

# Inclusion, autism spectrum, students' experiences

# Stephanie C. Holmes (b)

Abilene Christian University, US

**Objectives:** The aim of this study is to examine the gap that exists between the federal mandate to educate children with disabilities or special needs in the least restrictive environment, and the practice of inclusion of students with autism spectrum disorder (ASD) into the general education classroom or interactions with general education students both academically and socially. Practices that are defined as inclusive best practices are often determined and defined by local administrators and educators without the perspective of students on the autism spectrum.

**Methods:** Six American students with a formal diagnosis of differing levels of ASD with mixed exceptionalities, both male and female, participated in this phenomenological study. Personal interviews, documents, and artifacts were used to collect data. Once the data were collected, transcribed, coded, and analyzed, the results of findings were displayed in the study for future discussion on defining inclusion and barriers to inclusion from the perspective of those on the autism spectrum.

**Results:** The students had mixed reviews about their classroom teachers, stating from year to year the teachers' understanding of autism and their treatment in the classroom was different, which was confusing. The students felt distant and experienced a lack of connection with the student body. All six American students felt that both teachers and peers lacked basic awareness and acceptance of autism.

**Conclusion:** The students included in this study give practical suggestions of inclusive practices and describe harmful practices from their experience in the public school system. As researchers discuss best practices and outcomes, it is recommended that future research examine the experience and perspective of those on the autism spectrum.

**Keywords**: ASD, inclusive practices, autism in the classroom, autistic perspective, barriers to inclusion, muted group

#### Introduction

The voices of students on the autism spectrum are important to include in studies concerning inclusion to hear the perspectives of personal experience of inclusion or the lack thereof in the public-school system. The critical theory paradigm addresses 'inequities in power,' wherein researchers are called to stress the responsibility of themselves and the majority population to challenge and change the status quo for the betterment of those who have been marginalized (West and Turner 2018, p.73). Students on the autism spectrum have remained a muted group in research concerning their definition of inclusion and the impact of the lack of inclusion in a school setting.

The problem of practice for this examination is the gap that exists between the federal mandate to educate children with disabilities or special needs in the least restrictive environment, and the act of inclusion of

Correspondence to: Stephanie C. Holmes, Abilene Christian University, US. Email: dr.stephanie@holmesasr.com

students with autism spectrum disorder (ASD) into the general education classroom or interactions with general education students both academically and socially . When parents advocate for an inclusive education for their children on the autism spectrum, there is often conflict between school administration and parents because the terms mainstreaming, inclusion, and the least restrictive environment (LRE) are loosely defined by the federal mandates. Administrators may focus on providing the minimum expectations for a free and appropriate public education (FAPE). However, van der Werf (2014) stated that the public-school system is the first place a child will begin their academic journey in a formal setting, and it is the academic process of learning and development that prepares a student for other skills required for independent living as adults.

Ruijis et al. (2009) stated that students with special needs who are not socially included or do not receive social skills training end up with negative socio-emotional effects and are seen as less favorable by non-

Participant/ Student on the Spectrum	Gender	Race	Diagnosis	Highest level of education	School experience impact on mental health	Educational setting	Graduated from public school	Current employment
	Female	White	ASDL1 & other health issues (OHI)	Associates Degree	Negative	Mainstream with pullout and resources	No	Unemployed
N	Female	White	*Asperger's (ASDL1) & OCD/ Gifted	Graduate degree	Very Negative	Mainstream with para/ co-taught class/ segregated - autism segregated - BEH/BED/ mainstream	se/,	Part-time in chosen field
8	Male	White	ASDL3 Motor Disorder Non-speaking	High school	Very Negative	Mainstream with support Segregated	O.	Self-employed
4	Female	White	*PDDNOS (ASDL1)/ selective mutism	Bachelor's	Neither Negative nor Positive	Mainstream with support	Yes	Full-time teacher
2	Female	White	*Asperger's (ASDL1) Gifted	Graduate Degree	Negative	Resources and gifted placement	Yes	Full-time in chosen field
9	Male	African American	ASDL2	Bachelor's	Negative	Small class setting/co-taught setting pullout resources	Yes	Underemployed
*Older autism sp	ectrum diagno	sis translated int	*Older autism spectrum diagnosis translated into newer DSM-5 terminology of ASD Levels 1-3.	SD Levels 1-3.				

special-need students. Students on the autism spectrum are the most vulnerable to bullying, social exclusion, and isolation at school. Connolly et al. (2016) stated that of students they surveyed concerning bullying 18% of the general population stated they were bullied compared to 60% of students on the autism spectrum who indicated they were bullied. Because ASD is a neurological wiring that implies challenges in social skills, attending, social communication and emotional regulation (APA 2013), lack of these skills can, in fact, impede learning and academic potential (van der Werf 2014). Research indicates that social inclusion is imperative for positive educational outcomes for students on the autism spectrum (Baglieri *et al.* 2017, Little *et al.* 2017).

#### Literature review of inclusion

Studies concerning inclusion and best inclusion practices tend to be conducted from the perspective of clinicians, educators, administrators, and parents but rarely from the perspective or the voice of the student (Gordon 2010, Jones et al. 2021). Wang (2019) conducted a study of inclusion in physical education courses; Sproston et al. (2017) studied exclusion from the experience of female students on the spectrum and their parents. Views and experiences of inclusion in the mainstream classroom in the UK are found in Humphrey et al. 2008) study. Brede et al. (2017) studied nine students on the autism spectrum from England and the negative impact of exclusion in their schooling, and McGregor et al. (2015) studied the impact of exclusion on Australian students on the autism spectrum who found their second chance at education in alternative settings. Jones et al. (2021) argued that there is a research gap on inclusion and the experience of autistic adults and their experiences in life; the

Table 2 Student experiences superordinate themes

Recurring remark/theme	N
Did not feel safe at school/Safe to be me at school Did not feel included by student body in the school setting	6/6 6/6
Lack of peer awareness of understand about autism Lack of teacher understanding of autism/lack of individualization	6/6 6/6
Experienced teasing for autistic mannerisms or behaviors	6/6
Experienced some form of bullying Lack of social supports or social problem solving Mixed abilities/mixed exceptionalities Experienced social exclusion Was not invited to parties outside of school or events with peers	6/6 6/6 6/6 5/6 5/6
How I was treated by peers and teachers was a detriment to my mental heal or self-esteem	5/6
I didn't know how to ask for what I needed School did not always make the accommodations Wasn't treated as a person by school/peers (treated like a toddler, monster, burden, alien, animal, problem, outcast, bomb/explosion)	4/6 4/6 4/6

Table 1 Participant demographics

researchers concluded this lack of research and understanding is contributing to negative stigma on the autism community and urgently call for research that includes the voice and experiences from those in the autism community. While studies from the perspective of students are challenging to find; studies concerning inclusion in a general sense are easy to find and have been conducted for decades.

#### Teachers and inclusion

One of the highest contributing factors to how successful inclusion will be concerns the attitude of the teacher (Holmes 2020). Decades of research are available concerning teacher attitude or the teacher's perspective of inclusion (Cook 2001, Cook et al. 2007, Elhoweris et al. 2004, Fakolade et al. 2009, Hammond and Ingalls 2003, Mulholland et al. 2016). Cited factors about what contributes to teacher attitude about inclusion of students with needs include themes such as lack of understanding of autism among teachers, lack of teacher training, and lack of resources and support of administrators to the teachers providing inclusion of students on the autism spectrum (Barnes 2008, Carrington et al. 2016, Cook 2001, Cook et al. 2007, Elhoweris et al. 2004, Fakolade et al. 2009, Goodman et al. 2010, , Lindsay et al. 2013).

After lack of understanding or basic knowledge of autism, lack of training and resources is mentioned by teachers as causes of stress, burnout, or negative view concerning inclusion of students on the autism spectrum despite advocating for equality of education for all students (Carrington *et al.* 2016, Fennell *et al.* 2018, Goodman *et al.* 2010, Lakkala, *et al.* 2016, Lindsay *et al.* 2013, Nishimura *et al.* 2015, Shogren *et al.* 2015). Studies concerning training and resources as important to inclusion (Gülec-Aslan 2013, Pantić *et al.* 2015), as well the fact that future teachers are not being trained while in school (Barned *et al.* 2011) in addition to the lack understanding of special education law by mainstream teachers (O'Connor *et al.* 2016) contribute to studies concerning barriers to inclusion.

Multiple studies indicate that teachers feel that their administrators do not support an inclusive environment in the school, nor do they support the teacher's efforts of inclusive in the classroom and they feel inadequate and not prepared to work with students on the autism spectrum in the general education classroom (Boujut et al. 2017, Carrington et al. 2016, Goodall 2015, Goodman et al. 2010, Gülec-Aslan 2013, Lindsay et al. 2013, Mulholland et al. 2016, Pantić et al. 2015, Shogren et al. 2015).

#### Leadership and inclusion

Educational leadership which can include administration as well as those designated at a school to function as a local education agency (LEA) representative play a fundamental role in the climate and inclusive practices or lack thereof at the local public school (Holmes 2018, Holmes 2020, Holmes *et al.* 2020). Because of this importance, another prevailing theme in the inclusion literature concerns the LEA representative's role in inclusion with deciding placement for the child with the needs (Bai *et al.* . 2015, Ball et al. 2014, Harding 2009, Harpell *et al.* 2010, Horrocks *et al.* 2008, Pazey *et al.* 2014, Praisner 2003, Weber *et al.* 2017).

Praisner's (2003) ground-breaking study was one of the first studies and now one of the most cited to examine administrative attitude toward inclusion. Praisner (2003) found significance evidence that the attitude toward inclusion was largely affected by the administrator's own knowledge and training concerning various disabilities which was later supported by Ball et al. (2014). In this researcher's dissertation study concerning barriers to inclusion, administrators with special education training were more likely to fill out the survey concerning inclusion and were more inclined to promote inclusion (Holmes 2020). When administrators are more knowledgeable about behavior management techniques, administrators were more favorable toward inclusive practices (Harding 2009). Educational leaders who were proponents of inclusion had the attitude that all students abled, disabled and differently abled benefitted from inclusion. Administrators who were favorable were more prone to resource professional development for teachers (Ball et al. 2014, Harding 2009, Horrocks et al. 2008).

# Inclusive practices and fidelity of implementation

Earlier research by Inos et al. (1995) for the improvement of inclusive practices was foundational in the changing language of federal mandates concerning educating students with needs. Inclusion inventories or plans based on educators' and administrators' perceptions of inclusion (Becker et al. 2000, Lakkala et al. 2016) are very important in providing metrics and ideas to inform inclusion. Studies on interventions concerning social skills for better outcomes (Rogers 2000), effects of inclusion on students with and without special needs (Ruijs et al. 2009), factors that promote inclusion for students with autism (Segall et al. 2012), tips to fit in (Boutot 2007), defining inclusion (Shogren et al. 2015) reviews of inclusion literature (Weber et al. 2017), educating parents and educators about special education and inclusive practices (Wright et al. 2018a, Wright et al. 2018b, Yell 2019), and interventions that promote inclusion (Watkins et al. 2019) are all important to the body of growing literature about inclusion.

These studies represent an external locus of control driven by educators and leadership to determine the best interventions to promote the development of children with needs without including the voice of those to be included. In the 1970s and 1980s there was a paradigm in education which focused on the behavioral and the medical disability approach with protocols to help students reach appropriate norms and standards (Rees 2017).

# Theoretical frameworks Self determination theory

Wehmeyer et al. (2003) stated that early research by Richard Ryan and Edward Deci in the 1970s and 1980s argued that people have intrinsic need to be self-determining, competent and be able to master their own challenges. Federal mandates emerged in the 1970s concerning the education of students with disabilities in the United States, and the models of disability, have changed throughout the decades. In the light of selfdeterminism, Wehmeyer and researchers stated that new possibilities emerged for persons with disabilities to control their own lives and destinies reflecting empowerment noting self-determination exists on a continuum that encompasses the environment of the person, skill sets, knowledge, attitudes, and one's belief about themselves and abilities and how much they are allowed to choose or control their outcomes (Holmes 2020).

Researchers in the field of self-determination theory (SDT) propose that the three intrinsic needs of autonomy, competency, and relatedness are crucial to one's motivation and overall mental health and well-being (Ryan et al. 2000). The need for autonomy is linked back to Abraham Maslow's concept of self-actualization in Maslow's hierarchy of needs which include needs for self-respect and meeting one's potential (Olson 2013). While autonomy and agency are important for development of self, one's social environment can impact development as well (Deci et al. 2002). For most children, this environment consists of microsystems that will influence the child's development (Wehmeyer et al. 2003). Microsystems for children tend to consist of family, school, and one's peer group (Wehmeyer et al. 2003). Ryan et al. (2000) stated control is the opposite of autonomy.

Argued by Ryan *et al.* (2000) to add salience to the combination of autonomy and competency, is the third element of SDT, relatedness. Relatedness is not simply being connected to others in a social context but feeling connected with a sense of belonging to others within one's community or social context (Deci *et al.* 2002).

Belonging and safety are part of Maslow's hierarchy of needs in the attainment of self-actualization (Olson 2013). Ryan *et al.* (2000) argued that previous research based on attachment theory indicated that students who are in an academic environment with a caring and engaged teacher where they feel safe and competent will have higher intrinsic motivation and flourish. The converse was also true where students were engaged in

academic tasks with a cold or uncaring adult who was not providing feedback or ignoring the student's task altogether; researchers indicated that motivation was lower among those students. Ryan *et al.* (2000) further explained that relatedness and social context does not mean that the person has to be with others to have motivation or accomplish tasks; in fact, many intrinsically and self-directed behaviors can happen in isolation (which may be the preferred case for some students on the autism spectrum) but what is key is the element of a safe environment where support can be accessed by caring adults if needed and giving input about the supports.

Zimmerman (2000) argued that an empowerment approach changes the role of the person [student] who may require services from passive recipient into a more active role in choices, implementation, agenda, and possible solutions. An empowerment approach which embraces self-determination begins with a strength-based approach and shares locus of control with the individual thus empowers them interpersonally and behaviorally (Moran *et al.* 2017).

#### Muted group theory

Education for all students is a basic human right (Yell et al. 1999) and for those students with challenges and needs, Guðjónsdóttir et al. (2007) more firmly argued that inclusion in education is also a basic right for all students. White et al. (2012) suggested deinstitutionalizing education completely; the only education practices that represent social justice are inclusive. Thus, if children as students, and their families, are marginalized in the education system, they will continue to be marginalized by greater society and become further marginalized. The rhetoric of inclusion without follow-through is both confusing and detrimental to true inclusion (Humphrey et al. 2008). The environment or the climate of school is crucial to promoting inclusion (Carrington et al. 2016, Goodall 2015, Humphrey et al. (2008), Lindsay et al. 2013, Pantíc et al. 2015, Shogren et al. 2015), which in turn is important for fostering the climate of self-determinism which in turn promote better educational outcomes (Wehmeyer 1992).

However, students on the autism spectrum have remained a muted group in research concerning inclusive practices in the educational system (Holmes 2020). Theorists and researchers of Muted Group Theory (MGT) defined, 'any group that is silenced by the inadequacies of their language' (West and Turner 2018, p.495) with the silencing dominated from the majority group is a muted group (Ardener 2005, Barkman 2018). MTG researchers asserted that members of a marginalized or low power group are often silenced by control through the power of decision-making or lack thereof (Barkman 2018, West and Turner 2018). While the theory in part began in women's studies, Ardener (2005)

argued that MTG was never solely about women or merely suppression or repression of physical speech but considers also in what context and how much a marginalized group is allowed to speak on behalf of themselves. Barkman (2018) explained that MGT helps explain how groups become marginalized and any group that is marginalized is thus a muted group.

A call for voices and choices in policies and decisions from disability advocate Charlton (2000) in his book, Nothing About Us Without Us: Disability Oppression and Empowerment speaks to those with disabilities being marginalized and muted and often excluded from the dominant group. While is it ethical and moral to protect vulnerable and marginalized groups from harm as a subject of research, it is also important to include those who are marginalized in research that is about them as a group. As the literature review outlined, voices from students on the spectrum have been neglected in the body of research concerning inclusion. Social inclusion is crucial for optimal education outcomes and mental health; lack of inclusion and lack of social skills training shows poor outcomes as well as negative impact on mental health.

## Research design

The purpose of this study was to examine barriers to social inclusion and contributing factors to the inclusive climate for students on the autism spectrum in the public-school system. Through applied qualitative research using a phenomenological approach working from a critical paradigm, participants were located through purposive, convenience, and snowball sampling through criterion sampling.

#### **Paradigm**

The design of the study was explanatory (Creswell 2014, Leavy 2017) in nature with the question posed to ask a specific population about their unique experiences and observations which is best for a phenomenological study (Leavy 2017). This article reflects the voice of former students who are on the autism spectrum. The research question directed to participants of the study asked, 'What do students on the autism spectrum describe as barriers to inclusion?'

According to Moustakas (1994) and Groenewald (2004), when a researcher is looking to understand or explain a phenomenon or describe human experience, a phenomenological qualitative approach is the best research approach. The lens of the phenomenological approach in applied research views participants to be more than mere subjects of a research project but partners in the endeavor to describe their reality and their unique personal experiences which can contribute to the knowledge of solving problems or improve interventions and processes (Leavy 2017, Patton 2015). Groenewald (2004) noted that the researcher will not

prescribe or outline an action plan, but instead allow the participants to speak for themselves from their experience and draw conclusions from the data while staying true to the whole experience instead of analyzing specific units of data; phenomenological studies are existential and more about the whole and not about the sum of the parts (West and Turner 2018).

#### Ethical considerations

Before collecting data with human participants, approval was obtained from Abilene Christian University's (ACU) Institutional Review Board (IRB). Because this study sought to include former students who are on the autism spectrum who went through public education, the IRB classified this population as a vulnerable or special population-based on disability.

To ensure ethical measures of least amount of harm to a vulnerable population, an adult on the autism spectrum who works in disability leadership and a clinical social worker examined all materials and protocols to advise on any potential harm or stress for persons on the autism spectrum. Both indicated that discussing any bullying may cause stress but not harm and to proceed with caution. As a clinician and certified autism specialist, I am trained in dealing with stress and emotional dysregulation, and if the person was under any stress during the interview, they were given the option of email or dropping out of the study to ensure ethical research standards were applied to a vulnerable population.

Practices outlined through AASPIRE guidelines (Nicolaidis *et al.* 2019) for the proper inclusion of adults on the autism spectrum in research were followed. Nicolaidis *et al.* (2019) stated that building and maintaining trust as well as transparency of the study and goals were paramount for ethical guidelines for including adults on the autism spectrum. Being clear in communication, adapting surveys as needed, offering multiple modes of participation with a clear informed consent, and allowing autonomy and inclusion were among the best practice guidelines (Nicolaidis *et al.* 2019).

#### Data collection

Personal interviews, documents, and artifacts were used to collect data. Three of six students provided IEPs, one student provided their parent's report of goals in the IEP, and four of six students provided essays or journals from their experience in the public education system. The research question guiding the study for this population was one of four questions of a larger dissertation study, *Creating an Inclusive Climate for Students on the Autism Spectrum* (Holmes 2020) consisted of four research questions directed at different stakeholders in the public education system concerning barriers of inclusion to include educational leadership, general

classroom and special education teachers as well as paraprofessionals, parents of students on the autism spectrum, and former students who are on the autism spectrum.

# **Methods Participants**

After receiving permission and outlining parameters from the Institutional Review Board (IRB) including a vulnerable population, participants were invited to be part of the study. Parameters of the study from the IRB included that the students had to be over the age of 18 and not 'decisionally or mentally impaired.' If the participant was still under guardianship of a parent, both the student and guardian were to complete the informed consent. Participants were canvassed at autism conferences within the United States in NC, SC, and GA and through snowball sampling. An additional parameter of the study was stated the person have an official diagnosis of an autism spectrum disorder to include Asperger's Syndrome (AS), autism spectrum disorder (ASD) or pervasive developmental disorders, not otherwise specified (PDDNOS). Eight students originally agreed to participate, with seven completing informed consent and completing the interview process. Six students attended public school in the United States and met all criteria (Table 1).

The six students in the study represent all levels of the autism spectrum from Asperger's and Autism Level 1 to Level 3 with mixed exceptionalities and included both males and females. For all participants who answered the invitation to participate in the study, a pre-study survey through the Survey Monkey platform was completed to ensure the student met all parameters of the study. If the student met all qualifications, an invitation and informed consent was completed before establishing a time for the interview.

#### Materials

Semi-structured interviews were conducted with participants using modified materials. Permission was granted by Kent McIntosh from Positive Behavioral Interventions and Supports to use a modified version of the School Climate Survey Suite [SCSS] (La Salle et al. 2018) for a portion of the semi-structured interview. The SCSS is a survey measure constructed with a Likert scale, and I adapted the questions to open-ended questions for further explanation of answer choice. The SCSS introduction indicates that the measure is reliable and valid to assess perceived school climate in the areas of connectedness, structure for learning, school safety, physical environment, peer/adult relationships, and parental involvement (La Salle et al. 2018). To maintain full reliability, it was recommended to administer the survey as designed (La Salle et al. 2018). However, as a qualitative measure, I am interested in why the

respondent chose their answer to gather deeper descriptions from the data beyond a Likert scale response and adapted the questionnaire for the former students who are on the autism spectrum.

As part of the semi-structured interview, I asked students to define what they feel inclusion is to them, and whether they felt the school staff wanted them to do well, as well as what are/were the indicators or behaviors that suggest this? The interview began with specifics about their diagnosis and what age they were diagnosed and how they feel about their diagnosis. Questions from the SCSS student report portion were used for discussing school climate and perceived inclusiveness or lack thereof.

In addition to the above, the Center for Self-Determination Theory [SDT] (2019) has several instruments available for academic research with no charge. Because the study is examining inclusion through the lens of SDT, content and construct validity as well as reliability and generalizability were established through established instruments. Questions from the following abbreviated questionnaires were used to assess autonomy, competence, and relatedness (Ryan et al. 2000). Questions on the following instruments are Likert-scale in answer, but I used the scales in an open-ended fashion. Appropriate portions of the Basic Psychological Need Satisfaction in Relationships, and Aspirations Index was used for face, content, and construct validity. These measures have been used consistently with established reliability and validity (Center for Self-Determination Theory 2019).

#### Data collection and coding

Each of the interviews was audio-recorded and transcribed through a transcription service. The informed consent and assent covered permission to audio record and outlined the measures to ensure confidentiality and storage of data collected. To protect the identity of the participant and confidentiality of the information received from the participant, each participant will be coded by sample type and numbers such as Student on the Autism Spectrum 1-6.

Triangulation of data was achieved through prestudy selection surveys, interviews, and field notes during the interview process, documents, and artifacts. Artifacts that aid phenomenological studies may include official documents, essays, or poems by participants or follow up questions or thoughts by participants after their interview. Students over the age of 18 were asked if they have access to IEPs or asked if they wish to include any work such as essays or poems or papers, they wrote to describe their experience of having autism or experience of isolation or friendship to add to breadth of understanding of their personal experience.

After the interviews were transcribed, this researcher used simultaneous coding over the same passages of

#### Table 3 Practical recommendations from students: superordinate themes by guided question

#### Guided Question: How do you define inclusion/What practices would be more inclusive?

Do not punish behavior(s) that are associated with one's needs/understand the function of the behavior

Understand autism in general and the student on the spectrum individually

Treat the student like a human with needs and not a burden to manage

Model inclusion to your colleagues and our pears/Do not further stigmatize with exclusion

All staff in the building should be AS aware and trained

Presume competence of your student/Do not project failure

All students can be taught how to interact with those who are different

Social Skill groups should be AS children plus typical children to promote mutual inclusion

Celebrate the knowledge or expertise area of an AS student

More guidance and counseling support to help with sensory overwhelment and anxiety

Get to know your AS student by understand their passion/interest

Monitor and be aware of any bullying/teasing

More clubs and actives around interests of AS students

Know if the student has an IEP, then follow it without pushback or complaining

IEPs should be individualized to the need of the student academically and socially

Attend IEP meetings. It shows interest.

Collaborate with the student and their parents

Autism and IQ are separate. Many AS students have mixed abilities or exceptionalities

Modifications for group projects or public speaking

Help us and peers form friendships and include us in recess and lunchroom social situations with better skills in these areas of nonregulated school time

text to include descriptive coding, in-vivo coding, and pattern coding. All coding was done by this researcher. Once the data were collected, transcribed, coded, and analyzed, results of findings were displayed in the study for future discussion. Partial quotes and ideas from these students have been shared in *Exceptional Needs Today* (Holmes 2021a, Holmes 2021b).

#### Results

All six American students felt that both teachers and peers lacked basic awareness and acceptance of autism, and they felt stigmatized feeling their autism was deemed to make them less than others in the student body. Four of the six felt disempowered and did not know how to ask for what they need or felt pushback when they asked for the Individualized Education Plan (IEP) to be followed or called out a teacher for not making accommodations or modifications that were specified. Four of the six had behavior challenges at some point in their educational journey and felt that the teachers did not want them in their class or that they were a burden to a school. When I asked each person how they desired or would have wanted to be treated, each said in some way, 'to be treated like a human first.' When asked how teachers treated them, these descriptions came from the students: a freak, a toddler, an alien, a bomb, or explosion about to go off, a monster, and an animal that needs to be trained and managed. The four students who had behavior goals felt that the focus was so narrow on the behaviors that instead of being seen as a child, human, or student, they felt they were type-cast the 'problem child' or 'behavior problem.'

# Student experiences

The former students had mixed reviews about their classroom teachers stating from year to year the teacher's understanding of autism and their treatment was different, which was confusing. The students felt this same distance and lack of connection from the student body. The students were asked about their experiences. A list of superordinate themes of school experience is listed in Table 2. Students were promised that their ideas and opinions would be expressed as they stated them in their own voice and not merely listed as themes (Table 3).

#### Student 1's experience

If the student stated they felt excluded, a follow-up question was asked, 'What made you feel excluded?' Student 1 stated, 'I was just different, and that was not the thing to be. You had to be normal. You had to like everything everyone else likes.' When asked about life outside of school Student 1 said, 'I was never invited to do much of anything. I never got invited to parties or sleepovers. I was the odd kid out.' I asked her what she thought teachers needed to understand better. She explained, 'It's [autism] not always easy to see.' She elaborated that this is why a teacher needs to get to know their students personally that have an IEPs and not make assumptions about them. Because she had behavior challenges in elementary school she said, 'your behavior reputation follows you' from school year to school year and school to school. She felt the teachers had preconceived notions about her and her autism, and they treated her according to their bias.

<sup>\*</sup>Inclusion in the voice of the student also provided in Appendix A. AS, Asperger's Syndrome; IEP, Individualized Education Plan.

#### Student 2's experience

This student attended four different elementary schools by the third grade. She felt that the teachers and administrators did not want her or welcome her into the classroom. Oddly enough, she felt that most of her peers accepted her and understood she was different in elementary school. She stated that her mother would have the Autism Society do a special class on days she was not present to explain sensory issues and various behaviors. While she felt the teachers and administrators saw her as 'a bomb that could go off any second,' during this time, she felt included and liked by her peers; however, at the time, she did not realize she was not invited to parties or events outside of school. Classmates would come to her parties, but she was not invited to theirs. Most of the teasing, bullying, and exclusion was more obvious to her in middle school.

In middle school, because she was a star student and did not experience many behavior challenges, she felt most welcomed by her teachers but excluded and not wanted by her peer group. Those she felt were her friends would later tell her they were her friend out of pity. When asked about how she felt at school and her safety, she said, 'I disagree on multiple levels. I had a bunch of bullying during my freshman and junior years. It was a constant state of conflict, and I didn't like it.' When asked about friends in high school, she said, 'Some groups were very accepting, but you know how it is in high school. Cliques. I fell into the misfit clique where we were the group no one else wanted.' When asked how she felt treated by the staff at her school, she said that some understood her, most accepted her in middle and high school, but 'There were those who didn't understand, and they didn't care that they did not understand.'

Student 2 had copies of IEPs. The IEPS were heavy on behaviors in elementary school, and there were not goals socially or in communication. When asked about social goals, she said, 'You mean I could have had that? Well, that would have been helpful.' She began in the mainstream room, then next year had a para, and then ended up in self-contained classrooms where her behaviors were managed, but her gifted academic needs were not met. Another experience Student 2 wished to share was her time as an education major. She said in her entire curriculum, there was only one class about exceptionalities, and autism was discussed one day. She said the professor and classmates equated autism with mental impairment. Autism was mentioned briefly in a diversity class as part of the disability population but not enough teaching to understand it or how to include people with autism, only those persons with autism fell into a marginalized group that needed inclusion. In the lifespan development class, she described this experience,

My professor, knowing that I was on the spectrum, kind of let me say something about my experience with autism in the public-school setting to my peers. Then she went on with

that the textbook said. Even though the textbook was written in 2018, it was so outdated with the terminology. Schools don't update their textbooks and curriculums that much. I almost got in a couple of verbal fights in that class because some students couldn't get it in their heads that the textbook was wrong. I was like, 'Look, you all, I'm level I autism, and my IQ is three standard deviations above average. Don't you dare tell me that I have a low IQ because I have a paper that proves I don't!' Then they would say, 'And you can't be autistic because you have a high IQ.' They would get stuck on IQ.

#### Student 3's experience

Student 3 was asked to describe his school experience. Student 3 is Autism level 3 and nonspeaking. He communicated his answer on his letter board, and his communication partner wrote down his answers. He described his school experience as, 'In elementary school, I was in the regular classroom and pulled out. I was self-contained and in specials with the regular classroom. As I got older, I was completely self-contained.' I asked him to define the difference from his perspective from nonverbal and nonspeaking, as he identifies as nonspeaking. He explained,

Nonverbal indicates non-thinking, which cannot be further from the truth for nonspeaking autistics like me. It indicates having no language. I have complete receptive language but cannot output my thoughts due to motor planning deficits. As this recording demonstrated, I can speak per se but not reliably or meaningfully. (Note: Person 3 would speak a word he was spelling on his letter board and keep repeating that same word over and over as he continued to point and spell out his thoughts on the letter board). The majority of the time [at school], I was treated or spoken to or through as if I were a toddler.

I asked Student 3 if he felt his needs were met socially or academically at school. He responded emphatically on his letter board, 'No!' When asked if the school embraced the letter board or used it to educate him better or include him, he replied,

I got pushback from the school that my communication was not mine, and my intelligence was impossible. They begrudgingly allowed it [letter board] after much pressure. One teacher tried to use my methodology to teach me. My mother volunteered her time to the teacher on how to teach me. Otherwise, it would not have happened. It was short-lived, though, as the teacher left, and it became clear that the powers that be had no interest in furthering this with other personnel. After the teacher left [that had been trained on letter board], we would have had to start all over again with no support from the IEP team.

Student 3 was requesting a regular education degree but felt pigeon-holed into a special education diploma, and without a teacher using his preferred communication method, he had no hopes of being able to have meaningful on-grade level academic goals. He stated that he 'aced the GED preparatory test' in GED classes and was excited to pursue a GED. However, his communication method would not be allowed for the GED tests as well. I asked Student 3 what he wants educators

to know about autism or what it is they need to understand. He explained:

That we are the same as other students, yet different. That we have hopes, dreams, goals, feelings, and thoughts. We are competent despite our manifestation. That we are not less but are worthy of appropriate education and school opportunities and of human decency and respect.

When I asked about how he was treated or how he would describe his public-school experience, he described it this way:

It was a nightmare and a joke all rolled into one. And that was with extremely involved and aware parents trying to make the right thing happen. The system is significantly broken. Teachers who are real advocates for students are pressured not to be. The most disturbing thing is that once the error of their ways is pointed out, they still don't want to do the right thing. I haven't even touched on the irreversible damage their restraints and behavior programs produce. Parents who send their nonspeaking autistic child to public schools do so at great peril to their child. My body can behave badly at times, largely out of my intentional control. It is more likely to so do when I am stressed, anxious, demeaned, and ridiculed. It becomes a vicious cycle, and I am viewed as a monster.

Student 3 felt abused at the hands of para, and he had no way to tell his parents until years later when he began using the letter board. He was teased and excluded by peers, and he craved connection and relationship from peers, yet he felt as he got older, he was more and more isolated.

#### Student 4's experience

Student 4 described herself as successful academically at school, yet the school was not a place she felt safe to be herself, and she did not feel successful socially. She went to school in a rural area and had a small core group of friends, but overall, the student body did not feel welcoming or inclusive, treating her as an equal member of the school. Because she did well academically, she felt the teachers respected her and liked her. She wants to get the message out about accepting students with differences for who they are. She is now a teacher in a rural area, and she does not feel all teachers are aware or accepting of autism. She said, 'I think training for staff is important. Pretty much everyone has heard of autism by now but just a little bit more information on what it is, how it can present.' While she had some friends, she indicated she rarely invited to things outside of school, and she was not successful socially as indicated by being bullied and teased at school.

She stated that she attended IEP meetings occasionally, but it was uncomfortable hearing others talk about your challenges and weaknesses. She felt the IEP team treated her mother with respect, but when it came to insisting on higher academics, that it was a hard push from her mother to get her in advanced classes. She did not have any copies of her IEP, but she said she does

not recall any social-focused goals. Student 4 wanted to speak to teachers as a fellow educator. Some of the advice she gives to teachers for better understanding and inclusive practices:

Understanding that first of all, not everyone with autism is the same. A one-size-fits-all policy isn't always going to work. It's something broad like we will treat these people with respect. Then that is going to work just because one student with autism was helped this or needed to that, doesn't mean it's going to work for everybody as far as what they need to understand when dealing with the student. Getting to know the specific students and what helps them and then as far as training just spreading knowledge and informing people creates a better understanding and I think it's going to help people be able to better interact with those students that is really is important to have a good understanding because a lot of times people fear or dislike or aren't comfortable with things they don't know about. Providing that knowledge even if maybe they don't have a lot of students on the spectrum into their school can be very important and helpful. Be patient, which is difficult. I understand that even more now that I'm in the teaching field. A child on the spectrum may literally be unable to do something you're asking them to because of the autism, because of sensory overload, or maybe once they get to the point where they're super upset or in a meltdown, there may only be one thing that calms them down. You may feel like you are giving in or breaking the rules, but you have to look at the bigger picture, is this helping the child? Is it in their best interest? Realize you have to be flexible because sometimes they're inflexible. They're not purposely being stubborn; it's just how their brain is wired. By having a better understanding of the behaviors you're more likely to be able to come up with a solution that will work and not fail.

# Student 5's experience

Student 5 also felt she was successful academically because she was gifted and was able to succeed academically without supports. She was not diagnosed with Asperger's until her junior year of high school. Her diagnosis came when she experienced being taken advantage of by a student at the college campus, where she was doing dual enrollment. She was unable to read the social cues of the danger, and her social nativity was part of how she was put in danger. She told a teacher, and the school handled the matter, but in that process, she was diagnosed with Asperger's. While she had academic achievement, she said, 'I never had social connections nor the training to explain what entitled sexual actions.' While she did not have any social skills or social training, she felt she had teachers that she could trust who would help her when she was emotionally overwhelmed. However, what made her feel disrespected is when teachers would not show up for her IEP meetings. She felt that because she was academically achieving and did not have academic supports, a few teachers would not bother to show up, which made her feel like they did not want to understand her or the other challenges she faced at school. When asked about social inclusion, she described:

I was involved in the drama department, and though I was never very good, they were willing to include me.

Table 4 Aspiration's index of students on the autism spectrum

Importance of goal	VI	I	SI	NI
To grow and learn new things	3/6	2/6	1/6	0
To have good friends	5/6	0	1/6	0
To work for the betterment of society	3/6	2/6	1/6	0
To share my life with someone I love that would result in marriage or partnership	4/6	2/6	0	0
To have people comment on how attractive I am	0	0	1/6	5/6
To assist and help others	4/6	2/6	0	0
To choose my own career instead of being pushed into a career	5/6	1/6	0	0
To be accepted for who I am	5/6	1/6	0	0
To have people stay in a relationship with me	4/6	2/6	0	0

Note. VI = Very Important, I = Important, SI = Somewhat Important, NI = Not Important.

We went on retreats, and we went out to dinner after shows, and they were very inclusive, but outside of that specific group, I was mostly an academic tool for people. People would take me on to their projects because they knew, 'Well, she is one of the top ten students of the school, so if we have her on our group, we're likely to well.' That's a nice thought and certainly does feel wonderful to a point, but then to also know that the only reason I got invited to a single social function outside of the theater department was because someone wanted to be close to someone else near me definitely did not help the depression that I was facing.

When asked if she experienced bullying or teasing, she recalled a traumatic event of public bullying while a teacher watched and laughed.

#### She described the experience:

A lot of what they did bordered between those [bullying and teasing]. It definitely started as teasing. There were points where that did turn into what I would consider bullying, where some of the older males from the group would back me into a corner. There were times I was left hyperventilating on the ground, even in front of the teacher, who then walked out of the room and left me hyperventilating on the ground in a panic attack. I think she thought I was faking it because she was laughing. It wasn't funny. I was not faking it. There was one time I clearly remember being hit with a yardstick across my hand. I learned later one of the reasons one of the guys did this was because it was funny, and it was entertaining to him. When you are enjoying something that hurts someone else, that's where it becomes bullying.

I asked Student 5 to give some suggestions or advice to teachers and peers in public school. She said to teachers,

I'm as much autistic as I am female as I am human. It's all part of who I am; it does not mean I deserve any less respect. Everything you would do with another student. We deserve it as well.

To peers, she said, 'Just because we sit alone in class because it's stressful to approach someone doesn't mean we don't want to talk to anyone.' After our interview concluded, Student 5 emailed me this thought that she felt was important for this study,

It is so important that people realize that school is not just for prepping people for college or a job. That is an ideal outcome, even for someone who does not struggle with disability. The one common goal for everyone is independence. For some, that might mean getting a job and

having a family, but for others that might be graduating high school or even just being able to simply get their needs and wants met without being reliant on another person. For some people, even these goals may be quite difficult, but is it the job of schools to help reach them as much as possible. To help each and every student to become as independent as they're capable of being because this is dignity, and this is respect for our fellow humans.

#### Student 6's experience

Student 6 was diagnosed with more moderate autism and cognitive processing delays but not mental impairment. Overall, he felt successful at school but when asked if he felt safe at school, he said, 'Yes and no. I was bullied at times.' I asked him if he felt included by the student body, and he said, 'Well, not necessarily, because I mostly saw everyone at school or other school-related events like homecoming, football games, prom but never anything outside of school.' I asked him what would have made his school experience better socially? He responded, 'If people would learn to accept my differences and give me more of a chance.' He added, 'I want to say just because I can be a little weird; it doesn't make me less human.' He asked me if he could read part of a blog and journal, he wrote about stopping stigma against people with disabilities. He read out:

There's so much stigma with autism, and it has to stop. Some autistics are still being forced to hide themselves. For example, if an autistic does something out of the ordinary or makes mistakes, people tell them that they don't want to be friends or whatever. Society can force their way upon others who are different to hide or make their autism. That's now how it works, though, at least not in any way that's healthy. There shouldn't be a stigma. When you are accepting to be someone's friend, you should accept and try to understand all aspects of a person. We autistics shouldn't feel the need to hide anything. People view autism as a source of annoyance, disappointment, or worse in different ways to different degrees. It's not fair to place judgment upon someone when you don't even fully know them. Having a true friend is having someone who accepts you for you, regardless of your flaws. That's my article.

I asked Student 6 if he experienced teasing or bullying. He said he was teased for not being smart and not taking AP classes. 'I was called retard a lot.' About bullying, he said, 'One football player did punch me into the lockers.' I asked if he felt excluded, and he said, 'I never got invited to any parties. I saw pictures on

Facebook of people hanging out having fun. I didn't know anything about it. It really hurts when you find out about a party you were never invited to.'

## Defining inclusion

Inclusion to the participants of the study was defined beyond rhetoric that a school may use that all are welcome or a focus on mainstreaming versus segregation. Inclusion encompassed willingness for educators, leadership, and peers to understand autism differences and needs and have proper training in autism. To the participants it included how they were treated by peers on and off campus, the classroom and lunchroom and free time, and if the school community promoted understanding, friendship, belonging as well as teaching both neurotypical and atypical students to communicate better with each other versus a focus on making atypical students fit in better to the societal norms.

# Breaking myths about autism

It was important to each person I interviewed to break myths about autism and help educators know that autism does not stop people from having goals and dreams. They wanted to speak out because social situations can be stimulating, this does not mean they do not want to be invited to things or included. They wanted educators to know they have hopes and dreams and aspirations, and with support they can better reach whatever potential level they have on an individual basis.

Part of the index follows up by asking each person how likely they feel this goal will happen in their future (Table 4). The majority responded that it is not very likely to be accepted for who they are, and half felt they might not get married. But having good friends and people stay in their lives is an important goal. The likelihood of having life-long friends was felt to be somewhat likely to not likely. As the students kept saying, they want to be treated as equals and humans and for others to understand they have the same wants, goals, and desires and that social skills and social communication deficits can keep them from achieving their goals. Student 5 said, 'Inclusion is a lifelong process' it is not just about the academic portion of life but everyone's life journey.'

### **Discussion**

While this current study does not fit all the criteria for Community-Based Participatory Research or Community-based research (Leavy 2017), the research design is based upon a call to action or desire to build collaboration among key stakeholders to build an inclusive climate for students on the autism spectrum in the public school system to consider the voice of students on the autism spectrum in that collaboration as partners.

The students in the study indicated feeling teased, bullied, and socially excluded by peers at school, and half indicated not feeling welcomed by teachers or the school itself. All participants felt that school was not a safe place emotionally, by all, and physically, by half, to be themselves. While many interacted with students in extracurricular activities provided by the school and sometimes events associated with that activity, the students did not often receive invitations from peers to outside events or parties. Three females indicated they received 'pity' invites or invited because others wanted them in a group or project to use their skills and intellect but not truly want to be with them as people. Five of the six felt that how they were treated by peers or school staff was detrimental to mental health or had a negative impact on self-esteem and self-worth.

The students advocated that understanding of autism, support, and skill building is what students with autism need but were clear that they want to be accepted as autistic and not forced into social norms or forced 'neuro-typicalization' to be made to fit into society according to what non-autistic people decide is normal or acceptable. One student remarked that if 'normal society' or 'neurotypicals' are the more flexible and social part of society, why is the pressure to be flexible and conform placed on those with disabilities in the social arena? Each student emphasized to treat students with autism as people or human, because they did not feel humanized or individualized in their school settings. The six students' narratives and data reflect current research findings on important elements of inclusion to include teacher attitude, teacher understanding, teacher resources, school climate, and administrative support and attitude.

When students on the autism spectrum feel unwelcomed, unwanted, unsafe, excluded, and misunderstood and worse bullied, this leads to negative self-concept and impact on mental health which impacts academic or educational achievement (Bond *et al.* 2001; Côté-Lussier et al. 2016, Hamachek 1995). Untreated mental health concerns account for higher economic costs to the American economy than cancer or diabetes (Trautmann *et al.* 2016).

The clinical definition of Autism Spectrum Disorder recognized in the DSM5 (2013), International Classification of Disease [ICD-10], and definition of autism for IDEA (2004) eligibility all mention social impairment and clinical levels of impaired social development. For better inclusive practices, a student who is diagnosed with autism spectrum disorder of any level will need positive social supports and skill-building for self-esteem, autonomy, competency and relatedness to achieve more self-determined behaviors (Ryan *et al.* 2000) in the school setting, as well as understanding and acceptance by staff who serve them and peers in class with them for optimal education achievement and

life outcomes. A safe atmosphere with supportive adults and peers creates an atmosphere of relatedness where individuals can best achieve autonomy and feel competent (Ryan *et al.* 2000). The students in this study did not always feel supported by adults or an atmosphere conducive to self-determination. While the six students have various levels of academic success, all six reported their public-school experience negatively impacted their mental health and self-concept.

### Subjectivity statement/role of researcher

I have personally worked with students as a guidance counselor and community-based counselor with young adults on the spectrum who still suffer from anxiety, Posttraumatic Stress Disorder, Major Depressive Disorder or suicidal ideation from feeling different, excluded, or bullied during their schooling years. Mental health bears a great impact on overall achievement academically, socially, and when one is transitioning beyond school. Although my career and personal relationships involve persons on the autism spectrum, I seek the truth in discussing both barriers and doorways to inclusive education practices seeking the voice and perspective of those on the autism spectrum to achieve self-determination. I believe that promoting autonomy, competence, and relatedness (Ryan et al. 2000) throughout the school setting will enhance the outcomes and mental health for persons on the autism spectrum through empowerment and collaboration.

# Limitations

The sample size was a limitation of the study. The sample was canvassed through autism conferences held in the southeastern part of the United States. Assumptions were made that the participants reported information accurately and honesty and assumptions are made that others within the same population would share similar feelings. Emotions and incomplete memories can often affect one's memory or narrative concerning one's experience and must be considered.

Inclusion and required knowledge for success are constructs that are not clearly defined in the study, but neither are these constructs clearly defined in the law or best practices for inclusion, which is problematic for both the study and implementing inclusive practices with a sense of fidelity. Another limitation is having a single coder for the data. Recommendations for future studies include multiple coders and expanding the sample size and recruitment from all regions of the United States. Further research would examine mental health outcomes for students on the autism spectrum involving perspectives from clinicians in the field of autism as well as the voice of those on the autism spectrum.

# Reflections and implications

While autism is a neurological wiring issue and not a mental health disorder, many suffer from mental health issues based on how they are treated in school and community. Many clinicians, counselors, and researchers (Hadley et al. 2018, Kirby 2019), including myself, are seeing increases in suicide or suicidal ideation, and studies indicate there is unemployment or underemployment on the rise in the spectrum population, as well as concerns with transitioning form school to the world of work (Baldwin et al. 2014, Hurley-Hanson et al. 2020, Griffiths et al. 2016, Hloom n.d.; Krieger et al. 2012, Nord et al. 2016). Many parents, including personal experience, have lost hours of sleep worrying and spent many hours preparing for IEP meetings out of concern for our children on the spectrum and their future. Educators, usually work in an overcrowded classroom, are given little resources, supports, and training for autism inclusion, and are still mandated to provide free and appropriate public education (FAPE) in the least restrictive environment (LRE) under federal law

While there is a cost to better training and more funding is needed for consistent resources to support students on the spectrum, there is a greater cost to society economically when students who could achieve more are limited due to a lack of resource and mental health issues. It is a greater travesty that individuals with autism would view themselves as not worthy of accommodations, feel left isolated, and suffer from PTSD, anxiety, or depression from teasing, exclusion, bullying and simply not feeling wanted in the system where they will spend up to 12-16 years of their lives.

The experiences of these six American students were parallel to the nine students' experiences in England in the Brede *et al.* (2017) study. Australian students in the McGregor *et al.* (2015) study reported similarly feeling unwanted and excluded by peers and programs at their local schools. Students on the autism spectrum in the Brede *et al.* (2017) study stated overall their experience at an inclusive learning hub was negative as teachers were untrained and lacked basic knowledge of autism, student needs went unmet, inappropriate approaches implemented (even allegations of abusive practices), and many students were out of school significant amounts of time due to anxiety or formal school punishment for behaviors that were part of their autism profile.

McCluskey et al. (2016) argued that while exclusion rates and numbers are decreasing according to metrics kept by schools in the UK, vulnerable and special needs groups are still being marginalized despite the downward trend. While metrics indicated decline in trends of exclusion, they do not match the experience of what students on the autism spectrum have voiced in the UK.

Parents of those of the students and those on the autism spectrum have ideas and perspectives of inclusion

as well as the harm to mental health that comes from exclusion. While it is proper to protect vulnerable populations, we cannot as researchers, educators, or clinicians exclude or continue to mute their voice under the guise of protection.

As researchers discuss best practices and outcomes, it is recommended that future research examine the experience and perspective of those on the autism spectrum. Further research must include the voice of students on the autism spectrum for better understanding of what feels inclusive from their perspective and how they internalize some of the current practices of education.

#### **Conflict of interest**

No potential conflict of interest was reported by the authors.

#### **ORCID**

Stephanie C. Holmes http://orcid.org/0000-0002-4631-6698

#### References

- American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders*. 5th ed. American Psychiatric Publishing.
- Ardener, S. F. 2005. Ardener's "Muted Groups": The genesis of an idea and its praxis. Women and Language: WL Urbana, 28, 50-54.
- Baglieri, S. and Shapiro, 2017. Disability studies and the inclusive classroom: Critical practices for embracing diversity in education. 2nd ed. Abingdon: Routledge.
- Bai, H. and Martin, S. 2015. Assessing the needs of training on inclusive education for public school administrators. *International Journal of Inclusive Education*, 19, 1229–1243.
- Baldwin, S., Costley, D. and Warren, A. 2014. Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, 44, 2440–2449.
- Ball, K. and 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, 57–76.
- Barkman, L. 2018. Muted Group Theory: A tool for hearing marginalized voices. Priscilla Papers. The Academic Journal of CBE International, 32. https://www.cbeinternational.org/resources/article/priscilla-papers-academic-journal/muted-group/theory/tool/hearing/marginalized
- Barned, N., Knapp, N. and 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.
- Barnes, K. 2008. The attitudes of regular education teachers regarding inclusion for students with autism. *Dissertation Abstracts International Section A: Humanities and Social Sciences*. Michigan: ProQuest Information & Learning. https://search.proquest.com/openview/b877b759cd31426fab9a86a20723ac1b/1?pqorigsite=gscholar& cbl=18750&diss=y.
- Becker, H., Roberts, G. and Dumas, S. 2000. The inclusion inventory: A tool to assess perceptions of the implementation of inclusive education practices. *Special Services in the Schools*, 16, 57–73
- Bond, L., Carlin, J. B., Thomas, L., Rubin, K. and Patton, G. 2001. Does bullying cause emotional problems? A prospective study on young teenagers. *BMJ*, 323, 480–484.
- Boujut, E., Popa-Roch, M., Palomares, E., Dean, A. and Cappe, E. 2017. Self-efficacy and burnout in teachers of students with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 36, 8–20.

- Boutot, E.A. 2007. Fitting in: Tips for Promoting acceptance and friendships for students with autism spectrum disorders in inclusive classrooms. *Intervention in School and Clinic*, 42, 156–161.
- Brede, J., Remington, A., Kenny, L., Warren, K. and Pellicano, E. 2017. Excluded from school: Autistic students' experiences of school exclusion and subsequent reintegration into school. Autism & Developmental Language Impairments, 2, 239694151773751.
- Carrington, S., Berthelsen, D., Nickerson, J., Nicholson, J. M., Walker, S. and Meldrum, K. 2016. Teachers' experiences of inclusion of children with developmental disabilities across the early years of school. *Journal of Psychologists and Counsellors in Schools*, 26, 139–154.
- Center for Self-Determination Theory. 2019. Metrics and methods: Questionnaires. https://selfdeterminationtheory.org/questionnaires.
- Charlton, J. 2000. *Nothing about us without us*. California: University of California Press.
- Connolly, E. and Beaver, K. 2016. Considering the genetic and environmental overlap between bullying victimization, delinquency, and symptoms of depression/anxiety. *Journal of Interpersonal Violence*, 31, 1230–1256.
- Cook, B. G. 2001. A comparison of teachers' attitudes toward their included students with mild and severe disabilities. *The Journal of Special Education*, 34, 203–214.
- Cook, B. G., Cameron, D. L. and Tankersley, M. 2007. Inclusive teachers' concern and rejection toward their students. *The Journal* of Special Education, 40, 230–238.
- Côté-Lussier, C. and Fitzpatrick, C. 2016. Feelings of safety at school, socioemotional functioning, and classroom engagement. The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine, 58, 543–550.
- Creswell, J. 2014. Research design: Qualitative, quantitative, and mixed methods approaches. 4th ed. California: Sage.
- Deci, E. and Ryan, R. 2002. *Handbook of self-determination research*. Rochester: The University of Rochester Press.
- Elhoweris, H. and Alsheikh, N. 2004. Teachers' attitudes toward inclusion. *International Journal of Special Education*, 21, 115–118.
- Elias, M. 2014. Social-emotional skills can boost common core implementation. *Phi Delta Kappan*, 96, 58–62.
- Fakolade, O. A., Adeniyi, S. O. and 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, 155–169. https://files.eric.ed.gov/fulltext/EJ1052033.pdf.
- Fennell, B. and Dillenburger, K. 2018. Applied behavior analysis: What do teachers of students with autism spectrum disorder know. *International Journal of Educational Research*, 87, 110–118.
- Goodall, C. 2015. How do we create ASD-friendly schools? A dilemma of placement. Support for Learning, 30, 305–326.
- Goodman, R. and 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, 223–237.
- Gordon, M. 2010. Student voice key to unlocking inclusive educational practices. *Canadian Journal of New Scholars in Education*, 3, 1–11
- Griffiths, A., Giannantonio, C., Hurley-Hanson, A. and Cardinal, D. 2016. Autism in the workplace: Assessing the transition needs of young adults with autism spectrum disorder. *Journal of Busines* and Management, 22, 5–22.
- Groenewald, T. 2004. A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3, 26–42.
- Guðjónsdóttir, H., Cacciattolo, M., Dakich, E., Davies, A., Kelly, C. and Dalmau, M. C. 2007. Transformative pathways: Inclusive pedagogies in teacher education. *Journal of Research on Technology in Education*, 40, 165–182.
- 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, 2229–2246.
- Hamachek, D. 1995. Self-concept and school achievement: Interaction dynamics and a tool for assessing the self-concept component. *Journal of Counseling & Development*, 73, 419–425.
- Hammond, H. and Ingalls, L. 2003. Teachers' attitudes toward inclusion: Survey results from elementary school teachers in three southwestern rural school districts. Rural Special Education Quarterly, 22, 24–30.
- 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, 91–103.
- Harpell, J. and Andrews, J. 2010. Administrative leadership in the age of inclusion: Promoting best practices and teacher empowerment. *Journal of Educational Thought*, 44, 189–210.
- Hedley, D., Uljarević, M., Foley, K.-R., Richdale, A. and Trollor, J. 2018. Risk and protective factors underlying depression and autism suicide in. *Depression and Anxiety*, 35, 648–657.
- Hloom. n.d Finding success in the workplace: Career assistance for people with autism. https://www.hloom.com/blog/careers/planning/autism [accessed December 11, 2021]
- Holmes, S. 2018. Creating an Inclusive Climate for Students with Developmental Delays (as/ASD). Georgia Association for Positive Behavior Support Conference. https://digitalcommons.georgiasouthern.edu/cgi/viewcontent.cgi? article = 1303&context = gapbs
- Holmes, S. 2020. Creating an inclusive climate for students on the Autism spectrum. Doctoral dissertation Abilene Christian University. Digital Commons: https://digitalcommons.acu.edu/school\_ed\_leadership/5/.
- Holmes, S. 2021a. Do students on the Autism spectrum feel included in the school system? *Exceptional Needs Today*, 1, 59–63.
- Holmes, S. 2021b. Students on the spectrum have ideas about inclusion if we will listen? *Exceptional Needs Today*, 3, 21–23.
- Holmes, S. and Butcher, J. 2020. Educational leaders can lead the way for increased academic achievement for students on the autism spectrum. School Leadership Review, 15, 1–20.
- Horrocks, J., White, G. and Roberts, L. 2008. Principal's attitudes regarding inclusion of children with autism in Pennsylvania public schools. Journal of Autism and Developmental Disorders, 38, 1462–1473.
- Huang, C. 2011. Self-concept and academic achievement: A metaanalysis of longitudinal relations. *Journal of Social Psychology*, 49, 505–528.
- Humphrey, N. and Lewis, S. 2008. What does 'inclusion' mean for pupils on the autism spectrum in mainstream secondary schools? *Journal of Research in Special Educational Needs*, 8, 132–140.
- Hurley-Hanson, A., Giannantonio, C. and Griffiths, A. 2020. Generation A and Autism in the workplace. In: Autism in the Workplace. Palgrave Explorations in the Workplace Stigma. UK: Palgrave MacMillan.
- ICD10Data. 2020. 2020 ICD-10 CM Diagnosis Code F84.0. https://www.icd10data.com/ICD10CM/Codes/F01-F99/F80-F89/F84-/F84.0 Johns, B. (2016). Your classroom guide to special education law.
- Inos, R. H. and Quigley, M. A. 1995. Research review for inclusive practices [microform]/by Rita Hocog Inos and Mary Anne Quigley. Honolulu, HI: [Washington, DC]: Pacific Region Educational Laboratory: U.S. Dept. of Education, Office of Educational Research and Improvement, Educational Resources Information Center, 1995.
- Jones, S., Gordon, C., Akram, M., Murphy, N. and Sharkie, F. 2021. Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism Development Disorders*,
- Kirby, A. 2019. Suicide risk and autism. Autism Speaks. https:// www.autismspeaks.org/expert-opinion/suicide-risk-autism
- Krieger, B., Kinébanian, A., Prodinger, B. and Heigl, F. 2012. Becoming a member of the work force: Perceptions of adults with Asperger Syndrome. Work (Reading, Mass.), 43, 141–157.
- La Salle, T. P., McIntosh, K. and Eliason, B. M. 2018. School climate survey suite administration manual. Eugene, OR: OSEP Technical Assistance Center on Positive Behavioral Interventions and Supports. University of Oregon.
- Lakkala, S., Uusiautti, S. and Määttä, K. 2016. How to make the neighborhood school a school for all? Finnish teachers 'perceptions' of education reform arming towards inclusion. *Journal of Research in Special Educational Needs*, 16, 46–56.
- Leavy, P. 2017. Research design: Quantitative, qualitative, mixed methods, arts-based, and community based participatory research approaches. New York: The Guilford Press.
- Lindsay, S., Proulx, M., Thomson, N. and Scott, H. 2013. Educators' challenges of including children with autism spectrum disorder in the mainstream classroom. *International Journal of Disability*, *Development and Education*, 60, 347–362.
- Little, S., Swangler, J. and Akin-Little, A. 2017. Defining social skills. In J.L. Matson (Ed.) *Handbook of Social Behavior and Skills in children*. 9–17. Switzerland: Springer International Publishing AG. https://psycnet.apa.org/doi/10.1007/978-3-319-64592-6\_2Press.
- McCluskey, G., Riddell, S., Weedon, E. and Fordyce, M. 2016. Exclusion from school and recognition of difference. *Discourse: Studies in the Cultural Politics of Education*, 37, 529–539.

- McGregor, G., Mills, M., Te Riele, K. and Hayes, D. 2015. Excluded from school: Getting a second chance at a 'meaningful' education. *International Journal of Inclusive Education*, 19, 608–656
- Moran, T. E., Gibbs, D. C. and Mernin, L. 2017. The empowerment model: Turning barriers into possibilities. *Palaestra*, 31, 19–26.
- Moustakas, C. 1994. Phenomenological research methods. California: Sage
- Mulholland, S. and Cumming, T. 2016. Investigating teacher attitudes of disability using nontraditional theoretical framework of attitude. *International Journal of Educational Research*, 80, 93–100.
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M. and Joyce, A. 2019. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23, 2007–2019.
- Nishimura, T. and Busse, R. 2015. A factor analytic validation study of the scale of teachers' attitudes toward inclusive classrooms (STATIC). *International Journal of Special Education*, 30, 118–125.
- Nord, D. K., Stancliffe, R. J., Nye-Lengerman, K. and Hewitt, A. S. 2016. Employment in the community for people with and without autism: A comparative analysis. *Research in Autism Spectrum Disorders*, 24, 11–16.
- O'Connor, E., Yasik, A. and Horner, S. 2016. Teachers' knowledge of special education laws: What do they know? *Insights into Learning Disabilities*, 13, 7–18.
- Olson, A. 2013. The theory of self-actualization. *Psychology Today*. https://www.psychologytoday.com/us/blog/theory-and-psychopath-ology/201308/thetheory-self-actualization
- Pantić, N. and Florian, L. 2015. Developing teachers as agents of inclusion and social justice. *Education Inquiry*, 6, 27311–27351.
- Patton, M. 2015. Qualitative research & evaluation methods. 4th ed. California: Sage.
- Pazey, B. L., Gevarter, C., Hamrick, J. and Rojeski, L. 2014. Review: Administrator views and knowledge of instructional practices for students with autism spectrum disorders. Research in Autism Spectrum Disorders, 8, 1253–1268.
- Praisner, C. 2003. Attitudes of elementary school principals toward the inclusion of students with disabilities. *Exceptional Children*, 69, 135–145.
- 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, 30–39.
- Rogers, S. J. 2000. Interventions that facilitate socialization in children with autism. *Journal of Autism and Developmental Disorders*, 30, 399–409.
- Ruijs, N. and Peetsma, T. 2009. Effects of inclusion on students with and without special educational need reviewed. *Educational Research Review*, 4, 67–79.
- Ryan, R. and Deci, E. 2000. Self-determination theory and the facility of intrinsic motivation, social development, and well-being. *American Psychologist*, 55, 68–78.
- Segall, M. J. and Campbell, J. M. 2012. Factors related to education professionals' classroom practices for the inclusion of students with Autism Spectrum Disorders. Research in Autism Spectrum Disorders, 6, 1156–1167.
- Shogren, K. A., McCart, A. B., Lyon, K. J. and Sailor, W. S. 2015.
  All means all: Building knowledge for inclusive schoolwide transformation. Research and Practice for Persons with Severe Disabilities, 40, 173–191.
- Sproston, K., Sedgewick, F. and Crane, L. 2017. Autistic girls and school exclusions: Perspectives of students and their parents. *Autism & Developmental Language Impairments*, 2, 239694151770617–239694151770614.
- Survey Monkey. n.d!. Terms of use. https://www.surveymonkey.com/mp/legal/terms-of-use/
- Trautmann, S., Rehm, J. and Wittchen, H. 2016. The economic costs of mental disorders: Do our societies react appropriately to the burden of mental disorders? *EMBO Reports*. 17, 1245–1249.
- van der Werf, C. 2014. The effects of bullying on academic achievement. Segundo Semestre, 275–308.
- 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: APAQ, 36, 242–263.
- Watkins, L., Ledbetter-Cho, K., O'Reilly, M., Barnard-Brak, L. and Garcia-Grau, P. 2019. Interventions for students with autism in

- inclusive setting: A best evidence synthesis and meta-analysis. *Psychological Bulletin*, 145, 490–507.
- Weber, L. and Young, G. 2017. High school administrators and inclusion: A review of the literature. https://journals.lib.unb.ca/ index./viewFile/25167/29507
- Wehmeyer, M. 1992. Self-determination and the education of students with mental retardation. *Education and Training in Mental Health Retardation*, 302–314. https://www.researchgate.net/profile/Michael\_Wehmeyer/publication/232425333\_SelfDetermination\_and\_the\_Education\_of\_Students\_with\_Mental\_Retardation/links/56c227f 408ae44da37ff5af1.pdf.
- Wehmeyer, M., Abery, B., Mithaug, D. and Stancliffe, R. 2003. Theory in self-determination: Foundations for educational practice. Springfield: Charles C Thomas.
- West, R. and Turner, L. 2018. *Introducing communication theory:*Analysis and application. 6th ed. Chennai: McGraw-Hill Education.
- White, R. and Cooper, K. 2012. Critical leadership and social justice: Research, policy and educational practice. *US-China Education Review*, 517–532.
- Wright, P. and Wright, P. 2018a. From emotions to advocacy: The special education survival guide. 2nd ed. Deltaville: Harbor House Law Press.
- Wright, P., Wright, P. and O'Connor, S. 2018b. *All about IEPs: Answers to frequently asked questions about IEPs.* Deltaville: Harbor House Law Press.
- Yell, M. 2019. The law and special education. 5th ed. UK: Pearson.
  Yell, M. L. and Drasgow, E. 1999. A legal analysis of inclusion.
  Preventing School Failure: Alternative Education for Children and Youth, 43, 118–123.
- Zimmerman, M. 2000. Empowerment theory. Handbook of Community Psychology, 43–63. Berlin: Springer.

### Appendix A:

# Inclusion defined by students on the autism spectrum

Student 1 (AS): Make them [schools] more included and encourage it when they [student with autism] are excelling, but don't discourage them when they're failing. We're still human. Taking them [students with autism] out of the class makes all the other students notice their differences more.

Student 2 (AS): Autism is not a one size fits all. The minute you stop treating us like there's a Band-Aid to fix us, it's when you would automatically start seeing more students wanting to include them, or you will see them doing better in school because the teacher is taking time to get to know them. Don't punish the disability [behavior]. See me as a person, not a disability. Make a better effort to know the student and get to know their students and figure out what will work with that student.

Student 3 (ASD L3): I should have equal access to education at the appropriate skill level and with the support necessary to achieve this in the setting with peers of all types. We [people on the spectrum] are the same as other students yet different in that we have hopes, dreams, goals, feelings, thoughts. We are competent despite our outward manifestations. We are not less but worthy of appropriate education and social

opportunities and human decency and respect. Social relationships and interactions connect us to the community of human beings that education seeks to serve better.

Student 4 (AS): Understanding that first of all, not everyone with autism is the same. Different people on the spectrum have different quirks; they have different things that set them off, react differently to the same situations. A one size fits all policy is not going to work. Getting to know the specific students and what helps them and then as far as training, just spreading knowledge and informing people creates a better understanding. I think it's going to help people to be able to interact with those students [students with autism] that is really important to have good understanding because a lot of times, people 278 fear or dislike or aren't comfortable with things they don't know about. Providing the knowledge even if maybe they don't have a lot of students on the spectrum in their school can be very helpful and very important. For peers explain at age-appropriate levels their classmate's needs (later she added and of course maintain confidentiality and respect boundaries).

Student 5 (AS): All of us deal with people on the spectrum every day, know that's nothing but a label and labels don't really matter. I'm as much autistic as I am female as much as I am human. It's just part of who I am. It doesn't mean I deserve any less respect. Everything you would do with another student, we deserve as well. We may need some extra support in doing those activities. Don't invalidate your students. Most kindergarteners don't get excluded, even if a bit different. If we can start working on those skills of inclusion in peers, in our staff, having staff members at all levels of schools be actively inclusion. Inclusion is life-long; it starts at birth til the day you die.

Student 6 (ASD L2): Well, just because I am a little weird doesn't make me less human. I have feelings just like anyone else. I even wrote an article about stopping the stigma against people with disabilities. There shouldn't be a stigma. When you're accepting to be someone's friend, you should accept and try to understand all aspects of a person. People view autism as a source of annoyance, disappointment, or worse in different ways and different degrees. It's not fair to place judgment upon someone when you don't even fully know them. There are those who are non-verbal, and we need to learn how to better communicate with them.