A chronically anxious and depressed client from Afganistan has only known war and fighting all his life: might he, in addition to other issues, be neuro-diverse? Is there evidence that children born in war and persecution are more likely to be neuro-diverse? This seems intuitively to be the case, and the WHO believes it to be so:

"Available scientific evidence suggests that various factors, both genetic and environmental, contribute to the onset of autism spectrum disorders by influencing early brain development," said Khaled Saeed, a regional adviser for the WHO's Eastern Mediterranean offices. "Rates of mental disorder are significantly higher in countries with complex emergencies." 7

I haven’t been able to find any studies establishing whether this is true, and there is considerable controversy about the potential causes of autism (in particular) and maternal and environmental stress are often cited and then disproven.

Rates Around the World

What is most striking looking at studies of ASD and ADHD in other countries, particularly the Middle East, is the difference in apparent incidence between the two conditions. Studies (e.g. in Shiraz in Iran) show high levels of ADHD (10% overall, more in boys than in girls), and there is a degree of consistency in studies carried out around the globe. However, studies of autism show a different picture, with much greater variation between countries. Levels are very low in the Middle East, where recognition of autism and its study and care has been much more recent, in many countries starting only in the last 20 years. Diagnosis is often the preserve of the well-off.

Differences in perception of ADHD and ASD

It seems like ADHD is more acceptable than ASD.

This is hardly surprising, given that ADHD is seen as being medically treatable and that ASD is associated with intellectual disability, (estimated at around 50% of all those diagnosed with autism), and also with epilepsy.(8)

Unlike ADHD which is seen as all about behaviour, autism in its more severe forms is a major disability, and very difficult for parents to cope with. As such it is considerably feared and stigmatized in many countries. So a refugee child is less likely to have been diagnosed with autism, particularly high functioning autism, unless they came from a relatively wealthy urban family in an area with autism diagnoses and care.

This is despite the high co morbidity of ADHD and ASD: estimates suggest two-thirds of individuals with ADHD show features of ASD 9. Studies (e.g. Leitner 201410) show that between 30 and 50% of individuals with ASD manifest ADHD symptoms (particularly at pre-school age).

It is unlikely that only 2% of our clients are neuro-diverse. Neuro-diverse people generally are much more susceptible to depression and anxiety and many have been traumatised through a lifetime of being different, misunderstood and trying to fit in, which I believe would make them more susceptible to the trauma of persecution and exile.

As we increasingly work with refugee families, is there evidence that children born in the UK to refugee parents more likely to be neurodiverse?

How are the children of refugees affected?

There is most evidence addressing this question. Studies in both Sweden (11) and Minneapolis (12) found a very high incidence of level 1 and 2 autism (i.e. severely disabling) amongst children born to refugees from Somalia. They found that children born within a year of arrival were most likely to be autistic. However, high functioning autism appears relatively rare. Hypothesises include a lack of vitamin D13, the change in diet and the stress of the journey, arrival and integration.

Studies in Los Angeles (14) and in Australia (15) further suggest the incidence of disabling autism is most notable in refugees from Sub-Saharan Africa, and less noted in people from other areas such as Central America and Vietnam. Abdullah (14) also reviewed a study showing a higher incidence of ADHD in refugee children.

What is absent from these studies though is the incidence of high functioning autism, and it is thought that this may be because it is disguised as cultural and assimilation difficulties.

It is clear that developing culturally appropriate diagnostic tools has been a challenge, and may account for lower recognition of anything other than extreme presentations of autism in some communities. A study in Finland (16) found lower levels of high functioning autism amongst refugee children and put this down to a reluctance in these groups to use mental health services. This may be a two-way process: the National Autistic Society looked at the experience of BME neuro-diverse children here in the UK, finding that they were generally being overlooked and un-catered for (17).

I would argue from this that some form of neuro-diversity is quite possible amongst our refugee and asylum seeking clients, and whilst the needs of strongly autistic children will be clear, the needs of those who are high functioning or masking traits of ADHD or ASD may well slip under the radar, both in children and adults.

What difference would recognising this possibility make?

I ask two questions:

1. How would my own personal recognition of this affect how I work, my therapeutic approach and understanding of this child and their family?

2. Who else needs to know, and how would this help?

Looking through a neuro-diverse lens in addition to a trauma lens

How might one's work with a client be different? At one level, it might not make that much difference. If the presenting issue is extreme anxiety, inability to self-regulate, and difficulties socially, much of the work would focus on safety, self-regulation, (and in a family) teaching the parents to co-regulate, and working on the parents' own need for safety. What would a neuro-diverse lens add?

A neuro-diverse lens

Looking through a neuro-diverse lens doesn't mean that one approach will fit everyone, rather it is a sense of paying attention, even more than we might already be doing. Anxiety is likely to be massive (and some people with ASD are misdiagnosed with psychosis, bipolar disorders and schizophrenia prior to their ASD diagnosis). It is important that the therapist looks for potential sensory over-stimulation in the room and helps the client to be comfortable, and recognises that both ASD and ADHD clients are likely to have:

- a history of social difficulties;
- a tendency to catastrophise;
- a tendency to unpredictability; and
- a tendency to intolerance and frustration

ASD clients in particular are likely to need help with communication skills, and in relating what they are feeling physically to emotional labels (interoception). They are likely to need space, and may struggle with too much contact in the therapy room.

Depression is also likely to be a problem, due to a high level of cortisol which can interfere with memory, learning and communication, and the difficulties they experience in understanding others, leading to exhaustion, isolation and feeling bad about themselves.

Clients need us to go gently, pacing ourselves to their processing time, but not leaving long silences, and noticing our own counter-transference as we work together. Issues such as frustration may well come up, which can help us to understand the client's experience. With any form of neuro-diversity, it is important to tackle stigma and self-esteem by exploring and recognising their strengths. Writing this brings an adult client to mind, very unstable, with a lifetime of struggles with his family and himself, which culminated in an event which led to his need to leave his country of origin. ADHD wasn't something I considered at the time, but that additional sensitivity and perspective might have helped.

In many ways working with a person on the spectrum or with ADHD requires very similar skills to working with trauma, such as an intense sensitivity to what the person needs, fears, and can cope with in the process, and a deep commitment to finding out about their world, which may be very different from our own.

In particular, the concept of the Window of Tolerance, and different zones of arousal, is integral to working with ASD and with trauma, as self-regulation is key for both.

The client I worked with was chronically anxious, and we were concerned that she was experiencing psychosis at times. Our work developed an understanding of the deeply ingrained nature of her anxiety, and her real need to have her strengths seen and valued. I noticed how hard she worked to mask the sense of difference - not just the cultural difference but something else as well. This double "masking" is something to look out for, and may be a great drain on energy. With this particular child her differences were very noticeable when in a group of her fellow refugees. She was totally different in how she related to them.

Her mother was deeply worried about her, and at her wits end in how to support her. Work with her parents focused on their ability to create a more containing relationship. Would it have helped to name what the catalogue of "problems" which she listed at one point was most likely describing, exacerbated by the extreme trauma they had experienced? Or would it have been too much, too shameful, too dreadful to countenance?

The potential stigma of autism in our clients

It is quite likely that for a parent from the Middle East, this might well be the case
"Some parents still evince little inclination in acknowledging that their child may have an autistic issue. When told by a neurologist/psychiatrist, their first reaction is to erupt in an emotional rage, followed by a long duration of denial. This goes on to prove that the stigma around the condition is almost as pervasive as the disorder itself." Sharma 23
There is an inverse relationship between the level of services available for people with autism and the level of stigma attached to any such diagnosis, making it a particularly difficult issue for people from the Middle East, where services, as noted above, are in their infancy. Our Syrian clients (in particular) tell us about the social expectations of their community, of being seen to succeed and integrate well. This would further enhance the potential stigma, and risk of exclusion of anyone appearing different or deficient in some way, as Papadopolous (18) points out: "*Previous stigma research has found that collectivist cultures (which place priority on community interdependence and shared group norms and values) are generally more likely than individualist cultures (which place priority on personal independence, goals and values) to stigmatise people who deviate from the norm.*

This is partly because such people are more likely to be identified in the community due to high surveillance levels, which such cultures rely upon in achieving their goals of interdependence and group conformity".

Bankole (19) highlights the role of religion in creating stigma, particularly amongst her own Nigerian heritage community in the UK, who are more likely to see autism as a result of poor parenting, witchcraft, neglect or adultery. There is evidence that the Somali community in the UK places emphasis on exorcism as a response to their child being autistic (20). The impact of this stigma is felt by the child, but even more so by the parents and main caregiver. A recent study (21) showed that the mental health of the caregivers was adversely affected, as they feel isolated, blamed for their child's condition, and are avoided or pitied by their community. This in turn affects the developmental progress of their child. This means that any discussion of a potential diagnosis would need to be handled extremely sensitively and constructively.

Outside the family: engaging with the system

With the school I proceeded in stages, developing first the recognition that this was a vulnerable child with support needs, and getting them on the SENCO and pastoral radar. Once additional support was in place, I shared my concerns that the child might also be on the autistic spectrum, which may have helped them negotiate some of the social and behavioural issues that were manifesting. They took this on board, though the next step, obtaining a diagnosis, would require parental support and I didn't feel I could recommend this. In addition, there is a very long waiting list in that area, and limited support available. She would get extra time anyway for exams and so on, and the school were trying to support her socially – so maybe, was that enough?

Underpinning this particular child's story was an overwhelming need for safety, safety that she sought in many different ways, including from me as a therapist. She had been blown up when a year old, and rescued from under a fallen wardrobe. She was in the womb as her parents argued about which of them was responsible for the accidental death of her elder brother. She survived when all her subsequent siblings died. Isn't that enough for a therapist to be going on with?

And yes, it probably is. I asked myself whilst writing whether concern for neuro-diversity was a distraction from this incredibly harsh reality. It could be seen that way, but I do not think it is. We seek understanding, to help our clients understand themselves, accept and love themselves for who they are. Being neuro-diverse brings the challenges of being different, but it also brings gifts, and the more we know ourselves, the more of our gifts we can release and use. I would offer this lens as another one to try on for size, alongside the lenses of trauma and loss.

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Useful Resources

- Dr Arun Sharma, Medical Director Dubai quote from https://www.arabnews.com/node/1476196/middle-east
- National Autistic Society https://www.autism.org.uk
- Aspire Training (local and online training by two UKCP psychotherapists who specialize in neurodiversity) https://aspireautismconsultancy.co.uk
- Spectrum News (US based) https://www.spectrumnews.org
- ADDitude (US based, focused on ADD and ADHD) https://www.additudemag.com