The Trauma of Broad-Based Inclusion for Students with Autism

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Abstract

Inclusion is a model where students with disabilities spend most/all of their time in an educational setting with non-disabled students. This model has led many countries to pass laws requiring disabled students be educated in the least restrictive environment: they should be educated with students without disabilities to the maximum extent possible. However, this model ignores the very nature of Autism Spectrum Disorder (ASD). The autistic brain is different in both function and structure, making deficits in social interaction, inherent and appropriate for their development. This paper explores research on the autistic brain, comorbidities, child development, and trauma associated with forced inclusion for this population. Research on brain function indicates inclusion can be very stressful and can produce anxiety and post-traumatic stress in children with ASD.

Keywords: autism, inclusion, education, neurodevelopmental, trauma

1. Introduction

Inclusion can be generally described as a model where students with disabilities spend most or all of their time in an educational setting with non-disabled students. The idea of inclusion is based on the concept that it is effective for students with special needs to have a mixed experience in order for them to be more successful in social interactions, leading to further success in later life. It is also based on the concept that it is discriminatory to segregate students based on intellectual ability. This model of inclusion has led many countries to pass laws that require students with disabilities to be educated with students without disabilities to the maximum extent possible.

Shortly after the reenactment of Individuals with Disabilities Education Act (IDEA) in 2004, the United States Department of Education Institute of Educational Services published “The Condition of Education 2005” wherein a chapter advocates for “Inclusion of Students with Disabilities in Regular Classrooms.” This chapter appeared to emphasize education in the least restrictive environment. However, the chapter actually reports data and various statistics on the demographics of children with disabilities who were most likely to spend time in a “regular classroom.” The data indicates that White students with disabilities were more likely than students of any other ethnicity to spend at least 80% of their day in a regular classroom. Black students with disabilities were more likely than students of any other ethnicity to spend less than 40% in their regular classroom (United States Department of Education, National Center for Education Statistics, 2005). The data reported appears to speak more to racial disparities in regards to school or classroom placement, as oppose to diagnostic differences or individual needs. The chapter seems to imply that White students with disabilities are perhaps perceived as more competent or more able to participate in a regular classroom setting when compared to students of other ethnicities. It comes as no surprise that after the publication of “The Condition of Education 2005” schools may have felt pressured to assess their special education programs for fear of racial inequalities that could potentially result in their losing funding. This trend has continued over the years and today in a world with a heightened awareness of anti-discrimination and a perceived dearth of school funding, there has been a major push towards more inclusion of special needs students on school campuses, but with no identifiable goal. What is the goal of inclusion? Is the goal to teach children to learn social skills or to build relationships with other children? How would attempting to force relationships teach social skills? Or perhaps it is an attempt to refrain from racial profiling and prejudices.
Regardless, the pendulum swayed too far and has resulted in imposing a common practice of “inclusion” onto every child, regardless of the child’s ethnicity, but also regardless of their diagnosis.

One prime example of this is Autism Spectrum Disorder (ASD). While there is no “cure” for ASD, there are a plethora of treatments and attempts at alleviating related symptoms. Additionally, traditional school settings have been modified in an attempt to address specific needs for children with ASD. The Individuals with Disabilities Education Act (IDEA) and other similar laws would suggest that educators have a legal duty to keep students (of all ethnicities) in a regular classroom setting, unless they have diagnoses or special needs that are not compatible with the traditional school setting. While many children with Autism Spectrum Disorder would appear to meet this criterion for separate schooling, educators and parents alike have become convinced that forced socialization is inherently good for all, including those with ASD.

Currently, there are various levels of inclusion used with students with ASD. There is the most intensive form of inclusion (also called “mainstreaming”), wherein a child with ASD participates in a regular class with typical peers all day. Regular classes typically consist of many students with lots of distracting color and decorations, noise, movement etc. There is a slightly less intensive level of inclusion which involves social instruction. This kind of inclusion is often times done during “circle time,” or art or music class, and purports to teach children to engage in basic social interactions such as waving, greeting others, maintaining eye-contact, etc. Lastly, some children participate in “inclusion” on the playground during break times or during lunch. This kind of inclusion may be an attempt at getting children with ASD to play with typical children. Despite the varying levels of inclusion and their presumed goals, it completely disregards the very nature of Autism Spectrum Disorder.

2. Autism and the Autistic Brain

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder classified by persistent deficits in social communication and interaction, as well as restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013). Symptoms are typically recognized by the second year of life (12-24 months), and may be accompanied with language impairment. While some preschool aged children with ASD will eventually use spoken language, approximately 25-50% will remain nonverbal or minimally verbal (Baghdadli et al., 2012; Lord, Risi & Pickles, 2004; Sigman & McGovern, 2005). While not a diagnostic criteria, ASD has also been strongly associated with sensory processing issues and self-injurious behaviors (Duermen et al., 2012; Baghdadli, Pascal, Grisi, & Aussilloux, 2003; Rattaz, Michelon, & Baghdadli, 2015; Richards, Oliver, Nelson, & Moss, 2012). Research indicates various patterns of sensory processing issues with prevalence rates as high as 90% (Tomchek & Dunn, 2007; Tomchek, Huebner, & Dunn, 2014). Self-injurious behaviors (SIB) include but are not limited to biting, hair pulling, head-banging, and skin picking/scratching (Minshawi et al., 2014). Self-injurious behaviors are more common in children with ASD than in their typically developing peers. In fact, research suggests 30% of children with ASD in clinic-based studies engage in SIB (Minshawi et al., 2014; Soke et al., 2016).

The Autistic brain is different in both function and structure, which makes their deficits in social interaction, inherent and appropriate for their brain development. In Autism research, the “hyperarousal model” is a much supported model which in part states that gaze avoidance is an adaptive (appropriate) response because the face and eyes are strongly aversive to those with ASD (Corden at al., 2008; Dalton et al., 2005; Richer & Cross, 1976, Senju & Johnsons, 2009). Research also indicates a general hyperactivity in various areas of the autistic brain resulting in overstimulation which can explain a number of symptoms, in addition to just aversive responses to eye-gaze (Dichter, Fedler, Bodfish, 2009; Martineau, Andersson, Barthélémy, Cottier & Destrieux, 2010; Markram & Markram, 2010). One study in particular, found 90% of children with ASD had sensory abnormalities in multiple sensory domains (Leekam, Nieto, Libby, Wing, & Gould, 2007). It is this hyperactivity that causes children with ASD to be overly stimulated by light, sound, movement and touch, to name a few. Researchers found that there were generally six patterns of sensory processing issues in children with ASD i.e. low energy/weak, tactile and movement sensitivity, taste/smell sensitivity, auditory and visual sensitivity, sensory seeking/distractibility, and hypo-responsivity (Tomchek, Huebner, & Dunn, 2014). Additionally, many children with ASD are unable to filter or process external noise which may result in elevated internal noise, causing stress (Park, Schauder, Zhang, Bennetto, & Tadin, 2017).

In individuals with ASD there is an 18% prevalence rate of hyperacusis, an abnormally acute hearing due to sensory or neural sensitivity, characterized by intolerance for normal levels of sound (Kellerman, Fan, & Gorman, 2005). Subjecting these individuals to the levels of noise generated by their typical peers is not only painful but traumatic. Researchers also found that children with ASD have increased pain sensitivity and touch sensitivity (Riquelme, Hatem, & Montoya, 2016). Placing students with ASD in an inclusion environment, one in which other
students have no awareness or knowledge of their pain and touch sensitivities, only increases the chances of them being touched, hurt and traumatized. Similarly, placing them in an overly stimulating visual environment or one that has too much odor can also cause pain and thereby cause trauma in students with ASD.

Furthermore, the atypical pattern of mutual gaze or eye-contact in particular, has been studied and discussed in various clinical and experimental settings (e.g. Dalton et al., 2005; Pelphrey et al., 2002; Rutherford & Towns, 2008). Overstimulation is seen in the over-activation of the amygdala when eye-gaze is held for longer (Dalton, Nacewicz, Johnstone, Schaefer, Gernsbacher, Goldsmith, et al. 2005; Markram & Markram, 2010). In fact, as a result of these consistent findings, research has recommended that professionals do not try to engage in eye-contact with children with ASD “as this provokes more flight behavior” (Richer & Cross, 1976, p. 193). Forcing this kind of face or eye-gaze is too stimulating, can be fear-provoking, and may even cause physical pain, yet this remains a goal for children with ASD for some reason.

The most consistently reported and largest effect in terms of brain differences is in the fusiform gyrus which is activated during face processing in typical individuals, but is notably less activated in children with ASD. Dalton et al. (2005) studied this in more detail and found results suggesting that gaze fixation is associated with a heightened emotional response. This is because gaze fixation was more closely related to activation of the amygdala instead of the fusiform gyrus in children with ASD. The amygdala is an important structure for detecting threats and initiating appropriate behavioral responses, such as fear. Not only is the amygdala especially important in the recognition and management of fear, but functional imaging studies also indicate higher activation of the amygdala during fear learning (Higgins & George, 2013). This is why emotionally relevant memories are thought to be stored in the amygdala and may speak to the overlearning of unpleasant memories like in cases of Post-Traumatic Stress Disorder (PTSD) and anxiety. Furthermore, Haruvi-Lamdan, Horesh, & Golan (2008) found that there is a shared underlying mechanism for ASD and PTSD and thus ASD may serve as a vulnerability factor for PTSD. Specifically, an increased risk to those with ASD to the exposure of a traumatic event.

The following table summarizes the brain functions and related symptoms associated with autism.

<table>
<thead>
<tr>
<th>Brain function</th>
<th>Reference</th>
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<tbody>
<tr>
<td>Sensory processing issues with prevalence rates as high as 90%</td>
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3. Functional Behavior Assessments

The consequence of children with ASD becoming overwhelmed with the repeated exposure to pain and overstimulation, is manifested differently for each child and is also mitigated by their level of expressive speech. Many children resort to screaming, crying, eloping, withdrawing, crawling under tables/desks, turning off the lights, aggression, increased stimming, self-injurious behaviors, etc. Teachers, aides, and school districts are then held responsible for addressing these issues and typically respond with what is called a “functional behavior assessment” or an FBA. This has become a standard approach and is even part of the law:

Determination that behavior was a manifestation. If the LEA, the parent, and relevant members of the IEP Team make the determination that the conduct was a manifestation of the child’s disability, the IEP Team must.

1. Either-
   (i) Conduct a functional behavioral assessment, unless the LEA had conducted a functional behavioral assessment before the behavior that resulted in the change of placement occurred, and implement a behavioral intervention plan for the child; or
   (ii) If a behavioral intervention plan, and modify it, as necessary, to address the behavior’ and
2. Except as provided in paragraph (g) of the sections, return the child to the placement from which the child was removed, unless the parent and the LEA agree to a change of placement as part of the modification of the behavioral intervention plan. (IDEA, 2017)

An FBA has become the standard approach for addressing maladaptive or defiant behaviors evidently, without any knowledge of the limitations of an FBA; it cannot provide any answers that are not already observable to the human eye. An FBA was created with the intention of forming various hypotheses in order to eventually determine the “function” of a behavior (Maurice, Green & Luce, 1996). It is typically conducted by a Board Certified Behavioral Analyst (BCBA), in order to assume the function of a behavior. However, the FBA was developed using one very small subset of psychology called behaviorism. Early behavioral psychologists insisted that one could only measure what one sees. Therefore, the belief was that anything that cannot be observed cannot be scientifically studied, such as thoughts, emotions, sensations and any other intangibles (Myers & Dewall, 2017). These intangibles (e.g. thoughts, emotions, etc) were emphasized in the early 1920’s following various “insight” experiments, particularly when German researcher Wolfgang Kohler discovered that even chimpanzees have insight, confirming the existence of cognitive learning and the importance of internal processes (Myers & Dewall, 2017). However, since the FBA was developed without any understanding or consideration for things such as insight learning, cognitions, emotions, etc., the FBA is constantly misapplied with the assumption that it will reveal the function of a behavior, even though the “function” or expression of behavior is typically due to an internal process. This concept is best illustrated by an example. Suppose a nonverbal student with ASD has a severe migraine and hits their head. The standard FBA in this case determines the function of the behavior is a form of task avoidance, when in fact it is more likely to be a cry for help, an expression of an internal process which is unobservable.

Consequently, those who conduct an FBA are really just conducting experiment after experiment without realizing that an FBA can never measure or track internal processes. In fact some of the standard explanations used in an FBA such as escape, task avoidance or access to a desired object are unobservable and therefore unmeasurable resulting in at best a guess of what is really going on. Even worse, is that should an FBA ever truly suggest the function of a behavior, the understanding of these internal processes is far beyond the scope of BCBA’s as they are not psychologists. Moreover, BCBA’s are not required to take even a single class on child development, Autism Spectrum Disorder, general psychology, etc. (Behavior Analyst Certification Board. (n.d.)).

The behaviors of students with autism are generally the result of the over activation of their brains and as such, the real function of their behaviors is unobservable and difficult to pinpoint. The resulting unscientific functional behavior assessment and this lack of competency in understanding the autistic brain, sets the stage for continued exposure and prolonged trauma for this particular group of children. This is especially true for students placed in inclusion with the wrong treatment plan that resulted from a standard FBA. Unfortunately, school districts and teachers also rely on this FBA to inform Individualized Education Plans or Programs (IEP), making this trauma part of the child’s everyday school experience. Thus continuing the cycle, reinforcing fear learning and overactivation of the brain.
4. Long Term Consequences of Repeated Trauma

The changes in brain structure and function from the chronic stress and trauma caused by inclusion is strengthened with each exposure as seen in complex Posttraumatic Stress Disorder, consequently leaving lasting effects. This is likely due to the pattern or neural activation that becomes ingrained and automatic for the person with each exposure (Perry, Pollard, Blakley, Baker, & Vigilante, 1995). In childhood, this has a profound impact on the cognitive, behavioral, physical and emotional functioning (Perry, Pollard, Blakley, Baker, & Vigilante, 1995). Research has attempted to categorize domains of impairment in children exposed to complex trauma and have identified at least the following domains: attachment, biology, dissociation, affect regulation, behavioral control, cognition and self-concept (Cook et al., 2017). These domains were predominantly identified in typical children, and one can only imagine the severity and intensity of this impairment within the context of the Autistic brain, which is already overactivated and hyperaroused to begin with. This chronic stress, trauma, and further over-activation of the brain due to forced inclusion, only contributes to abnormal levels of fear and increased anxiety, as well as other neuropsychiatric comorbidities (Amaral et al., 2003; Murris et al., 1998; Perry, Pollard, Blakley, Baker, & Vigilante, 1995).

Furthermore, multiple or repeated trauma “in childhood can lead to outcomes that are not simply more severe than the sequelae of single incident trauma, but are qualitatively different in their tendency to affect multiple affective and interpersonal domains” (Cloitre et al., 2009. P. 405). Research demonstrates this stress can interfere with cognitive, biological and emotional development, and often manifests in somatization, behavioral issues, learning disabilities, poor self-regulation, aggression toward self and others, etc, (e.g., Cook, Spinazzola, Ford, Lanktree, Bluestin, Cloitre, DeRose, Hubbard, Kagan, Liataud, Mallah, Olafson, van der Kolk, 2017; Streeck-Fischer, van der Kolk, 2002).

5. Consequences of Broad-Based Inclusion

In addition to differences in brain structure and function, and preexisting hypersensitivities, research has also found important differences and consequences when inclusion interventions are used with children with ASD, when compared to typical children and children with other special needs. Research has found that mainstream schooling or “full inclusion” has actually led to more social isolation, rejection and bullying among children with ASD even when compared to other special education needs students (Symes & Humphrey, 2010; Zablotsy, Bradshaw, Anderson, & Law, 2013). Humphrey and Lewis (2008), found that social naive can make youth with Autism Spectrum Disorder easy targets for teasing and deception, which might account for higher rates of bullying. This can undoubtedly exacerbate the predispositions for depression, anxiety and PTSD. Research has also noted ASD as a vulnerability factor for suicidal ideation and attempts. In fact, Mayes, Gorman, Hillwig-Garce, & Syed (2012) found prevalence rates of suicidal ideation and attempts in people with ASD to be significantly higher than typical, non-depressed peers. Furthermore, a critical meta-analysis discovered that school-aged youth with ASD were at greater risk of bullying and school victimization in general, when compared to their typical peers (Maiano, Normand, Salvas, Moullac, & Aimé, 2016). Maiano and colleagues (2016) also found the prevalence of bullying victimization was lower in special education settings compared to regular school or mixed school settings. This data continues to suggest that perhaps special education or mixed school settings are actually less damaging and more appropriate for children with this specific diagnosis.

In fact, children in full inclusion classrooms are “more likely to be victimized than those who spend the majority of their time in special education settings” (Zablotsky, Bradshaw, Anderson, & Law, 2013, p. 1). In a survey conducted by the National Autistic Society (2006), 1400 families affected by ASD reported that bullying had damaged their child’s self-esteem, mental health, and relationships. Moreover, “the unique characteristics of ASD may determine which events are experienced as particularly traumatic (e.g., social insults and degradation, sensory overstimulation, abrupt changes in known routines) and affect both the manifestation and severity of posttraumatic sequelae among diagnosed individuals” (Haruvi-Lamdan et al., 2018, p. 1). This is just some of the documented data indicating the negative impacts of full inclusion.

Forcing social interaction onto children with ASD is not only useless and stressful since their brain structures respond differently, but it can continue to cause further trauma and anxiety-related symptoms with each subsequent exposure, as previously discussed. While some “higher functioning” children with ASD may want to engage in social activities and may be apt to do so, flooding is not the solution. A structured approach that does not overload the Autistic brain, and is collaborative, taking into account the child’s preferences and overall psychological well-being would be the appropriate approach. Furthermore, forcing all children with ASD (especially those who cannot communicate), to interact with others in ways that they are unable to is anxiety provoking, and can elicit abnormal fear responses and learning.
The chronic stress of being forced to participate in inclusion activities should not be taken lightly. Even in situations such as “circle time” which may be viewed as an easy task, research indicates great difficulty for children with ASD. This is due to “the rapidly changing social and communicative events inherent” to instruction and social communicative interactions (Quill, 1997. P. 707). This research and others have indicated impairment in various aspects of social interaction which is presumably the goal of inclusion—to teach children with ASD to socialize. This goal is inconsistent with research and unrealistic for many children with ASD. Research indicates that many children with ASD only respond to perceptual movements or instructions when the function is to obtain an object. When researchers pointed to various objects merely to make a comment or remark (considered a higher, non-functional level of communication), the children with ASD did not understand the significance or purpose and so they would not respond, or they would instead attempt to obtain the object. These results indicate a prioritized functional basis for communication or interaction as opposed more abstract social constructs (Baron-Cohen, 1989). Put simply, an opinion or statement that does not amount to anything functional, does not result in the acquiring of any need or want, will be confusing, misunderstood and is of no value to most children with ASD. Therefore, this kind of social interaction should not be imposed on all children.

6. Conclusion

The goals of inclusion attempt to force a child with Autism Spectrum Disorder to engage in and to learn how to behave in a socially “appropriate” manner; however, in doing so, one inadvertently activates the emotional center of the brain. Unfortunately, unlike broken bones, one is unable to see the changes and the impact stress and trauma has on neurodevelopment. This is why it is especially important to understand various brain functions and structures in diverse populations before experimenting with any interventions i.e. inclusion. Furthermore, repetitive exposures and stresses of forced inclusion over time, can produce the same neurological and psychiatric results we see in patients with PTSD.

It is not enough to have accommodations such as visual schedules or assigned paraprofessionals when there are so many stimuli that can overload, cause pain, and distract children with ASD. Research indicates that up to 95% of children with ASD demonstrate some dysfunction in sensory processing (Tomchek & Dunn, 2007). Even the lowest level of inclusion wherein a child with ASD is forced to have lunch breaks with many other children, can still cause significant stress. Although these children might not be subjected to a regular classroom with an abundance of stimuli, they still endure the chaos and painful overload of stimuli when they are brought to the playground for inclusion purposes. Children with ASD may eventually overlearn this stress and pain, and each exposure will subsequently strengthen the neural connections to further maintain this trauma, similar to complex posttraumatic stress.

Despite the inability to process faces and social information from the outside world, the anxiety and fear-provoking stimuli, the oversensitivity to sight, sound, smell and touch, the chronic stress and risk for overlearning fear and inducing complex posttraumatic stress disorder, and creating further barriers to language functioning, educators, paraprofessionals, and even some parents continue to advocate for inclusion while ignoring the inherent brain function and the nature of Autism Spectrum Disorder.

The majority of children with ASD do not have the physiological capacity to interact the way many advocates of inclusion believe is possible, and more importantly, these advocates are inadvertently causing harm. To try and undo the very deficit that defines ASD makes little sense - especially when taking into account that ASD is a neurodevelopmental disorder, not a behavioral disorder or learned consequence. It is not something that can be “cured” or undone, it can only be treated if warranted. For a child with ASD, the least restrictive environment is an environment that promotes the child’s social, emotional, and cognitive development with the least amount of communication barriers including anxiety, chronic stress, and fear-provoking stimuli—which is not congruent with forced inclusion.

Teaching and parenting practices in general can be a contentious subject and are often met with defensiveness, criticisms, or confusion. However, in considering the last 20-30 years of research, it is evident the trauma-inducing practice of inclusion causes harm for many students with ASD, and the long-term effects are even more pronounced. Perhaps it is time to move away from the “one size fits all” approach and instead consider available research, and each child’s diagnosis, needs, and well-being individually.

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