



Autistic Voices are Missing in Research on Inclusion Best Practices



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Abstract

In this researcher's dissertation and further educational research, literature on the perspective of inclusion and school experience from the voice of those on the autism spectrum is uncommon. Research is robust and spans decades from the perspectives of clinicians, administrators, educators, and researchers. Students on the autism spectrum have experienced well-meaning inclusion practices that have not felt inclusive to practices of exclusion and even bullying from peers and educators. Educational organizations primarily focus on education practices in inclusion defining inclusion as mainstreaming or increased time with peers but neglect the important of social inclusion and the importance of social skills for both students on the autism spectrum and their non-autistic peers for meaningful social interactions and inclusion. This review is a call to action for further educational research on school experiences from the perspective of those on the autism spectrum and clinical research on the impact on mental health and outcomes for students on the autism spectrum whose social skills are and were neglected and who experienced exclusion through segregation and/or bullying in the school system.

Keywords: ASD; Inclusive practices; Autistic perspective; Bullying; Mental health; Call to action; Autistic voice; Social skills building

Introduction

This researchers' original dissertation research, "Creating an Inclusive Climate for Students on the Autism Spectrum" [1] is the basis for the mini review. In this phenomenological study, a total of 35 participants which included administrators, educators, school psychologists, paraprofessionals, school counselors, parents of children on the autism spectrum, and individuals on the autism spectrum were surveyed through semi-structured interviews concerning barriers to inclusive educational practices and suggestions for more inclusive practices for students on the autism spectrum. In further research, "Inclusion, autism spectrum, students' experiences" [2], in creating a literature review of available research from the students' perspectives, comes this call to action for further research from the voices of those on the autism spectrum on inclusive best practices in the educational system.

A previous literature review of research concerning inclusion from the perspective of autistic students included: Brede et al. [3], Humphrey et al. [4], Gordon [5], Jones et al. [6], McGregor et al. [7], Sproston et al., [8], and Wang [9]. Lack of research and understanding of students on the autism spectrum is contributing

to negative stigma and lack of understanding of the autism community [2,6].

Research spanning the last two decades has focused on the importance of teacher attitude concerning inclusion [1, 7-15] and what contributes to teachers' attitudes toward inclusion [1,14,16-19].

A section of research has indicated teachers who do value inclusion or desire to be inclusive are not supported by their administrators and lack resources and training to include students on the autism spectrum in the general classroom [1,14,17,18,20-24]. Inclusion literature also focuses on the importance of the administration or educational leadership in building a climate of inclusion within the school as well the responsibility for training and resources and understanding of the laws concerning inclusion [1,16,25-32].

Furthermore, you can find research on factors that promote inclusion [33], tools for inclusion [34], tips for inclusion [35], defining inclusion [36], special education law and inclusion [37-39], interventions that promote inclusion [40], effects when there is not inclusion [41] and a review of other inclusion literature [32].

All of the above studies are important and have their place on the topic of inclusion. However, we need to move from the paradigm of disabilities and differences from the medical or professional approach addressing behaviors and treatments and protocols to reach appropriate norms and standards [42] to an empowerment and partnering approach with the autism community on what practices are defined inclusive to them [1].

Discussion

Now referred to as autism spectrum disorder (ASD), Blumberg et al. [43] explained that ASD is a complex neurological disorder that includes the following former diagnostic labels, such as autistic disorder, Asperger's Syndrome, and pervasive developmental disorder, not otherwise specified (PDDNOS). The Centers for Disease Control and Prevention [CDC] [44] reported the current prevalence of ASD to be 1 in 59 children with 1 in 6 children in the United States having some form of developmental disability from mild to severe making, autism the fastest-growing developmental disorder in the United States [1,16]. The World Health Organization cites autism globally as 1 in 100 children [45].

While pediatrician Dr. James Coplan, a neurodevelopmental pediatrician from the University of Pennsylvania, argued the rates of autism are due to changing criteria and lack of record keeping of autism in the school system before 1975, Dr. Martha Herbert, a pediatric neurologist at Harvard Research School of Medicine, examined the rates based on changing criteria and found that of the 1200% increase of diagnostic rates only 400% of that increase could be attributed to change in criteria alone leaving an 800% increase [31] over 25 years not related to change in diagnostic criteria [1,46]. While research is not certain concerning the causal attributes to the increased rate of autism, the CDC [44] reports that ASD is found equally among races, ethnicities, and socioeconomic backgrounds [1]. In the Bai et al. [47] five country cohort study of 2.1 million participants does suggest an 80% heritability rate of autism spectrum disorder; therefore, we can project autism rates to increase. Autism is reshaping special education, and the public school system has not adapted or responded to handle the increase of students to be served on the autism spectrum over these past 40 years [1,16,48].

According to Watkins et al. [40], students with ASD will have limited or hindered success in an inclusive or general education classroom if they are in a general education classroom without supports or resources and social skills [1]. The classroom experience is social with numerous social interactions a student will have with the teacher(s) and peers across many activities, both structured and unstructured throughout the day, which is challenging because of the core deficits in ASD center on social communication [1].

According to Stichter et al. [49], the level of social skill deficit will manifest differently from student to student on the spectrum with varying degrees of severity. Students on the spectrum have difficulty in the areas of Theory of Mind (ToM), emotion

recognition, and executive functioning. Cited by Stichter et al. [49], Baron-Cohen et al. [50] described the inability to understand intentions and thoughts of others or understand that others have different perspectives and thoughts than one's own is what is referred to as Theory of Mind. Coupled with lack of emotional recognition, the student with ASD has an understanding of basic emotions but may not recognize nuances in emotions or facial, gestural, or inflections in tone which may cause the student not to be able to follow social communication in activities in the classroom [49].

Vermeulen [51] stated social communication has contextual sensitivities that may be missed by those on the autism spectrum. Without intervention, social skills training with contextual sensitivities [51], and supports, the student with ASD may exhibit problematic behaviors, which may lead to internalizing, anxiety, or becoming socially withdrawn [52]. Isolation or exclusion can create a negative impact on the student's mental health and academic performance and create further deficits in other developmental skills [53,54].

Social skills training is important not only for those students on the autism spectrum but also their neurotypical peers and educators. Crompton et al. [55] stated that effective information transfer requires social skills and found miscommunication from mismatched neurotype. Autistic to autistic communication was found to be effective as well as neurotypical to neurotypical communication information transfer; the challenges arose in autistic to non-autistic persons transferring information through communication. This indicates that autistic and non-autistic people have difficulty communicating with each other and reading each other's social cues. Therefore, social skills programs in schools should include both neurotypical peers and those on the autism spectrum instead of autism only social skills building groups.

Understanding that friendship and belonging are crucial toward mental health and better life outcomes, Boutot [35] wrote that merely increasing favorable attitudes toward peers with disabilities and placing them side by side in class is not enough to promote inclusive behaviors that lead to friendship [1]. Parents and teachers must work together to promote friendships within and outside of the classroom.

Listed among characteristics of being unpopular or excluded, Boutot listed those who tend to play alone, those children that do not have athletic skills, children with inappropriate or extreme behaviors, and those with poor social skills that are difficult to engage in cooperative play make the list. While ASD was not specifically mentioned in the study, these characteristics are part of the ASD symptomatology listed in the DSM 5 [56]. Boutot [35] noted that many times, teachers and schools hide behind confidentiality, claiming parents do not want other students to know about their child's issues [1]. However, research supports that most parents of children with ASD are longing for their child

to have one friend and are willing to disclose the diagnosis if asked. Boutot suggested that preparing the students in the general education classroom before the student(s) with disabilities or differences arrive is important to explain behaviors, any devices or supports the student may need, and provide time for students to ask questions to lessen fear or confusion of behavior the child to be included may display [1].

Boutot suggested promoting a system of peer mentoring or peer tutoring rotating students to be a buddy or lunch friend to promote inclusive behaviors and build friendship behaviors. One-way schools may try to implement and promote inclusion has been through special education clubs aimed at pairing neuro-typical students with special education students for social inclusion. Such programs ask nondisabled students to volunteer to eat lunch with or attend school functions with students who are not able to be part of the mainstream class due to severe disabilities or mental impairment. This practice would fall under peer support, as outlined by Cowie & Hutson [57]. Cowie and Hutson stated that to promote truly inclusive behaviors, classroom peers need to spend time with peers with differences and disabilities intentionally. Peer support behaviors in schools are those that promote befriending, peer counsel, peer tutoring, lunch conversation, and inclusive play in nonroutine portions of the school day.

Wanting to know what knowledge and understanding school-aged children possess about students with autism, Dillenburger et al. [58] surveyed 3,353 children and youth (p. 766). Overall, children and youth were aware of autism and had basic knowledge concerning strengths and challenges children on the spectrum face. It was found that 43% of students knew someone personally on the autism spectrum and reported a favorable attitude (p. 769). Increased levels of autism and knowledge were associated with a more favorable attitude toward having a student on the autism spectrum in one's class [1]. While awareness and attitude were keys to promoting acceptance and understanding, the students surveyed also indicated at a high rate a lack of knowledge on how to engage with persons on the spectrum and how to intervene if they witnessed bullying. One out of six students surveyed in the Dillenburger et al. study reported witnessing someone with autism being bullied, and one in ten of those stated they did nothing to help while the majority stated they wanted to intervene or told someone in authority [1].

Conclusion

Negative socio-emotional effects and less favorable outcomes are cited for students with special needs who are not receiving social skills training [41] or being social included [1]. "However, to date as indicated by the students in my study [1,2], neither they nor their parents were asked about what practices would build peer or teacher understanding and social inclusion." For suggestions on inclusion and what feels inclusive, students have suggestions if educators and professionals dare to ask [1,2,59,60]. Therefore, future research on best practices for inclusion and

social skills building curriculum and training must include the voices and perspectives of those on the autism spectrum. While it is important and ethical to protect individuals with disabilities and differences from exploitation of research, we cannot continue to use protection as the reason voices and perspective of those on the spectrum are excluded from research [1]. Guidelines exist, such as AASPIRE, to outline ethical practice for including adults on the autism spectrum in research [61].

All persons need autonomy and relatedness as fundamental needs at home or school; additionally, autonomy and relatedness are crucial for increased learner outcomes for both student and teacher [62]. Self-determinism can be applied to many facets of educational practices to promote learning and increase the competence of one's abilities as this produces intrinsic motivation and personal growth for better academic outcomes [63]. Klassen & Usher [64] cite Albert Bandura's work on self-efficacy and define it as the core belief one can achieve one's goals. Self-efficacy is important in educational setting because to achieve educational goals and goals beyond the education setting, individuals want to exercise a measure of control over their life and believe they can help architect their destinies [64].

An autism friendly, supportive, and inclusive school would begin with supportive administration that promotes a positive and favorable climate for inclusion through visionary leadership while supporting and providing resources and training to all staff in a sensory-friendly environment with multiple layers of support of staff [22]. Building on the body of research concerning inclusion, researchers are now called to include those on the spectrum when building best practices for inclusion. To conclude with the words of disability advocate Charlton [65], "Nothing about us, Without us!" Persons with disabilities and differences need to be included on what is best for them and be empowered in personal involvement in practices outlined for them [66-69].

Researcher's Role

My professional and personal life involves daily interaction with students and adults on the autism spectrum. As a mental health provider and certified autism specialist, I have had the experience of counseling parents and family members whose loved ones on the autism spectrum struggled with suicidal ideation or completed suicide. I have personally worked with students as a guidance counselor and community-based counselor with adults on the spectrum who still suffer from anxiety, stress, even PTSD from their school experience. This call to further research is both from personal experience as a mother of a young adult on the spectrum but also professional experience in the fields of education and mental health.

Acknowledgement

This mini review reflects research from the author's previous research and dissertation studies (Holmes 2018, Holmes 2020, Holmes 2022, and Holmes and Butcher, 2020). Suggestions given

by students in non-peer reviewed resources which also informed this review can be found in *Exceptional Needs Today* (Holmes 2021a, Holmes 2021b).

References

1. Holmes S (2020) Creating an inclusive climate for students on the Autism spectrum [Doctoral dissertation, Abilene Christian University]. Digital Commons.
2. Holmes S (2022) Inclusion, autism spectrum, students' experiences. *International Journal of Developmental Disabilities*.
3. Brede J, Remington A, Kenny L, Pellicano E (2017) Excluded from school: Autistic students' experiences of school exclusion and subsequent reintegration into school. *Autism & Developmental Language Impairments* 2.
4. Humphrey N, Lewis S (2008) What does 'inclusion' mean for pupils on the autism spectrum in mainstream secondary schools? *Journal of Research in Special Education Needs* 8(3): 132-140.
5. Gordon M (2010) Student voice key to unlocking inclusive educational practices. *Canadian Journal of New Scholars in Education* 3(2): 1-11.
6. Jones S, Gordon C, Akram M, Murphy N, Sharkie F (2021) Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism Development Disorders* 52: 1131-1142.
7. McGregor G, Mills M, te Riele K, Hayes D (2015) Excluded from school: Getting a second chance at a 'meaningful' education. *International Journal of Inclusive Education* 19(6): 637-656.
8. Sproston K, Sedgewick F, Crane L (2017) Autistic girls and school exclusions: Perspectives of students and their parents. *Autism & Developmental Language Impairments* 2: 1-14.
9. Wang L (2019) Perspectives of students with special needs on inclusion in general physical education: A social-relational model of disability. *Adapted Physical Activity Quarterly* 36(2): 242-263.
10. Cook BG (2001) A comparison of teachers' attitudes toward their included students with mild and severe disabilities. *Journal of Special Education* 34(4): 203-214.
11. Elhoweris H, Alsheikh N (2004) Teachers' attitudes toward inclusion. *International Journal of Special Education* 21(1): 115-118.
12. Fakolade OA, Adeniyi SO, Tella A (2009) Attitude of teachers toward inclusion of special needs children in general education classroom: The case of teachers in some selected schools in Nigeria. *International Electronic Journal of Elementary Education* 1(3): 155-169.
13. Hammonds H, Ingalls L (2003) Teachers' attitudes toward inclusion: Survey results from elementary school teachers in three southwestern rural school districts. *Rural Special Education Quarterly* 22(2): 24-30.
14. Holmes S, Butcher J (2020) Educational leaders can lead the way for increased academic achievement for students on the autism spectrum. *School Leadership Review* 15(20): 1-20.
15. Mulholland S, Cumming T (2016) Investigating teacher attitudes of disability using nontraditional theoretical framework of attitude. *International Journal of Education Research* 80: 93-100.
16. Barnes K (2008) The attitudes of regular education teachers regarding inclusion for students with autism. Dissertation Abstracts International Section A: Humanities and Social Sciences. ProQuest Information & Learning.
17. Carrington S, Berthelsen D, Nickerson J, Walker S, Meldrum K (2016) Teachers' experiences of inclusion of children with developmental disabilities across the early years of school. *Journal of Psychologists & Counsellors in Schools* 26(2): 139-154.
18. Goodman R, Burton D (2010) The inclusion of students with BESD in mainstream schools: Teachers' experiences of a recommendations for creating a successful inclusive environment. *Emotional and Behavioural Difficulties* 15(3): 223-237.
19. Lindsay S, Proulx M, Thomson N, Scott H (2013) Educators' challenges of including children with autism spectrum disorder in the mainstream classroom. *International Journal of Disability, Development and Education* 60(4): 347-362.
20. Barned N, Knapp N, Neuharth-Pritchett S (2011) Knowledge and attitudes of early childhood preservice teachers regarding the inclusion of children with autism spectrum disorder. *Journal of Early Childhood Teacher Education* 32: 302-321.
21. Boujut E, Popa-Roch M, Palomares E, Dean A, Cappe E (2017) Self-efficacy and burnout in teachers of students with autism spectrum disorder. *Research in Autism Spectrum Disorders* 36: 8-20.
22. Goodall C (2015) How do we create ASD-friendly schools? A dilemma of placement. *Support for Learning* 30(4): 305-326.
23. Gülec-Aslan Y (2013) A training programme for a teacher working with a student with ASD: An action research. *Educational Sciences: Theory and Practice* 13(4): 2229-2246.
24. Pantić N, Florian L (2015) Developing teachers as agents of inclusion and social justice. *Education Inquiry* 6(3): 333-351.
25. Ball K, Green R (2014) An investigation of the attitudes of school leaders towards the inclusion of students with disabilities in the general education setting. *National Forum of Applied Education Research Journal* 27(1/2): 57-76.
26. Harding S (2009) Successful inclusion models for students with disabilities require strong site leadership: Autism and behavioral disorders create many challenges for the learning environment. *International Journal of Learning* 16(3): 91-103.
27. Harpell J, Andrews J (2010) Administrative leadership in the age of inclusion: Promoting best practices and teacher empowerment. *Journal of Educational Thought* 44(2): 189- 210.
28. Holmes S (2018) Creating an inclusive climate for students with developmental delays (AS/ASD). Georgia Association for Positive Behavior Support Conference.
29. Horrocks J, White G, Roberts L (2008) Principal's attitudes regarding inclusion of children with autism in Pennsylvania public schools. *Journal of Autism Developmental Disorders* 38(8): 1462-1473.
30. Pazez BL, Gevarter C, Hamrick J, Rojeski L (2014) Review: Administrator views and knowledge of instructional practices for students with autism spectrum disorders. *Research in Autism Spectrum Disorders* 8(10): 1253-1268.
31. Praisner C (2003) Attitudes of elementary school principals toward the inclusion of students with disabilities. *Exceptional Children* 69(2): 135-145.
32. Weber L, Young G (2017) High school administrators and inclusion: A review of the literature. *Proceedings from the 2016 Atlantic Education Graduate Student Conference* 7(1).
33. Segall MJ, Campbell JM (2012) Factors related to education professionals' classroom practices for the inclusion of students with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders* 6(3): 1156-1167.
34. Becker H, Roberts G, Dumas S (2000) The inclusion inventory: A tool to assess perceptions of the implementation of inclusive education practices. *Special Services in the Schools* 16(1/2): 57-73.

35. Boutot EA (2007) Fitting in: Tips for Promoting acceptance and friendships for students with autism spectrum disorders in inclusive classrooms. *Intervention in School and Clinic* 42(3): 156-161
36. Shogren KA, McCart AB, Lyon KJ, Sailor WS (2015) All means all: Building knowledge for inclusive schoolwide transformation. *Research and Practice for Persons with Severe Disabilities* 40(3): 173-191.
37. Wright P, Wright P (2018) From emotions to advocacy: The special education survival guide (2nd edn.). Harbor House Law Press.
38. Wright P, Wright P, O'Connor S (2018) All about IEPs: Answers to frequently asked questions about IEPs. Harbor House Law Press.
39. Yell M (2019) The law and special education (5th edn.). Pearson.
40. Watkins L, Ledbetter-Cho K, O'Reilly M, Barnard-Brak L, Garcia-Grau P (2019) Interventions for students with autism in inclusive setting: A best evidence synthesis and meta-analysis. *Psychological Bulletin* 145(5): 490-507.
41. Ruijs N, Peetsma T (2009) Effects of inclusion on students with and without special educational need reviewed. *Educational Research Review* 4(2): 67-79.
42. Rees K (2017) Models of disability and the categorization of children with severe and profound learning difficulties: Informing educational approaches based on an understanding of individual needs. *Educational & Child Psychology* 34(4): 30-39.
43. Blumberg S, Bramlett M, Kogan M, Schieve L, Jones J, Lu M (2013) Changes in the prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007-2012. *National Center for Health Statistics Reports* 65: 1-12.
44. Centers for Disease Control (2018) Data and statistics on autism spectrum disorder.
45. World Health Organization (2020) Autism.
46. Scalise E, Holmes S (2015) Light it up blue: Understanding autism spectrum disorder. *Christian Counseling Today* 20(2): 11-16.
47. Bai D, Yip B, Windham G (2019) Association of genetic and environmental factors with autism in a 5-country cohort. *JAMA Psychiatry* 76 (10): 1035-1043.
48. Claypool M, McLaughlin J (2017) How autism is reshaping special education: Unbundling of IDEA. Lanham, MD: Rowman & Littlefield.
49. Stichter J, Herzog M, Visovsky K, Schmidt C, Randolph J, et al. (2010) Social competence intervention for youth and Asperger syndrome and high functioning autism: An initial investigation. *Journal of Autism and Developmental Disorders* 40(9): 1067-1079.
50. Baron-Cohen S, Leslie AM, Frith U (1985) Does the autistic child have a 'theory of mind'? *Cognition* 21: 37-46.
51. Vermeulen P (2015) Context blindness in autism spectrum disorder: Not using the forest to see the trees as trees. *Focus on Autism and Other Developmental Disabilities* 30(3): 182-192.
52. Bauminger N, Shulman C, Ayan G (2003) Peer interaction and loneliness in high functioning children with autism. *Journal of Autism and Developmental Disorders* 33: 489-507.
53. Ostmeier K, Scarpa A (2012) Examining school-based social skills program needs and barriers for students with high-functioning autism spectrum disorder using participatory action research. *Psychology in the Schools: Special Issue: High-Functioning Autism Spectrum Disorders in the Schools* 49(10): 932-941.
54. Rogers SJ (2000) Interventions that facilitate socialization in children with autism. *Journal of Autism and Developmental Disorders* 30(5): 399-409.
55. Crompton C, Ropar D, Evans-Williams C, Flynn E, Fletcher-Watson S (2020) Autistic peer-to-peer transfer is highly effective. *Autism* 24(7): 1704-1712.
56. American Psychiatric Association (2013) Diagnostic and statistical manual of mental disorders (5th edn.) American Psychiatric Publishing.
57. Cowie H, Hutson N (2005) Peer support: A strategy to help bystanders challenge school bullying. *Pastoral Care in Education* 23(2): 40-44.
58. Dillenburger K, Jordan J, McKerr L, Lloyd K, Schulbotz D (2017) Autism awareness in children and young people: Surveys of two populations. *Journal of Intellectual Disability Research* 61(8): 766-777.
59. Holmes S (2021) Do students on the Autism spectrum feel included in the school system? *Exceptional Needs Today* 1: 59-63.
60. Holmes S (2021) Students on the spectrum have ideas about inclusion if we will listen? *Exceptional Needs Today* 3: 21-23.
61. Nicolaidis C, Raymaker D, Kapp SK, Baggs A, Ashkenazy E, et al. (2019) The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism* 23(8): 2007-2019.
62. Ryan R, Powelson C (2014) Autonomy and relatedness as fundamental to motivation and education. *Journal of Experimental Education* 60(1): 49-66.
63. Deci E, Vallerand R, Pelletier L, Ryan R (1991) Motivation and education: The self-determination perspective. *Educational Psychologist* 26(3/4): 325-346.
64. Klassen R, Usher E (2010) Self-efficacy in educational settings: Recent research and emerging direction. In: Urdan, TC, Karabenick SA (Eds.), *The decade ahead: Theoretical perspectives on motivation and achievement (Advances in Motivation and Achievement, Vol 16 Part A)*, Emerald Group Publishing Limited: 1-33.
65. Charlton J (2000) *Nothing about us without us*. University of California Press.
66. Bai H, Martin S (2017) Assessing the needs of training on inclusive education for public school administrators. *International Journal of Inclusive Education* 19(12): 1229-1243.
67. Cook BG, Cameron DL (2010) Inclusive teachers' concern and rejection toward their students. *Remedial & Special Education* 40(A): 230-238.
68. Patton M (2015) *Qualitative research & evaluation methods* (4th edn.). Sage.
69. Ryan R, Deci E (2000) Self-determination theory and the facility of intrinsic motivation, social development, and well-being. *American Psychologist* 55(1): 68-78.



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