The Family Perspective

Supporting Autistic Adults and Children, and Individuals with Other Neurodiversities

Written by Hannah McAuliffe and Marion O’Shea,

July 2020

Studio 3 Clinical Services and Training Systems

Introduction

Autism is a condition that continues to be misunderstood and stigmatised in society today. This can make it increasingly difficult for autistic individuals and their families to access support structures. In this article, we will offer an insight into supporting autistic individuals from a family perspective.

The role of a caregiver is a rewarding and fulfilling one. However, it can also be challenging. When caregivers are not provided with the skillset or support to undertake this role, it can be an overwhelming task. It is important that the wellbeing of caregivers is also considered when supporting adults and children. Research has shown that caregivers for autistic individuals show elevated psychological distress (Lovell, Moss, & Wetherell, 2012; Sawyer et al., 2010). The stress buffering hypothesis outlines that, as a function of greater coping resources, stress appraisals are lower for caregivers who feel supported (Cohen & Ashby Wills, 1985). This article is one that can be used by families to gather more information about their child's diagnosis and the implications for their wellbeing.

1. Understanding the Diagnosis

For some families, receiving a diagnosis of autism will often confirm their own prior beliefs that their child had autism. However, for other families, it may come as a surprise. When a family member first receives a diagnosis of any kind, there is an adjustment period for both the family and the individual. Receiving a diagnosis of autism can often be met with feelings of fear and uncertainty. Families may worry about what this diagnosis will mean for their child as they grow up. Families often grapple with misconceptions and misinformation when a member of their family is first diagnosed with autism, which can make adjusting to and understanding the diagnosis more difficult. The word autism is derived from the Greek word ‘autos,’ meaning ‘self.’ The literal translation of autism means ‘self-state’ or ‘self-ness.’ Williams (1996) argues that the origin of the word autism itself reinforces the stereotypical view that people with this diagnosis avoid or reject the company of others. We now know, with the aid of autistic academics who have written extensively on this topic, that this is an outdated and inaccurate view of the autistic person.

One of the most widespread misconceptions that can come with a lack of understanding of autism is the perception that autistic people lack in empathy. Milton et al. (2018) has postulated that rather than there being a lack of empathy on the side of autistic people, that the challenge in fact lies with double empathy. That is to say that neurotypical individuals, such as carers, teachers, health professionals and sometimes family members, struggle to empathise with how autistic people experience the world. This can in part, explain the pathologising of autism by professionals who don’t see the world in the same way (McDonnell, McCreadie† & Dickinson, 2019).

2. Autism as a Developmental Difference

Understanding autism as a developmental difference moves away from the historic deficit model and towards understanding an individual’s unique developmental profile. The medical, deficit model meant that the thoughts and behaviours of people with neurological and developmental differences were pathologised. In recent years, there has been a change in how we understand and subsequently support autistic people. This renewed understanding has been informed by positive psychology, and is one that empowers autistic people to recognise their strengths and to cope with the challenges they face (Groden, Kantor, Woodard & Lipsitt, 2011).

As we grow, there are more expectations and responsibilities placed upon us. When individuals have developmental conditions, sometimes supporters expect more from them than they can cope with. We would encourage parents of autistic individuals, particularly those who are adolescents and adults, to reflect on their child's emotional and cognitive abilities, and not just their chronological age.

The widespread misconceptions surrounding an autism diagnosis can also affect how a child or their family are treated by others.

3. Informing Individuals of Their Diagnosis

With the misconceptions and fear that can come with a diagnosis of autism, families may worry that if they reveal to their child, and to others, that they have a diagnosis of autism, they will be judged and seen as an outsider. However, if we adjust our way of thinking as a society, and recognise the strengths and insights that can come with neurodiversity, a diagnosis of autism is not so daunting. Parent and advocate Elly Chapple calls this approach ‘flipping the narrative’ (2018).

In addition, informing someone of their diagnosis can be empowering and reassuring for the individual. Living with neurodiversity in a society that doesn't understand you can be confusing, isolating and stressful. Many autistic people recognise that they are different, but may not understand why. Understanding their diagnosis can help to answer some of their questions.

4. Behaviour as Communication

It is important for practitioners and families alike to recognise that all behaviour is a form of communication. If we overlook the underlying causes of behaviour, we are not considering the complexity of how people attempt to cope with distress. As practitioners, we always strive to interpret what someone’s behaviour might mean. Behaviours of concern - a term often used to describe behaviours that are of a high frequency, intensity or duration - are almost always an indication of distress. This can mean physical distress or pain, or that the individual is highly stressed or in a distressed mental state.

Behaviour is complex and can be determined by many different factors. As caregivers, it is important that we understand how levels of stress can influence an individual's behaviour. If an individual is exhibiting behaviours of concern, it is likely that they are communicating their stress levels or an unmet need to us. Therefore, fundamental to the reduction of these behaviours is a reduction in their overall stress levels, as well as reducing demands in the moment. A focus needs to be placed on asking why a person is engaging in such a behaviour, meeting the needs of the individual and managing their stress levels, rather than attempting to change the individual’s behaviour (Pitonyak, 2005). Trying to understand behaviour can help your child to feel reassured and supported, which may prevent an escalation in a behaviour that is difficult to cope with. Oftentimes, when someone is in a heightened state of physiological arousal, they have less control over their behaviour. At this point, they are no longer able to communicate, or to process someone else’s attempts to communicate.

Behaviour management should aim to reduce the frequency or intensity of behaviours of concern without seeking to change the individual or to punish their behaviour. By investigating what their behaviour is communicating, it makes it easier to separate the actions from the person. It is important that we focus on supporting and empowering autistic young people, not changing them. Furthermore, behaviour change takes time, and it usually occurs when the factors that are influencing the behaviours are better understood and managed.

5. The Stress Response in Autism

Stress for autistic people is a central theme to this article. The world is a chaotic, confusing and stressful place for autistic people for a myriad of reasons. When we consider the challenges that they face in terms of social interactions and sensory stimuli in their environment, we can gain a greater understanding of how certain environments can be overwhelming for people. Furthermore, autistic people experience stress in different ways to what we might expect for a neurotypical person (Donnellan, Leary & Robledo, 2006). The intensity and presentation of stress can often be different and, in some cases, more pronounced for autistic people (ibid.). Research has shown that autistic individuals have higher levels of stress hormone responses, such as cortisol, in their nervous system (Nason, 2014; Lopata et al., 2008). Even when in a relaxed state, increased levels of these hormones persist within their nervous system. This is often a result of how they interpret and experience their sensory environments on an unconscious, neurological level (Vermeulen, 2012).

Stress can have damaging effects on both mental and physical health, for carers and individuals alike (Stalder et al., 2016). As carers, we can often inadvertently add to the stress of the people we support (Lazarus & Folkman, 1984). Correlations have been shown between behaviours of concern and caregiver stress (Lecavalier, Leone & Wiltz, 2006). Research has also looked at the transactional relationship between an individual and their environment (Lazarus & Launier, 1978; Lazarus & Folkman, 1984). This research posits that people appraise their environment in order to determine whether or not there are stressors in their vicinity. People naturally become physiologically aroused when they sense stressors in their environment. By reducing environmental stressors, we can reduce physiological arousal and psychological distress. Remember, we are part of that environment too, and our actions can lead to increased arousal and distress. As carers, focusing on reframing our cognitions about the person we support can help us to develop an insight into their stress signals and triggers, and better support them in reducing their overall stress. By reducing the stress of both supporters and individuals themselves, behaviours of concern can also be reduced (Rippon et al., 2020). As such, we must place stress management at the centre of our support structures, for both the autistic individual, as well as for their families and carers.

6. Autistic People are Trying Their Best

In his book *The Explosive Child* (1998), psychologist Ross Greene describes how children are often trying to do their best despite appearing to behave ‘badly.’ If the language that we use to describe an individual implies that they are ‘bad,’ they can often start to internalise this, believing that they are inherently ‘naughty.’ This can have negative implications for their self-esteem. Therefore, it is important to consider the language that we use to describe an individual and their behaviour by understanding the implications that such language can have. When we reframe our schemas surrounding behaviour and the intentions of autistic people, we can become more empathic in how we support them. As discussed above, all behaviour is communication and what it often communicates is distress.

Autistic people are placed under a great deal of pressure to act appropriately or to ‘normalise’ their behaviours. Even today, there are schools of thought that will try to eradicate certain behaviours, such as stimming, that autistic people engage in, simply because, to a typically developing person, they may seem unusual. By encouraging autistic people to change their ‘autistic behaviours’ we may be disarming them by removing their coping strategies. For example, discouraging an individual from stimming or engaging enthusiastically with their special interest can have drastic consequences for their mental health. Rather than encouraging autistic people to try to be more like typically developing people, we should be empowering them to self-regulate with their own, unique tools.

7. Inclusion, Not Exclusion

It is important to understand that although an autistic person may develop and maintain relationships differently to people who are typically developing, it is still important for them to have people around them, be that family, friends or a care support team. Loneliness is as detrimental to the wellbeing of autistic people as it is to people who do not have a diagnosis. Autistic people may find it difficult to connect with others, however this does not mean they want to be alone as such; it is important to ensure that the people we support are socially engaged, to the level that is most suitable for them (Pitonyak, 2004).

Some approaches to autism can further compound these feelings of loneliness and isolation. Exclusion is a restrictive practice that is still used in schools and services today. In a report published by Inclusion Ireland in September 2018, the findings showed that 1 in 4 children in schools with an intellectual disability or a developmental condition such as autism have been put on short school days. In Ireland, schools do not have a clear definition of restrictive practices, whereas there are definitions within health and social care settings. The use of seclusion in schools has been banned in New Zealand. In terms of hospital settings, Murphy, Bush and Puzzo (2017) found that autistic people in psychiatric wards found it more difficult to cope in those environments compared to those without a diagnosis of autism. As a result, they experience more frequent, and longer periods of seclusion. For families, finding the right school or service for their child can be a challenge.

8. Pathway to Support Services

In addition to supporting their children’s needs, parents are also tasked with engaging with statutory and support agencies. Parents of autistic children, like parents of children with other disabilities, are faced with confronting systemic issues in order to advocate for their child. Curran et al. (2001) conducted a study which found that 67% of mothers who have children with disabilities are unable to maintain paid employment, which places economic pressures on the family, and could potentially result in mothers feeling more isolated.

Autistic people are unique individuals, and their support should acknowledge this individuality. We believe that, for a service or a school to be effective in supporting an autistic child, they need to adopt a bespoke, autism-informed approach for each individual. We also recommend that people supporting an autistic child be trained in Low Arousal Approaches.

9. Self-Regulation and Co-Regulation

Self-Regulation

Emotional regulation is a construct defined as the extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions (Thompson, 1994). A lack of ability to regulate one’s own emotions, particularly in autistic individuals, results in behaviours which have been described as behaviours of concern. These can include behaviours such as aggression, self-injury and a defiant attitude to name a few. Emotions are a result of our cognitive evaluations of external cues, therefore, the ways in which we deal with emotion-related issues, particularly when it comes to individuals with neurodiversities, can be extremely diverse (Oatley & Johnson-Laird, 1987). With this in mind, it is evident that emotional regulation strategies should be tailored to meet the needs of each individual.

A person’s ability to emotionally regulate can have a significant impact on their quality of life. Emotional dysregulation can be a precursor for anxiety, depression, explosive behaviours and inadaptability (Torrado, Gomez & Montoro, 2017).

Co-Regulation

When we consider co-regulation, we must also consider the transactional nature of stress (see Section 5: The Stress Response in Autism)**.** If our stress is transactional, then our ability to regulate can also be transactional. One of the main tenets of the Low Arousal approach is appearing calm when supporting someone who is distressed (McDonnell, 2019). We will not always feel calm in these situations; however, simply modelling a calm exterior for the people we support will encourage co-regulation. Under the medical model, autistic people have been told that they need to alter their behaviour, when in fact it is often more important for carers and parents to alter our own behaviour, and how we perceive the behaviour of others (ibid.).

Carer burnout is also important for family members when considering their own wellbeing (Heim et al., 2000). Research has shown that supporting individuals who engage in behaviours of concern can lead to high levels of stress, and may have implications for the level of care provided to an individual (Cudré-Mauroux, 2011).

Furthermore, our own emotions are also challenged when we experience distressing behaviour. It is important that we recognise this and learn to separate our own feelings and emotions from those that we support.

10. The Trauma-Informed Approach

Traumatic experiences can lead to complex responses for people. Post-traumatic stress has been well researched by both historians and clinicians for centuries. Post-traumatic Stress Disorder (PTSD) was first categorised as a mental disorder in the 1980 edition of the Diagnostic and Statistical Manual of Mental Disorders (Spitzer, First, & Wakefield, 2007). PTSD is characterised by the continued re-experiencing of the event through intrusive and distressing recollections, persistent avoidance of triggers and hyperarousal towards stimuli associated with the event, among other symptoms (Dhillon, Nikhil, Singh, Divinakumar & Bhat, 2015).

Trauma is a factor in many behaviours of concern. An individual who has experienced trauma is much more vigilant of further threats to their safety. They can often rely on their stress response to keep them safe. Stress and trauma are fundamentally linked. As one’s stress levels fall, their vigilance towards perceived threats also fall.

Autistic individuals may not necessarily be diagnosed with a psychological trauma-related disorder, however, they can often show clear signs of trauma. Although trauma can have significant long-term effects on individuals and those who support them, one can often recover from traumatic events with the right support. Using knowledge of trauma and how it can impact an individual is crucial in understanding their behaviour.

11. Special Interests

As discussed, for many years, traits of autism have been pathologised by clinicians. For example, one of the defining symptoms of ASD is repetitive behaviours and ‘special interests’ (American Psychiatric Association, 2000). This special interest can be described as an enthusiasm for and focus on the particular interest, which can be more pronounced in autistic people than in people who are neurotypical in their development. Historically, the ability to focus and engage with special interests was categorised as an obsession and these interests would often be sought to be reduced in interventions. However, in more recent years, many autistic people consider these interests to be an important strength and a way of relieving stress. If we view this immersion and involvement through the lens of Seligman's research on flow and the PERMA model, encouraging this engagement can be very beneficial for one's wellbeing (Seligman, 2018). What was previously described as 'disordered' behaviour, may now be seen as someone entering into a flow state.

12. Wellbeing

Sleep

Sleep problems are common in autistic children, with prevalence rates of approximately 50% to 80% compared with 9% to 50% in neurotypical children (Reynolds & Malow, 2011). There is a very intricate association between sleep and the stress response. Heightened levels of stress, which affect the functioning of cortisol in our body, can alter our sleep patterns and reduce our quality of sleep. Furthermore, sleep disturbances can contribute to increased stress. As such, disruption to sleep and the stress response are doubly linked. Sleep disturbance has been found to increase overall levels of stress for families who have children with autism and developmental disabilities (ibid.).

There are ways that families can work to improve their sleep hygiene. Tracking an individual's sleep history can identify where some of the challenges lie. Sleep education programmes can also help with the treatment of insomnia in autistic individuals (ibid.). Reynolds and Malow recommend that healthy sleep hygiene can be divided into daytime habits, evening habits, sleep environment, and bedtime routines. Beneficial daytime habits could include ensuring that the individual takes part in adequate physical activity and gets sufficient exposure to daylight. Evening habits could include decreasing stimulation and activity, exposure to light and implementing a bedtime routine that occurs at the same time and place each night. Consideration must also be given to the fact that autistic individuals might be hyper or hypo-sensitive to light, touch and noise. These factors can be manipulated to ensure that one's environment is optimal for a good night's sleep. Furthermore, a combination of sleep hygiene and melatonin may be useful before considering other medications for autistic individuals experiencing sleep problems. Fundamental to successful treatment of sleep disorders in autistic individuals is understanding the underlying causes of sleep problems.

Physical Activity

A person's relationship with physical exercise can be complex. Oftentimes, people avoid exercise or feel that it is a chore. However, research has continually shown the countless positive implications that physical activity can have on an individual's wellbeing. For example, exercise can positively influence an individual's mental health. Exercise helps to moderate cortisol levels in the body, while also releasing endorphins into the body, which triggers positive feelings and emotions. These mechanisms can help an individual to self-regulate, whilst also improving their mood. A meta-analysis looking at the influence of physical activity on young autistic people found that it had a range of effective outcomes such as the development of motor skills, locomotor skills, skill-related fitness, social functioning, muscular strength and endurance (Healy et al., 2018). Furthermore, physical activity is associated with the production of melatonin, which promotes the initiation of sleep and can improve a person’s quality of sleep at night.

A lack of physical activity for young autistic people can often lead to them being more susceptible to feelings of isolation if they are not active, as they tend to spend more time participating in independent activities.

13. Impact of Puberty

Puberty can be a significantly challenging time for young people, as this is a period in which the importance and complexity of social interactions and peer relationships grows (Roisman, Masten, Coatsworth, & Tellegen, 2004). When we consider the social difficulties experienced by autistic people, we can see that this period of time can be more uncertain and challenging for them. As we know, baseline levels of stress are already often much higher for autistic people. Adolescence is associated with alterations to the stress response (Romeo, 2010). For example, during adolescence, there is an apparent maturation of the circadian rhythm which results in higher basal cortisol levels in older adolescents (Adam, 2006; Walker, Walder & Reynolds, 2001). Given the already increased levels of cortisol for autistic people, puberty can further increase these elevated levels.

A study conducted by Eriksen (2016) found that autistic young people who reported menstrual symptoms indicated experiencing a greater burden of behavioural and emotional symptoms than neurotypical young people experiencing menstruation.

Previous research on developmental conditions such as autism focuses primarily on the cause, onset and early years of these conditions. As a result, less is known about the onset of puberty and adolescence for young autistic people and other developmental conditions.

Conclusion

It is evident that there are a number of challenges and concerns that parents and families face when their child receives a diagnosis of autism. However, as outlined in the article above, there are a number of things they can do in order to empower their child to live the best life that they possibly can. Although it is important that the needs of the individual are acknowledged so that appropriate support can be provided, we encourage parents and families to focus on the positive aspects of an autism diagnosis and to embrace the diversity and complexity that it may bring. This will in turn alter your thinking and responses towards your autistic loved one. As John Elder Robison once said, our duty in supporting autistic people "is not to cure but to relieve suffering and to maximise each person's potential.

If you need help with crisis intervention, training, or clinical support, please do not hesitate to contact Studio 3. For more information about our services, visit www.studio3.org or contact us at admin@studio3.org.

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